

Getting There With Parents: interactional processes surrounding withdrawal of life-sustaining treatments in a London NICU

Submitted by
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UCL

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Declaration

I, Jean-Frédéric Ménard, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

In the neonatal intensive care unit (NICU), healthcare professionals regularly conclude that withdrawal of life-sustaining treatments would be in their patients' best interests. Recently, the legal disputes between parents and healthcare professionals when the former disagree with the latter's recommendation to withdraw life-sustaining treatments have attracted much attention. This thesis seeks to examine and evaluate lesser-known informal interactional processes taking place before such disagreement reach the court. To do so, I devised *grounded normative theory*, a research methodology combining the insights of empirical ethics and legal pluralism with grounded theory. Based on fieldwork I conducted in and around the NICU of a London paediatric hospital, I constructed a model of the determination and operationalisation of the best interests of NICU patients in that unit. This qualitative model, entitled *Getting There With Parents*, highlights two main processes: 'Justifying intensive care' and 'Getting there with parents'. In the first, I show how a child's best interests are first appreciated in terms of 'medical best interests' and only then modulated considering 'wider best interests', which includes a projection of the child's future quality of life and the preferences of parents. In the second, I examine the process through which healthcare professionals seek to persuade parents to accept recommendations to withdraw life-sustaining treatments. I then turn to ethically evaluating the grounded normative model. On one hand, using the concept of legal chronotope, I demonstrate how intertwined understandings of time and space overly narrow the scope of the determination of best interests. On the other, I relate the doubts of healthcare professionals about parents' capacity to assess best interests to cognitive biases and I argue that even if some strategies they deploy amount to manipulating parents, they might nonetheless sometimes be justified.

Impact Statement

This thesis focuses on identifying, describing and evaluating an often neglected phenomenon: informal interactional decision-making processes surrounding withdrawal of life-sustaining treatments in neonatal intensive care. This interdisciplinary work sits at the crossroad between law, medical ethics and medicine. It is of interest for researchers reflecting on the concept of the best interests of the child, for practitioners—from physicians and social workers to judges—endowed with the responsibility to assess the situation of children in light of the same principle, and to policy-makers concerned with the protection and promotion of the welfare of children.

Grounded normative theory, the methodology proposed in this thesis to study these interactions rests on the foundations offered by empirical ethics and grounded theory but also contributes to knowledge by enriching them with legal pluralism's attention to informal normative processes. It helps identify and assess new objects of inquiry and throw a new light on those we already know. Grounded normative theory also has the potential to be deployed beyond clinical settings to deepen our understanding of the normativity of a broad range of contexts.

Getting There With Parents, the grounded normative model at the heart of this thesis offers a rich and detailed picture of the normativity of neonatal intensive care in the London NICU. This level of detail allows to target specific assumptions, practices and processes for revision, improvement or reform. Other researchers might use Getting There With Parents to formulate or verify research hypotheses. The model might also form the basis of comparative analyses, either between similar settings in the United Kingdom or with international settings.

The quality of the ongoing public debate on withdrawal of life-sustaining treatment might also be increased by introducing a nuanced portrayal of the processes healthcare professionals go through before recommending withdrawal of life-sustaining treatments from a neonate or infant.

The assessment of *Getting There With Parents* articulated in the last two chapters of this thesis illustrates both the critical potential of the grounded normative model and of the methodology which produced it. The critiques presented therein are susceptible to bear on the development and revision of guidelines on withdrawal of life-sustaining treatments for neonates and infants, as well as on training programmes for professionals practising in neonatal and paediatric intensive care. For instance, the detailed analysis of potentially manipulative strategies deployed in the parental consent process substantiates and develops an emerging trend in the literature on decision-making in neonatal and paediatric intensive care. Furthermore, it bridges a gap in knowledge between cognitive biases in paediatric decision-making, the appropriate ethical responses to interventions harnessing cognitive biases and the ethics of decision-making in paediatrics.

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Précieuse Elsa, ma reconnaissance pour ton appui et les sacrifices que tu as faits pour me permettre de réaliser mon rêve est sans borne. Je t'aime.

Table of abbreviations

CEC	Clinical ethics committee
CICU	Cardiac intensive care unit
CPAP	Continuous positive airway pressure
DNR	Do not resuscitate
ECHR	European Court of Human Rights
GMC	General Medical Council
GNM	Grounded normative model
GTWP	Getting there with parents
HCPs	Healthcare professionals
ICU	Intensive care unit
JIC	Justifying intensive care
MDT	Multidisciplinary team meeting
NEC	Necrotising enterocolitis
NHS	National Health Service
NICU	Neonatal intensive care unit
PALS	Patient advice and liaison service
PICU	Paediatric intensive care unit
RCPCH	Royal College of paediatrics and child health
WLST	Withdrawal of life-sustaining treatments

Table of contents

Declaration.....	2
Abstract.....	3
Impact Statement.....	4
Acknowledgements.....	6
Table of abbreviations.....	8
Table of contents.....	9
Chapter I - Introduction.....	15
1. Overview of theoretical assumptions.....	17
1.1 Pragmatism and a contextual focus.....	18
1.2 Social constructivism.....	20
1.3 Legal pluralism.....	21
2. Focusing on the normativity of interactions in the London NICU.....	24
3. Constructing a grounded normative model of decision-making.....	28
3.1 Justifying intensive care.....	31
3.2 Getting there with parents.....	32
4. From the descriptive to the normative: challenging the GNM.....	33
4.1 The chronotope of best interests in the NICU.....	35
4.2 Can you take any road to get there?.....	36
Chapter II - Grounded normative theory.....	38
Introduction.....	38
1. Why empirical law and ethics?.....	39
1.1 Grounding research in social context.....	39
1.1.1 'Achieving contextual understanding'.....	42
1.1.2 'Understanding meaning'.....	43
1.1.3 Expanding the intuition set.....	44
2. Toward Grounded Normative Theory.....	45
2.1 What is Grounded Theory?.....	46
2.2 Adapting grounded theory.....	50
2.2.1 Grounded normative theory.....	51
2.2.2 Modified focus groups aimed at reflexive balancing.....	54
3. An exemplifying case study of WLST in a NICU.....	57
3.1 Overview of the data generation process.....	60
3.1.1 Contextualising and orienting the data generating process.....	60

3.1.2 Generating rich data	62
3.1.2.1 Topic guides	65
3.1.2.2 Transcription of audio recording of interviews	66
3.1.3 Research ethics considerations	67
3.2 Analysing data to construct a grounded normative model	69
3.2.1. Seeing connections in data through coding	69
3.2.2 Developing data analysis through memo writing	72
Conclusion	75
Chapter III - Justifying intensive care	77
.....	77
1. A collegial and deliberative process	79
1.1 '[W]e are hugely swayed by medical things' [Physician #5] :	
medical evidence as a central norm	80
1.2 Collegiality as a central norm	81
1.3 The process is partially driven by the NICU consultants	84
1.4 A process of formal and informal deliberation	86
2. Balancing the present and future of the child, balancing life and death	89
2.1 Point of departure: a presumption in favour of treatment	90
2.2 Extending and deepening the timeframe	91
2.3 The future of the child	94
2.3.1 Survival expectancy	94
2.3.2 Functional outcome	95
2.4 Pain and pleasure: the present of the child in the NICU	96
2.4.1 Burdensome experiences	98
2.4.2 Beneficial experiences	100
2.4.2.1 The benefits of being treated in a high-level unit	100
2.4.2.2 The benefits of relationships	100
3. Normative implications	101
3.1 'It's quite heart-breaking when you are inflicting pain for no sort of bigger gain': the burden of treatment must be justified	102
3.2 Death might be the most desirable outcome	103
3.2.1 A proximate relationship with death	104
3.2.2 A plausible conclusion	105
3.2.3 The manifestation of a specific ethos	105
3. Conclusion: 'Nursing a corpse in the bed'	107
Chapter IV - Wider best interests	110
Introduction	110
1. Is future quality of life relevant to assessing wider best interest?	
Who gets to make that assessment?	111
1.1 Quality of life as a euphemistic placeholder for severe disability	115

1.1.1 Severely disabled children.....	115
1.1.2 A pessimistic view of life with severe disability.....	117
1.1.3 The optimistic counter-argument.....	122
2. The preferences of parents.....	126
3. Resisting the pull: Excluded factors.....	131
3.1 Ressource allocation.....	132
3.1.1 A subordinated consideration.....	135
3.2 Protecting the reputation of the hospital.....	137
Conclusion.....	142

Chapter V - Getting there with parents..... 145

Introduction.....	145
1. A fundamental dilemma between the autonomy of parents and their capacity to assess best interests.....	146
1.1 Parental consent is necessary for WLST.....	147
1.2 Suspicions about the capacity of parents.....	148
1.2.1 A contextual incapacity.....	149
1.2.2 An intrinsic incapacity.....	150
1.2.3 A broad ranging incapacity.....	151
1.3 Resolving the dilemma: building a common frame of reference.....	153
1.3.1 Expectations as building blocks of the frame of reference.....	153
1.3.2 HCPs also have expectations.....	154
2. Getting there with parents: managing the frame of reference.....	156
2.1 Parents and HCPs come from a different place.....	158
2.2 HCPs get there first.....	159
2.2.1 Doing everything: difference in points of departure.....	161
2.3 '[A] "disease that decides" [...] conversation': informing the parents.....	162
2.4 Supporting parents.....	164
2.4.1 Being there for parents: psychosocial support.....	164
2.4.2 Easing the burden from the parents' shoulders.....	166
2.4.3 Giving parents time to get there.....	169
3. Not getting there.....	171
3.1 HCPs are reluctant to abandon getting there with parents.....	174
3.1.1 The clinical ethics committee is not the ideal forum to solve disagreements with parents.....	174
3.1.2 Going to court is not the preferred option.....	177
3.1.2.1 Going to court means not getting there with parents.....	177
3.1.2.2 Going to court is an expensive process by all accounts.....	179
3.1.2.3 Going to court is often redundant.....	182
3.2 Potential distortions of the process.....	183
3.2.2 Putting parents first.....	184
3.2.1 Pushing the parents to get there.....	185

Conclusion	188
Chapter VI - The chronotope of best interests in the NICU	190
Introduction	190
1. The NICU as a transitional space	192
1.1 WLST as the destination of a passage through the NICU	192
1.2 A gloomy outlook on the future of children with severe disability	194
1.3 The body of the child as the focal point of best interests in the NICU	195
2. The chronotope of best interests in the NICU	197
2.1 A projection of human experience	198
2.2 Fencing off the body of the child	199
2.3 Competing chronotopes in the case law	203
2.3.1 The chronotope of intensive care at work	203
2.3.2 A rejection of the chronotope of best interests in intensive care	205
3. The initial determination of best interests is not sufficiently ideal	207
3.1 Morning rounds: best interests behind closed doors	209
3.2 An ideal determination of best interests as a point of departure	210
3.3 From the ideal to the reasonable	213
Conclusion	216
Chapter VII - Can you take any road to get there? Best interests, influence and manipulation	220
Introduction	220
1. The ideal of rationality in paediatric shared decision-making	221
2. Manipulative strategies in GTWP	224
2.1 Manipulation as failure to track reasons	224
2.1.1 Reasonable and paternalistic manipulation	225
2.2.2 The strength of Gorin's account	227
2.2 Four manipulative strategies	229
2.2.1 Omitting withdrawal of treatment as a likely outcome	229
2.2.2 Emphasising data supporting the teams' recommendation	229
2.2.3 Frequently repeating the recommendation	231
2.2.4 Triggering social or religious norms	231
3. Deciding with 'upset traumatized people' : do parents lack capacity?	233
3.1 The robust challenge fails	234
3.2 The weak challenge is more plausible	237
3.2.1 An inherently autonomy-limiting position	238
4. Heuristics and biases in parental decision making	240
4.1 A brief overview of the heuristics and biases research program	240
4.2 Heuristics and biases in the GNM	242
4.2.1 Impact on understanding	243
4.2.2 Impact on intentionality	246

4.2.3 Impact on absence of alienating influence.....	249
5. Justifying manipulative strategies.....	252
5.1 When are manipulative strategies justified?.....	255
5.2 The need for transparency.....	256
5.3 The need for proportionality.....	257
5.3.1 Assistance in identifying preferences.....	258
5.3.2 Respecting strong preferences.....	259
6. When you can't get there: going to court as the ethically superior option.....	261
Concluding overview.....	265
1. Research questions.....	265
2. Grounded normative theory: research methodology and design.....	265
3. Getting There With Parents: a grounded normative model.....	266
3.1 Justifying intensive care.....	267
3.2 Getting there with parents.....	269
4. Assessing Getting There With Parents.....	270
4.1 The chronotope of best interests in the NICU.....	270
4.2 Best interests, influence and manipulation.....	271
Bibliography.....	274
Appendix A: The legal framework applicable to withdrawal of life-sustaining treatment from infants and young children.....	290
Introduction.....	290
1. The default legal position: parental responsibility.....	292
1.1 Parents as primary decision makers.....	292
1.2 The specificity of the medical context.....	293
2. Interventions by the courts.....	295
2.1 The jurisdiction of the High Court.....	296
2.2 The interpretation and application of best interests by the courts.....	299
2.2.1 Best interests are paramount and must be assessed objectively, afresh, and independently.....	301
2.2.1.1 Deference toward medical expertise.....	302
2.2.1.2 The relevance of medical guidelines.....	303
2.2.1.3 Unease toward the views of parents.....	304
2.2.2 Best interests are to be assessed from the perspective of the child.....	306
2.2.2.1 Appointment of a children's guardian.....	306
2.2.3 Best interests are to be assessed by balancing a broad range of considerations.....	307
2.2.3.1 Balancing burdens and benefits.....	308
2.2.3.2 Futility is no different from other considerations.....	311

2.2.3.3 Pain and suffering in the balance.....	312
3. Recent controversies.....	314
3.1 The significant harm threshold argument.....	314
3.1.1 The Charlie Gard case: no significant harm threshold applies.....	315
3.1.2 The Alfie Evans case: the absence of a significant harm threshold is not discriminatory.....	316
3.2 The illegal detention argument.....	318
3.2.1 An 'entirely misconceived' application.....	319
3.2.2 Hospitalisation does not amount to detention.....	319
Conclusion.....	320
Appendix B: Information and consent sheet.....	322
1. Information and consent sheet.....	322
Appendix C: Topic guides.....	329
1. Topic guides for interviews.....	329
1.1 Topic guide - Specific case - HCP v1.....	330
1.2 Topic guide - Specific case - HCP v2.....	331
1.3 Topic guide - HCP v1.....	334
1.4 Topic guide - HCP v2.....	337
1.5 Topic guide - HCP v3.....	341
1.6 Topic guide - Legal Team.....	344
1.7 Topic guide - Surgeons v1.....	347
1.8 Topic guide - Surgeons v2.....	350
1.9 Topic guide - Clinical ethics committee v1.....	353
2. Topic guides for discussion groups.....	356
2.1 Topic guide - Discussion Group - Consultants v1.....	356
2.2 Topic guide - Discussion Groups - Nurses - v1.....	360
Appendix D: Summary presented to CEC.....	363
1. Outline – CEC Discussion Group.....	363
Appendix E: Sample interview transcripts.....	371
1. Interview with Physician #1.....	371
2. Interview with Senior Nurse #2.....	395
Appendix F: Sample focus group transcripts.....	412
1. Discussion group with nurses #3.....	412
2. Discussion group with consultants.....	433

Chapter I - Introduction

The decision to withdraw life-sustaining treatment from a critically ill neonate or infant is one of the most fraught decisions that healthcare professional (HCPs) and parents can be confronted with. Indeed, it will seem counter-intuitive to most people entrusted with a child's care. Yet, in certain extreme circumstances, it can appear as the only way to uphold the child's dignity and best interests. This perspective is not always shared by everyone and disagreement can arise between parents and HCPs.¹ Recently, the issue was at the forefront in the cases involving Charlie Gard and Alfie Evans, two infants who found themselves at the centre of hotly debated court cases about whether it was in their best interests to withdraw life-sustaining treatment considering their unfortunately critical medical conditions.² These cases, along with others, have drawn significant attention both from the public and experts all over the world.³ For these reasons, among others, withdrawal of life-sustaining treatment has extensively been discussed, both in the legal and ethical literature.⁴

In this thesis, I seek to add and contribute to these conversations on withdrawal of life-sustaining treatments ('WLST') in a resolutely contextual manner. My purpose is to achieve a deeper understanding of the decision-making dynamics of a

¹ Rob Heywood, 'Parents and Medical Professionals: Conflict Cooperation, and Best Interests' (2012) 20 Medical LR 29, 29–30.

² *Great Ormond Street Hospital v Yates & Ors [2017] EWHC 972 (Fam)*. *Alder Hey Children's NHS Foundation Trust v Evans [2018] EWHC 308*.

³ See eg Emma Cave and Emma Nottingham, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2018) 26 Medical LR 500. Jo Bridgeman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles' (2017) 17 Med Law Intl 285. JJ Paris and others, 'The Charlie Gard Case: British and American Approaches to Court Resolution of Disputes over Medical Decisions' (2017) 37 J Perinatol 1268; Arthur Caplan and Kelly McBride Folkers, 'Charlie Gard and the Limits of Parental Authority' (2017) 47 Hastings Cent Rep 15.

⁴ See e.g. Anne Morris, 'Selective Treatment of Irreversibly Impaired Infants: Decision-Making at the Threshold' (2009) 17 Medical LR 347; Dominic Wilkinson, *Death Or Disability?: The 'Carmentis Machine' and Decision-Making for Critically Ill Children* (OUP 2013); Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Hart 2019); Hazel E McHaffie, *Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants* (Radcliffe Medical Press 2001); Joe Brierley, Jim Linthicum and Andy Petros, 'Should Religious Beliefs Be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?' (2013) 39 JME 573.

representative clinical setting, to formulate a pointed critique and make concrete recommendations for improving the way WLST decisions are made. I will focus on how the best interests of a critically ill child is understood by HCPs and how it is operationalised in the clinical context, especially where HCPs take the view that best interests coincide with WLST. Accordingly, this thesis will be much less concerned with the court cases just mentioned or with how future cases should be solved than with the processes that take place before such disagreements are brought to court for resolution.

I will achieve this contextual perspective mainly by elaborating a grounded normative model ('GNM') of decision-making based on fieldwork I conducted in the neonatal intensive care unit of a London university affiliated paediatric hospital (the 'London NICU'). I named the GNM 'Getting There With Parents'. It seeks to represent the overall process surrounding WLST in the London NICU. It brings together two main processes for making decisions about WLST in the London NICU. The first is called 'Justifying intensive care' ('JIC'). JIC models the way in which the NICU team collaboratively elaborates a hypothesis about the best interests of a child under their care. The second process gives its name to the whole model and is called 'Getting there with parents' ('GTWP').⁵ GTWP models the way in which the hypothesis coming out of JIC is introduced to the child's parents with a view of obtaining their consent and implementing it.

The GNM focuses on the way healthcare professionals practising in the London NICU approach WLST to interpret the processes through which they make these difficult and complex decisions.⁶ The perspective of HCPs is important to consider because of their central role in WLST situations. Unlike parents, HCPs are repeatedly confronted with the same issues, such that a relatively stable consensus

⁵ Throughout this thesis, 'Getting there with parents' and the acronym GTWP designate the second process of the GNM as described in chapter V. The title of the overall GNM is capitalised as "Getting There With Parents".

⁶ Kathy Charmaz, *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (2nd edn, SAGE 2014) 17.

is susceptible of emerging in the practice of a clinical setting.⁷ Thus, I am starting from the hypothesis that healthcare professionals are heavily involved in framing the decision-making and that even in those instances where the substantive decision is left to others, most often parents, HCPs will implement the decision or part of it and will, therefore, bear some responsibility for it. Although I have not interacted with parents of critically ill neonates or infants, the perceptions of HCPs about their interactions with the parents of their patients are an important dimension of the grounded normative model I have constructed.

In the second part of this thesis, I reflect on the GNM to propose a grounded critique of the practice of WLST in the London NICU. I focus on some issues that my interactions with HCPs practising in the London NICU and the analysis of the data we generated together led me to consider as problematic or requiring further exploration.

1. Overview of theoretical assumptions

Before delving further into the results of my research, I wish to outline the theoretical assumptions upon which I built this project.⁸ These assumptions cut across many debates and controversies, notably in epistemology and jurisprudence. In devising my research, I sought a way of apprehending my subject that was flexible without being *ad hoc*. Consequently, while I recognise the importance of being aware of my philosophical and methodological assumptions and of their alternatives, I also take the view that it would be unproductive to endorse too strongly any position. This led me to adopt a pragmatic position. Articulating a pragmatic posture provides me with a way to acknowledge those debates, while avoiding that their intractable nature paralyse my analysis.⁹

Hence, what follows is not a rigid theoretical framework. Rather, it is my best attempt

⁷ Pascale du Pré and Joe Brierley, 'Challenges in Managing Parental Expectations in Paediatric Care' (2018) 183 Br J Haematol 15, 18.

⁸ Charmaz (n 6) 12.

⁹ Eric Racine, 'Which Naturalism for Bioethics? A Defense of Moderate (Pragmatic) Naturalism' (2008) 22 Bioethics 92, 96.

to articulate my guiding assumptions. Attention to this dimension of the research process is often called 'reflexivity' and 'carries the connotation that social researchers should be reflective about the implications of their methods, values, biases, and decisions for the knowledge of the social world they generate'.¹⁰ Accordingly, it is an attempt at being reflexive about my research, mapping out where I started and where I hoped to go.¹¹

I will briefly discuss the three main theoretical postures that I adopted in conducting the research reported here: pragmatism, social constructivism and legal pluralism.

1.1 Pragmatism and a contextual focus

I found in the intellectual tradition of pragmatism some general tools to guide me in the conduct of this study. I take pragmatism to require paying attention to practical problems, to '... "problems we encounter in practice" specific and situated problems, as opposed to abstract idealised, or theoretical problems'.¹² This provides a justification for elaborating and deploying an empirical methodology, for going into a NICU to find legal and ethical issues rather than engaging primarily with the literature or the case law on the topic to identify issues that ought to be problematic.¹³

Pragmatism appears particularly suitable to clinical ethics.¹⁴ Seeking expedient yet principled solutions to the concrete issues arising in the practice of medicine, clinical ethics is significantly different from philosophical bioethics or applied ethics, although it feeds itself off the work of the latter two.¹⁵ It implies paying attention to the

¹⁰ Alan Bryman, *Social Research Methods* (4th edn, OUP 2012) 393.

¹¹ Jonathan Ives and Michael Dunn, 'Who's Arguing? A Call for Reflexivity in Bioethics' (2010) 24 *Bioethics* 256, 263; See also Jean-Frédéric Ménard, 'Cobayes de la relève : l'artiste et le chercheur à la rencontre de l'expérience' (2016) 5 *BioéthiqueOnline* <<https://www.erudit.org/en/journals/bo/1900-v1-n1-bo03553/1044276ar/abstract/>> accessed 3 November 2020.

¹² Hilary Putnam, *Ethics without Ontology* (Harvard University Press 2005) 28.

¹³ Jonathan Ives and Heather Draper, 'Appropriate Methodologies For Empirical Bioethics' (2009) 23 *Bioethics* 249, 251.

¹⁴ Joseph Fins, Franklin G Miller and Matthew D Bacchetta, 'Clinical Pragmatism: A Method of Moral Problem Solving' (1997) 7 *Kennedy Inst Ethics J* 129, 130.

¹⁵ Jörg Stübing, 'Research as Pragmatic Problem-Solving: The Pragmatist Roots of Empirically-Grounded Theorizing' in Antony Bryant and Kathy Charmaz (eds), *The SAGE Handbook of grounded theory* (SAGE 2012) 590–591.

perspective of those implicated in a practice while identifying and defining the problems arising out of it. John Dewey famously wrote that the:

individuals of the submerged masses may not be very wise. But there is one thing they are wiser about than anybody else can be, and that is where the shoe pinches, the trouble they suffer from.¹⁶

The HCPs I interacted with in this research cannot be likened to ‘the submerged masses’: they are specialised, highly educated professionals. I would not say they are unwise. Quite the contrary, it is a belief in their accumulated practical knowledge that incited me to bring the debates of law and medical ethics directly to them. Not only do they know ‘where the shoe pinches’ but their views as to how to fix it can significantly contribute to the normative debate.

A fruitful way of understanding concepts and ideas is to inquire into how they are used. Practice embodies a significant body of knowledge and my research seeks to make it more explicit and engage with it. My position as a researcher is not that of the arbiter of truth or morality nor is it that of passive observer. I hoped to be able to facilitate the expression of this body of knowledge while also contributing to its expansion and refinement.¹⁷ I offered HCPs occasions to reflect upon their practice, to question it, and to elaborate justifications for it. In this process, my role was that of a fellow traveller, offering assistance whenever possible, whether in the form of prompts, probing questions or by suggesting working hypotheses.

Of course, I will also contribute my reflections and connect the GNM to a broader range of critical perspectives when I discuss it in this thesis’ last two chapters. However, I will do so in a spirit of modesty, acknowledging the fallibility of such an intellectual enterprise. Such modesty implies a fundamental openness to examining the underlying assumptions in our thinking and a willingness to revise our beliefs. Jonathan Ives spells out the implications of adopting such a position:

This pragmatic and fallibilist characterisation of bioethics replaces any search for ‘*the solution*’

¹⁶ John Dewey, *The Later Works, 1925-1953* (SIU Press 1987) 219.

¹⁷ Fins, Miller and Bacchetta (n 14) 131.

with the search for 'a solution that we can live with, and which goes some way toward resolving the problem we currently have'. In this sense, bioethical inquiry becomes a process of 'noble failure'—a never-ending attempt to produce 'better' normative accounts, with an acceptance that the constantly changing social and technological landscape will generate new problems that force us to revise the accounts we currently have.¹⁸

This means eschewing the search for eternal, universal truths and recognising that a suitable concrete solution to today's problem might not hold forever.¹⁹

1.2 Social constructivism

This also relates to the way I approached the empirical component of my research, adopting the posture of social constructivism. I do not pretend therefore to be able to gather independent and objective social facts. Rather, I take the view that the interactions between the researcher and the research subjects generate empirical data. Dunn and Ives write:

Engaging with participants can be understood as an intersubjective process of interpretation and reinterpretation, in which meaning is co-produced during the research process itself. Emerging data can only ever be constructions of social reality, not only because they are historically, culturally and socially embedded, but also because they are contingent on the nature of the complex interactions between researcher and participant.²⁰

Similarly, Kathy Charmaz suggests that:

If [...] we start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher's position, privileges, perspective, and interactions into account as an inherent part of the research reality. It, too, is a construction.²¹

To give a simple illustration, the formulation of interview questions informs the answers provided to those questions and these answers inform subsequent questioning. Dunn and Ives apply this idea to empirical bioethics, noting that:

[i]n attempting to have 'encounters with experience', the researcher must be aware that the research encounter is a unique experience in its own right where both parties offer a performance to present themselves as moral persons of a particular kind. The researcher never simply 'grasps' meanings held by participants, but is involved actively in creating those

¹⁸ Jonathan Ives, 'A Method of Reflexive Balancing in a Pragmatic, Interdisciplinary and Reflexive Bioethics' (2014) 28 *Bioethics* 302, 304.

¹⁹ Angus Dawson, 'IAB Presidential Address: Contextual, Social, Critical: How We Ought to Think About the Future of Bioethics' (2013) 27 *Bioethics* 291, 293.

²⁰ Michael Dunn and Jonathan Ives, 'Methodology, Epistemology, and Empirical Bioethics Research: A Constructive/Ist Commentary' (2009) 9 *AJOB* 93, 93.

²¹ Charmaz (n 6) 13.

meanings through the process of collecting and analysing data.²²

This does not mean the answers will not be reliable or authentic. Rather, close attention needs to be paid to this process in conducting the research and in interpreting its results.

1.3 Legal pluralism

In this thesis, I am adopting a legal pluralist definition of legal and ethical issues. As observed by William Twining, definitions can serve different purposes and different theoretical projects can require different definitions.²³ Indeed, I needed a definition of law encompassing the plurality of sources of norms acknowledged and deployed by HCPs to reflect on how they make decisions concerning WLST.

In conducting my research, I relied on the conception of law elaborated by Roderick A. Macdonald from the definition of law initially proposed by Lon L. Fuller. In *The Morality of Law*, Fuller suggests that law is the ‘enterprise of subjecting human conduct to the governance of rules’.²⁴ Macdonald modifies Fuller’s definition to read as follows: ‘[i]n the legal pluralist hypothesis, people are engaged in reflection about law whenever they direct their attention to **“the endeavour of symbolising human conduct and interaction as governed by rules”**’.²⁵ With this definition, Macdonald aims at casting as wide a net as possible and to dispel the idea of a strictly top-down – from lawmakers to legal subjects – conception of law and law-making. This justifies in his view the choice to drop the reference to ‘subjecting’ human conduct from Fuller’s original definition.²⁶

The legal pluralism Macdonald articulated is thus, following John Griffith’s classical

²² Dunn and Ives (n 20) 94.

²³ William Twining, *General Jurisprudence: Understanding Law from a Global Perspective* (CUP 2009) 117.

²⁴ Lon L Fuller, *The Morality of Law* (Revised ed, Yale University Press 1969) 106.

²⁵ Roderick A Macdonald, ‘Here, There and Everywhere... Theorizing Legal Pluralism; Theorizing Jacques Vanderlinden’ in Nicholas Kasirer and Lynne Castonguay (eds), *Étudier et enseigner le droit: hier, aujourd’hui et demain. Études offertes à Jacques Vanderlinden* (Yvon Blais 2006) 393.

²⁶ *ibid.*

taxonomy, a strong legal pluralism.²⁷ Macdonald's broad definition of law does not discriminate between normative phenomena. The normative orders of sports, etiquette or morality, and their interactions and intertwinement are all covered by Macdonald's definition. It accounts for the diversity of norms described above and allows considering them together, without insisting on their purported differences. The idea of continuity between the law of everyday interactions and the highly formalised and institutionalised legal apparatus of the modern state appears susceptible of producing significant insight in the context of the present study.²⁸

Macdonald's definition allows concentrating on understanding the norms and normative processes at play in the clinical setting rather than classifying them according to their sources. It also allows me to approach my case study with the hypothesis that the London NICU is a normatively rich environment and that a variety of stakeholders are involved in identifying, interpreting and applying a variety of norms.²⁹ Indeed, HCPs are conscious many rules govern WLST. Without aiming for exhaustivity, I observed they acknowledge, among others, positive state law (statutes and case law), deontological duties, ethical guidelines, administrative rules of the hospital, informal norms of the unit, and religious and ethical commitments.

All those norms not only co-exist, they are also intertwined.³⁰ Werner Menski develops the notion of a plurality of normative sources while also addressing to the need for deciding in concrete circumstances. He argues that law is a 'plurality of pluralities'.³¹ Describing what he calls 'the kite model of law', Menski writes:

[L]aw always needs to be navigated between [four competing corners, namely natural law and positivism and socio-legal norms and international norms. Law, being internally plural, is then

²⁷ John Griffiths, 'What Is Legal Pluralism?' (1986) 18 J Leg Plur Unoff Law 1, 61; Roderick A Macdonald, 'Custom Made—For a Non-Chirographic Critical Legal Pluralism' (2011) 26 Can J Law Soc 301, 302.

²⁸ Roderick A Macdonald, *Lessons of Everyday Law* (McGill-Queen's University Press 2002) 6–7. Daniel Jutras, 'The Legal Dimensions of Everyday Life' (2001) 16 Can J Law Soc 45, 63–64.

²⁹ See e.g. Charles Foster and José Miola, 'Who's in Charge? The Relationship between Medical Law, Medical Ethics, and Medical Morality?' (2015) 23 Medical LR 505.

³⁰ Wibren van der Burg, *The Dynamics of Law and Morality: A Pluralist Account of Legal Interactionism* (Ashgate 2014) 102–103.

³¹ Werner Menski, 'Flying Kites in a Global Sky: New Models of Jurisprudence' (2011) 7 Socio-Leg Rev 1, 14.

its own 'other' all the time, causing constant conflicts and tensions.³²

Legal questions can rarely, if ever, be solved from within the confines of only one of the corners of the kite. Participants' outlooks are equally plural. Different perspectives emerge as different normative sources are ranked according to their relative 'persuasive authority',³³ as different sources reinforce or oppose each other.

In constructing the GNM, I therefore sought to pay attention to how norms emerge from the internal normative debates of participants and from their interactions with their colleagues. Indeed, the interactional dimension of law is also an important building block of the perspective I adopted in researching this thesis. For Macdonald, law 'implies relationships with other human symbolizers who themselves are both agents and patients of the agency of others'.³⁴ Law is also relational, 'lying in the relationship more than the field within which the relationship is built'.³⁵ Furthermore, although rules are constructed in the context of interactions and relationships, they are also conceived as 'norms or general prescription that pre-exist the human behaviour that is being symbolised'; they are 'held to pre-date the action'.³⁶

Macdonald's conception of law is also echoed in Emmanuel Melissaris' definition of law as 'shared normative experience, that is the way normativity and beliefs about the world are merged in the common self-understanding of various communities'.³⁷ Melissaris highlights that law is performative, that it is used to move from how the world is to how it ought to be. It also suggests that as law crystallises fundamental beliefs about the world, it constitutes or at least forms an important part of a community's worldview.

Notwithstanding the pluralist perspective that I have adopted in researching this

³² *ibid* 13.

³³ H Patrick Glenn, 'Persuasive Authority' (1986) 32 McGill L J 261.

³⁴ Macdonald, 'Here, There and Everywhere' (n 25) 394.

³⁵ *ibid*.

³⁶ *ibid*.

³⁷ Emmanuel Melissaris, *Ubiquitous Law Legal Theory and the Space for Legal Pluralism* (Ashgate 2009) 127.

thesis, I must acknowledge that the institutional world of law with states, legislatures, statutes, courts, judges, enforcement mechanisms, and so on, is held, both by many lay observers and by the significant number of lawyers and legal theorists who adhere to legal positivism to represent the paradigmatic instance of law. I did not discuss the definition of law with participants, but it can be inferred they intuitively adhered to a more traditional positivist conception of law. Yet, although the main purpose of my research was not to engage in a doctrinal interpretation and critique of English Law on WLST, to make sense of my interactions with participants, I needed an understanding of the black letter law framework used by the courts to approach the cases brought before them. I therefore needed to be familiar with the evolution and controversies of this area of the law of England and Wales to model the normative order of the London NICU. For this reason, I synthesised the legal framework applicable to withdrawal of life-sustaining treatment from infants and young children and included it to this thesis as Appendix A .

Having spelt out some of the most basic assumptions of my project, I can now turn to introduce it in more detail. First, I will circumscribe my study's subject, namely interactions in the London NICU concerning WLST, then situate it in relation to the existing literature. I will then turn to outlining the results of my study. I will outline the main elements constituting the GNM. Finally, I will present the essence of my critique of the GNM.

2. Focusing on the normativity of interactions in the London NICU

This thesis explores the informal processes of interaction between HCPs and parents in the NICU, as understood and experienced by the former. Charmaz, upon whose work on grounded theory I relied for devising the empirical methodology I used in this thesis, defines a process as follows:

A process consists of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between. The temporal sequences are linked in a process and lead to change.³⁸

³⁸ Charmaz (n 6) 17.

In a recent book chapter, Louise Austin and Richard Huxtable identified, ‘five key processes for resolving disagreements about the care of critically ill children: discussions between families and clinicians; second-opinion experts; clinical ethics committee; mediation and court proceedings’.³⁹ As already mentioned, the overarching process I am interested in is that of deciding whether to withdraw life-sustaining treatments from a child in the NICU. It significantly overlaps with the first process identified by Austin and Huxtable, but the scope of my study is broader. I am interested in such a process, independently of whether decisions are disputed or not. I also consider other processes identified by Austin and Huxtable, notably resort to the hospital’s clinical ethics committee or court proceedings, but only briefly and insofar as they relate and shed light on the first one.⁴⁰

Acknowledging informal interactional processes as central to decisions on WLST warrants paying increased attention to them. An interactional process between HCPs and parents appears inevitable. It is the first step both in situations that unfold without difficulties or disagreement and in those where disagreement, intractable or not, emerges. Informal interactional processes are by far the most commonly used, yet they attract much less attention than other means of deciding about the care for critically ill children, chiefly the court system.⁴¹

Both judicial pronouncement and ethical guidelines recognise the central role of interactions between HCPs and parents, although it is unclear what these interactions should involve. The tension experienced by HCPs between the best interest of the child and the need to find a consensus with parents before

³⁹ Louise Austin and Richard Huxtable, ‘Resolving Disagreements about the Care of Critically Ill Children: Evaluating Existing Processes and Setting the Research Agenda’ in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Hart 2019) 208.

⁴⁰ But see Giles Birchley and Richard Huxtable, ‘Critical Decisions for Critically Ill Infants: Principles, Processes, Problems’ in Catherine Stanton and others (eds), *Pioneering Healthcare Law: Essays in honour of Margaret Brazier* (Routledge 2016).

⁴¹ But see Austin and Huxtable (n 39) 208; Louise Austin, ‘Literature Review: UK Processes for Resolution of Disagreements in Care of Critically Ill Children’ (Nuffield Council on Bioethics 2018) <<https://nuffieldbioethics.org/wp-content/uploads/Austin-L-2018-UK-processes-for-resolution-of-disagreements-in-care-of-critically-ill-children.pdf>> accessed 18 December 2019.

approaching the court is inherent to their normative position and requires resolution on the ground.⁴²

The case law supports giving priority to informal means of resolving disputes before applying for judicial determination. Notwithstanding the controversies generated by the cases reaching the High Court and the public attention they garner, it also provides a useful reminder of the exceptional status of these cases. As noted by Austin, published court cases almost invariably show HCPS taking informal steps before bringing an application to the High Court to authorise WLST.⁴³

Already, in the seminal case of *Re J*, Lord Donaldson stated:

No one can dictate the treatment to be given to the child – neither court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contra-indicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents for their part can refuse to consent to treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors and the court or parents.

This cooperation is reinforced by another consideration. Doctors nowadays recognise that their function is not a limited technical one of repairing or servicing a body. They are treating people in a real-life context. This at once enhances the contribution which the court or parents can make toward reaching the best possible decision in all the circumstances.⁴⁴ [my emphasis]

Similarly, the European Court of Human Rights' decision in *Glass v United Kingdom* stands for the necessity for physicians to obtain either parental consent or court authorisation before treating an incapable child.⁴⁵ However, *Glass* does not imply an 'either/or' choice between obtaining parental consent and court authorisation. Rather, it can be read as supporting the notion that consultations with parents should be conducted to obtain consent on what the best interests of the child requires.⁴⁶

⁴² See Giles Birchley, 'Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care' (2014) 22 Health Care Anal 203.

⁴³ Austin (n 41) 5. See also Birchley and Huxtable (n 40) 120.

⁴⁴ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, 41.

⁴⁵ *Glass v United Kingdom* [2004] ECHR 102 [83].

⁴⁶ Giles Birchley, 'What Limits, If Any, Should Be Placed on a Parent's Right to Consent and/or Refuse to Consent to Medical Treatment for Their Child?' (2010) 11 Nursing Philosophy 280, 284. Vic Larcher and others, 'Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A

Bridgeman summarises the principle as follows: '[w]here alternative means to resolve the disagreement have been exhausted, the Trust is under a duty to refer the matter to court'.⁴⁷ Yet, what needs to be done before referring the matter to the court is often neglected in legal discussions. Bridgeman observes that 'there is no clear guidance on the steps or measures the law requires clinicians or Trusts to take prior to referral to court'.⁴⁸ This is because clinicians discharge that duty at the prejudicial stage and it is, therefore, not usually captured by legal analysis.⁴⁹ This is a gap in knowledge this study aims at beginning to understand.

Clinical and ethical guidance are more explicit on the matter. However, it emphasises the various means which HCPs can deploy. For instance, the General Medical Council's guidance on end-of-life care for children lacking capacity insists on informally resolving disagreements before turning to courts:

If disagreements arise about what course of action would be in a child or young person's best interests, it is usually possible to resolve them by, for example, involving an independent advocate; seeking advice from a more experienced colleague; obtaining a second opinion; by holding a case conference or ethics consultation; or by using local mediation services. If, after taking such steps, significant disagreement remains, you should seek legal advice on applying to the appropriate court for an independent ruling. Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's interests have been properly considered in the decision.⁵⁰

For its part, the Royal College of Paediatrics and Child Health's ('RCPCH') framework on making decisions to limit treatment in life-limiting and life-threatening conditions in children emphasises discussing with parents,⁵¹ then alternative means to resolve disagreements such as 'Patient Advice and Liaison Service (PALS), Clinical Ethics Services, [and] chaplaincy', leaving the 'courts as the ultimate arbiter

Framework for Practice' (2015) 100 *Archives of Disease in Childhood* s1, s11. Jonathan Herring, 'Medical Decisions about Children' in John Eekelaar (ed), *Family Law in Britain and America in the New Century* (Brill 2016) 156. Giles Birchley and others, "'Best Interests'" in *Paediatric Intensive Care: An Empirical Ethics Study* (2017) 102 *Arch Dis Child* 930.

⁴⁷ Bridgeman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom' (n 3) 290.

⁴⁸ *ibid.*

⁴⁹ Birchley, 'Deciding Together?' (n 42) 207.

⁵⁰ General Medical Council, 'Treatment and Care towards the End of Life: Good Practice in Decision Making' (2010) para 18 <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>> accessed 28 November 2019.

⁵¹ Larcher and others (n 46) s12.

of best interests'.⁵² The framework goes one step further in laying down the ethical norms that are applicable at this stage in the process, stating that: '[p]rofessionals should not manipulate, coerce or deceive patients into doing what they (the professionals) believe would be in the patients' best interests'.⁵³

In this thesis, I contribute to knowledge about this interactional process. Although my doctoral research was initiated well before Austin and Huxtable issued their plea for further research into processes for resolving disagreement about the care of a critically ill child, this thesis seeks to contribute to filling the research gap they identify when they write that 'further work is needed to understand, in the context of resolving child healthcare disputes, what the current situation actually *is* and what the situation *should be*'.⁵⁴ Indeed, the research questions guiding this study are closely aligned with these.

3. Constructing a grounded normative model of decision-making

The main research question for this thesis is: *how can the way healthcare professionals approach legal and ethical issues relating to WLST in the London NICU be improved?* Although the main research question is a normative one, it requires answering an important descriptive sub-question. Indeed, constructing a fine-grained model of the way decisions regarding WLST are approached in the London NICU constitutes one of the central contributions to knowledge that this thesis makes.

That descriptive question is: *how do healthcare professionals in the London NICU approach legal and ethical issues relating to WLST?* Chapter I presents the methodology I developed and used for constructing the GNM. Building on the recent developments in empirical ethics and grounded theory, a well-established qualitative research methodology, I sought to develop a research method to explore the normativity of decision-making in the London NICU, which I labelled 'normative

⁵² *ibid* s5.

⁵³ *ibid* s10.

⁵⁴ Austin and Huxtable (n 39) 230.

grounded theory'. Of course, although I aimed for the GNM to be descriptive, it does not mean that it is not concerned with normative matters. Rather, it means that instead of asking whether decisions are right or wrong, it asks how and why they were made.⁵⁵ Judgements and values are central to the GNM. I inquired into the normative perspective of the participants I interacted with; yet, at that stage, I refrained as much as possible from normatively evaluating such perspectives and the processes I inferred from our interactions in creating the GNM.

The GNM is based on the fieldwork I conducted in the London NICU. I generated the case study's data over a period of 27 months between September 2014 – when I first followed the morning rounds in the London NICU – to December 2016, when I ran the last focus group discussion session with HCPs. I generated the bulk of the data through interviews and focus group discussions with healthcare professionals either directly involved in the care of critically ill neonates and infants or indirectly through their involvement in the clinical ethics committee and the process leading to a court application. However, I also observed the functioning of the NICU and of the hospital's clinical ethics committee on several occasions during that period of time. I then carefully analysed the transcripts and my field notes to generate a series of code and memorandum which coalesced in the elaboration of the two main processes which constitute *Getting There With Parents*.

The GNM thus articulates the substantive answer to the descriptive research question. In its entirety, *Getting There With Parents* delineates how HCPs practising in the London NICU understand and operationalise the principle of the best interests of the child. It is presented in detail in chapters III to V. Unsurprisingly, considering the place it occupies in English law, in ethical guidelines and in the paediatric ethics literature, HCPs acknowledge the best interests principle as the main normative idea on which they base a WLST recommendation for one of their patients.⁵⁶ Often, it was

⁵⁵ Stacy M Carter, 'Grounded Theory and Empirical Ethics' in Antony Bryant and Kathy Charmaz, *The SAGE Handbook of Current Developments in Grounded Theory* (SAGE 2019) 557.

⁵⁶ Larcher and others (n 46); Sarah Elliston, *Best Interests of the Child in Healthcare* (Routledge-Cavendish 2006); Jo Bridgeman, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' (2017) 25 *Medical LR* 363; Geoffrey Miller (ed), *Pediatric*

I who first uttered the phrase 'best interests' to probe if it resonated with HCPs. Yet, HCPs often lit up upon hearing it mentioned and acknowledged it as an important, often crucial consideration. In our discussion, the details of the processes through which HCPs assess their patients' best interests and seek to implement that decision started to emerge.

The GNM offers a theory of the way HCPs' understanding of best interests is expressed and materialised in the organisation of the NICU and the interactions between those involved with it. Rather than examining how individuals understand best interests in the abstract, I focused on how HCPs purport to put best interests to work in the NICU in their everyday interactions with each other, and with their patients and their families.

The GNM converges with the results of similar studies conducted in the United Kingdom, suggesting that the London NICU is representative of decision-making for neonates and young children in the United Kingdom. The most general point of convergence with previous research in this area is that decisions about withdrawal of life-sustaining treatment in the NICU take a similar form to what I describe in this thesis. First, professionals achieve a consensus among themselves, then interactions with the child's parents follow.⁵⁷

A second process then aims at convincing parents to act upon the teams' recommendation by consenting to the course of action they propose.⁵⁸ In a seminal study of Scottish NICUs, McHaffie *et al.* identified a process whereby physicians would seek to persuade parents to go along with their recommendation as to the best interests of the child, including in cases where it was deemed best to withdraw life-sustaining care.⁵⁹ More recently, Birchley *et al.* conducted a qualitative study of

Bioethics (CUP 2010).

⁵⁷ Austin and Huxtable (n 39) 214; Brierley, Linthicum and Petros (n 4) 573.

⁵⁸ Austin and Huxtable (n 39) 214; Birchley and others (n 46) 933; Brierley, Linthicum and Petros (n 4) 574; McHaffie (n 4) 399–401; Chloe Shaw and others, 'Parental Involvement in Neonatal Critical Care Decision-Making' (2016) 38 *Social Health Illn* 1217, 1237.

⁵⁹ McHaffie (n 4) 399–401.

decision-making 'with a particular focus on decisions about (non-) treatment' in the paediatric intensive care units of three English hospitals.⁶⁰ They too identified 'a process of advocacy to advance the clinical view of best interests' whereby '[i]f a child's prognosis was poor and parents did not share the clinicians' view of the child's "best interests", clinicians reframed their description of the medical plan in terms they thought would be more acceptable to the parents'.⁶¹

3.1 Justifying intensive care

JIC is the process through which HCPs elaborate a hypothesis as to the best interests of a patient. It represents the way in which HCPs in the NICU put into practice the general idea of prioritising the child's interest by placing it ahead of the broader interest of the child's family and by excluding what they consider irrelevant to that determination. This process for determining a child's best interests can be modelled as bringing together a series of factors. I identified two main sets of factors constituting the assessment of best interests by HCPs, which I characterise, respectively, as primary or *prima facie* factors of best interests and as secondary factors of best interests. The latter modulate the assessment of best interests resulting from the combination of primary factors.

I designate the first set of factors as 'medical best interests'. The position resulting from the combination of these factors arises out of interactions between HCPs, most significantly the consultants involved in the care of the child. In these interactions, medical science and evidence constitute the dominant paradigm. For as long as the focus of the team is on diagnosing the causes of the child's critical condition with a view of elaborating a treatment plan, the question of best interests remains largely implicit and is equated with the basic purpose of the unit, namely that of curing the child while minimising long-term impact. In the words of one of the NICU's doctors:

best interests to us aren't the best interests of the courts about the child's potential future options being university or state school... Or you know, are you going to make a decision to change inotropes based on how many brothers the kid has and how old they are? Not really.

⁶⁰ Birchley and others (n 46) 930.

⁶¹ *ibid* 932.

[Physician #5]

Adopting the formulation of another participant, I designate the second set of factors as 'wider best interests'. It is concerned with the integration of elements HCPs perceive as further removed from the medical dimensions of the child's situation. This is where HCPs seek and consider the views of the child's parents. A broader range of HCPs are also susceptible of being involved in that latter process, including notably psychosocial professionals. Nonetheless, it takes place against the backdrop of the process of establishing medical best interests. It modulates the normative position resulting from the first process, without fundamentally challenging it. This is why I consider the integration of 'wider best interests' as a secondary process.

Finally, I also identified certain considerations HCPs mention as potentially relevant to the decisions made for patients of the NICU, but which they explicitly reject as not factoring into the assessment of best interests. The conclusion as to the best interests of the child reached by combining the two types of factors then serves as the premise for the second main process constituting the GNM.

3.2 Getting there with parents

GTWP is the pragmatic answer to a dilemma HCPs often perceive between their commitment to parental autonomy and their critical view of the capacity of parents to appreciate the best interests of their child. I will therefore introduce that second process through the normative tension pervading how HCPs approach decisions to withdraw life-sustaining care.

Essentially, GTWP rests on the idea that obtaining parental consent to WLST from a child is the result of an interactional and iterative process for elaborating a common frame of reference through repeated interactions between HCPs and parents. The juxtaposition of the factual and normative expectations of both HCPs and parents constitutes that normative frame of reference. GTWP conveys the idea that parents do not immediately nor automatically accept a suggestion that WLST might be in the best interests of their child. Often, HCPs will see it as their duty to support parents

along the path leading to such acceptance, which implies a change in their expectations. It is about the way HCPs go about obtaining such consent from parents while maintaining their commitment to uphold the best interests of the child.

GTWP implies transmitting norms from HCPs to parents. Although it is often presented as consisting in the ordering of medical facts, significant normative commitments buttress the process for determining the best interests of the child. As part of these commitments, is the openness to the possibility that it might be in that child's interest to withdraw life-sustaining therapy such that death will follow. Yet, parents do not all share the same point of departure. HCPs observe that not all parents come to the NICU adhering to this proposition. Some might never have contemplated that possibility, while for others it might run against some of their most fundamental values and beliefs. Even parents who might agree with the proposition in the abstract, may not agree that the circumstances of their child's illness warrant its application. When they discuss with parents and make a recommendation, HCPs therefore attempt to instil in parents the norms and principles that underlie their interpretation of the best interests of the child and give meaning to the course of action they propose.

Another implication of GTWP is that HCPs 'get there first', meaning the point of departure for HCPs and the path leading to a conclusion are different to parents. The concept of getting there with parents also involves the possibility that parents might be reluctant to assent to the HCPs' suggestion and that as a result HCPs might increase the pressure on them to 'get them there'. Finally, some parents might not 'get there' at all, therefore creating the necessity for HCPs to explore other avenues to implement their view of best interests, such as consulting the clinical ethics committee or filing a court application.

4. From the descriptive to the normative: challenging the GNM

Conceiving the GNM as a primarily descriptive endeavour was a means to approach

fieldwork in the London NICU with as open a mind as possible.⁶² I cannot pretend I had no prior knowledge of the legal and ethical dimensions of neonatal care. Before engaging in postgraduate studies, I worked as a clinical ethicist in a paediatric hospital in Montréal, Canada. I had been confronted to some dilemmas concerning WLST in the NICU and studied the normative literature on these issues. I also had a working knowledge of the legal and ethical frameworks about WLST in paediatric settings in England and Wales, in France⁶³ and in my home jurisdiction, the Canadian Province of Quebec.

However, in examining the normative side of my research question, my goal was not only to answer the questions I already had. Perhaps more importantly, I wanted to deepen my understanding of the context surrounding WLST, to either formulate new questions or envision new ways of answering the questions I had. After constructing a rich and detailed account of the way HCPs in the London NICU approach decision-making about WLST, my challenge was to examine the GNM to make recommendations as to how to improve the practice of the unit.

Notwithstanding the undeniable benevolence underlying the approach of HCPs, I can nonetheless address criticisms to the GNM. In chapters VI and VII, besides highlighting concrete issues and potential improvements to the way HCPs approach WLST in the London NICU, I hope to illustrate the potential of the GNM as a grounded point of departure for thinking about the processes that are deployed to make and implement decisions about WLST for critically ill neonates and infants. I ensured that each chapter closely tracks one of the two processes forming the GNM to preserve this thesis' contextual orientation.

I started from the features of the GNM that struck me as requiring further exploration to identify authors and approaches that might shed light on them rather than forcing

⁶² Charmaz (n 6) 130.

⁶³ Jean-Frédéric Ménard, 'Offering a Reasonable Future: Withdrawal of Life-Sustaining Treatment from Infants in French Law with Illustrations from a Parisian Neonatal Resuscitation Unit' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Medical Decision-Making on Behalf of Young Children: A Comparative Perspective* (Hart 2020).

the hypotheses of the GNM through a predetermined theoretical framework. This led me to adopt heterogeneous theoretical perspectives in interpreting and critiquing the GNM in chapters VI and VII.

This inductive and open-ended approach also allowed me to engage with the literature and case law in novel and productive ways. I let the model I constructed guide me in determining what was relevant and what was not, instead of abiding by the traditional hierarchy of legal sources or responding to issues raised in the literature. For that reason, although the question whether to modify the legal threshold for challenging the decision of parents from the child's best interests to significant harm to the child has gained tremendous visibility in academic and public debates, I only deal with it tangentially in my discussion of the GNM.⁶⁴

I was also careful to connect the theoretical arguments I made to the GNM and thus to the context under study. I hope that I could show-case not only the relevance of these theoretical arguments to understanding the practice of the London NICU, but also how the experience of HCPs illuminates more abstract debates.

4.1 The chronotope of best interests in the NICU

In chapter VI, 'The chronotope of best interests in the NICU', I discuss JIC through a socio-legal lens. Applying the notion of legal chronotope developed by Mariana Valverde to the NICU, I demonstrate how intertwined understandings of space and time – according to which the presence of the child in the NICU is transitional and the life-sustaining treatments she receives are both burdensome and a threat to her integrity – shape the recommendation to withdraw life-sustaining treatments.

This phenomenon, I argue, coalesces in the chronotope of best interests in the

⁶⁴ See e.g. Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 *Theor Med Bioeth* 243; Giles Birchley, 'Harm Is All You Need? Best Interests and Disputes about Parental Decision-Making' (2016) 42 *JME* 111; Johan Christiaan Bester, 'The Harm Principle Cannot Replace the Best Interest Standard: Problems With Using the Harm Principle for Medical Decision Making for Children' (2018) 18 *AJOB* 9; Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should Have the Final Say over a Child's Medical Care?' (2019) 78 *Cambridge LJ* 287.

NICU, which contributes to the constitution of a distinct normativity and allocates decision-making authority primarily to NICU consultants. Furthermore, I also show that the chronotope of best interests in the NICU is effective beyond the London Unit and is likely to influence the way judges approach cases where HCPs favour WLST.

From there, I argue that the two-step process through which HCPs elaborate a recommendation, first focusing on medico-physiological aspects of the child's situation, then modulating it by integrating a wider range of considerations, including the perspective of parents results in a narrowing down of the child's identity. I then conclude that adopting a more ideal posture before moving on to the necessary specification of the normative requirements of the situation would improve the initial assessment of best interests.

4.2 Can you take any road to get there? Best interest, influence, and manipulation

In Chapter VII, 'Can you take any road to get there? Best interests, influence and manipulation', I turn to GTWP, the second main process making up the GNM. I seek to explore and question the claim made by HCPs that parents lack capacity to make decisions that are in the best interests of their child, which is one of the main justifications offered by HCPs for deploying GTWP as a steering process.

The question whether it is ethically acceptable for HCPs to steer parents toward the outcome favoured by the treating team during the consent process led me to the interface between behavioural sciences and philosophical ethics. First, using Moti Gorin's account of manipulation as failure to track reasons, I explain how some strategies HCPs indicate using to 'get there with parents' can be characterised as manipulative. I then show that while there is no reasonable basis to claim that parents with a child in the NICU are lacking legal capacity in the traditional sense, the report of HCPs suggests that the peculiar and exacting circumstances of the NICU make parents particularly vulnerable to cognitive biases in how they reason about the best interests of their child. Finally, I connect this account of manipulative strategies with the suspicions of HCPs toward the parents' capacity to assess the

best interests of their child and detail the circumstances in which resort to such strategies would be ethically justifiable and those in which they would not.

As above-mentioned, this thesis proceeds in two main steps. In the first part, I begin by introducing the methodology I devised and used for constructing the GNM (Chapter II). I then develop the GNM over three chapters. The first two, 'Justifying intensive care' (Chapter III) and 'Wider best interests' (Chapter IV) present the first process through which HCPs assess the best interests of a child hospitalised in the London NICU. The third chapter constituting the GNM and giving it its title, 'Getting there with parents' (Chapter V) then presents an interpretation of the way HCPs put the conclusion of the first process to parents with the goal of securing their consent to the team's recommendation.

The second part is a critique of aspects of the two main processes forming the GNM. In 'The chronotope of best interest in the NICU' (Chapter VI), I discuss the normative impact of the spatiotemporal frame through which HCPs approach the process of justifying or not their recourse to prolonged, painful and invasive care. I show that the 'chronotope' of the NICU induces a narrow perspective on the child that is limited to medical and physiological aspects and therefore allocates decision-making authority disproportionately to HCPs at the expense of parents.

Finally, in 'Can you take any road to get there? Best interests, influence and manipulation' (Chapter VII), I critically examine four strategies that HCPs report using in their attempts to persuade parents that they should consent to WLST. While I conclude these strategies may be characterised as manipulative, I also explore the intuition of HCPs that the reasoning of parents can be clouded by cognitive biases, such that in certain circumstances these strategies could ethically be justified.

Chapter II - Grounded normative theory

Introduction

In the introduction, I sketched out the background and theoretical assumptions underlying this thesis. These assumptions, which can be summarised as pragmatism, constructivism and legal pluralism, led me down the way of empirical law and ethics as a broad paradigm.

In this chapter, I will focus on the methodological choices that guided me in conducting this research. Integrating law, ethics and empirical findings to formulate recommendations requires a renewed understanding of empirical methodology and methods.⁶⁵ In the first section, I argue in favour of combining empirical research with normative analysis to formulate a legal and ethical critique and to make recommendations along the same lines. Empirical ethics provide a good model for anchoring my research in a practical context. Empirical data connects a normative inquiry with the concerns of practice and clarifies the meaning of certain key terms. It also adds a layer of intersubjectivity in a domain where recommendations are likely to be dismissed as expressing the subjectivity of a single individual.

I then introduce 'grounded normative theory', a variation on grounded theory methodology. First, I outline the origins and methodological tenets of grounded theory, to isolate the elements I adopt and those I modify as part of normative grounded theory. Then, I underline the distinguishing features of grounded normative theory, which proceeds in three main stages. The first feature entails interpreting the normative dimension of decision-making through observation and in-depth interviewing to elaborate an emerging normative model of the London NICU. The second involves confronting the results of this first stage to the normative scrutiny of

⁶⁵ Michael Dunn and others, 'Toward Methodological Innovation in Empirical Ethics Research' (2012) 21 Camb Q Healthc Ethics 466.

healthcare professionals in focus group discussions. The second stage of this iterative process results in a grounded normative model. Finally, the third stage consists in a critical assessment to highlight how to improve the GNM.

In the last part of this chapter, I will explain how these methodological considerations played out in my research design. I will therefore present the case study I conducted in the London NICU. I will start with an overview of the processes through which I generated the data for elaborating the grounded normative model. This will also lead me to address research ethics considerations. Finally, I will conclude by presenting the analytical process that led to the elaboration of the GNM, insisting on how I relied on the two leading tools of grounded theory: coding and memo writing.

1. Why empirical law and ethics?

Empirical legal research has a rich and varied tradition.⁶⁶ Yet, the role of empirical methods in legal scholarship is not always understood and it can be contested both by lawyers as alien to legal scholarship and by social scientists as not meeting disciplinary standards. More recently, a movement now known as ‘empirical ethics’ or ‘empirical bioethics’ has emerged in favour of integrating empirical methodologies. Similarly, this movement has stirred some controversies and debates as to the role and relevance of empirical methodologies and methods.⁶⁷

In justifying my choice to put qualitative research at the centre of this project, I want to insist on one main justification for relying on empirical data in a normative project, namely that of anchoring normative research in social context.

1.1 Grounding research in social context

Recent years have seen the emergence of several sophisticated approaches to the

⁶⁶ See e.g. Mark C Suchman and Elizabeth Mertz, ‘Toward a New Legal Empiricism: Empirical Legal Studies and New Legal Realism’ (2010) 6 *Annu Rev Law Soc Sci* 555.

⁶⁷ Rachel Davies, Jonathan Ives and Michael Dunn, ‘A Systematic Review of Empirical Bioethics Methodologies’ (2015) 16 *BMC Medical Ethics* 15, 2–3. Jonathan Ives, Michael Dunn and Alan Cribb, *Empirical Bioethics: Theoretical and Practical Perspectives* (CUP 2018).

relation between empirical data and normative analysis, especially in bioethics.⁶⁸ Stella Reiter-Theil insists on the strength of the ‘dialectical concept’⁶⁹ that emerges when ‘[e]thics and the empirical interact – more specifically, [when] they challenge each other mutually and in a stepwise manner.’⁷⁰ This literature displays an ongoing discussion on why and how these challenges and interactions between the empirical and the normative should occur.⁷¹

Indeed, the main reason for integrating an empirical element in my study is to anchor it to the social context of critical care. I first introduce the critique of philosophical bioethics emanating from the social sciences, which is credited for sparking the interest for empirical (bio) ethics. I then discuss some justifications for integrating empirical and normative methodologies offered by several authors working in empirical ethics.

Adam Hedgecoe synthesised a wide range of critical literature on bioethics emanating from the social sciences. He argues that the ‘social science critique’⁷² challenges philosophical bioethics for putting too much emphasis on abstract rationality and for limiting itself on the ‘application of pre-prepared ethical theories to specific situations’.⁷³ Correlatively, the social and cultural context of clinical practice is neglected.⁷⁴ As a result, the issues addressed are those that appear to be salient from a philosophical, rather than a practical point of view.⁷⁵ Conversely, bioethics un-reflexively adopts several assumptions, from the relevance of moral categories such as that of the autonomous individual to the classification of diseases.⁷⁶

⁶⁸ Davies, Ives and Dunn (n 67) 8–9.

⁶⁹ Stella Reiter-Theil, ‘What Does Empirical Research Contribute to Medical Ethics?’ (2012) 21 Cambridge Q Healthcare Ethics 425, 426.

⁷⁰ *ibid.*

⁷¹ Ives, Dunn and Cribb (n 67).

⁷² Adam M Hedgecoe, ‘Critical Bioethics: Beyond the Social Science Critique of Applied Ethics’ (2004) 18 Bioethics 120, 121. For an early statement of the social science critique of philosophical bioethics, see Barry Hoffmaster, ‘Can Ethnography Save the Life of Medical Ethics?’ (1992) 35 Soc Sci Med 1421.

⁷³ Hedgecoe (n 72) 124–125.

⁷⁴ *ibid* 125.

⁷⁵ *ibid* 126.

⁷⁶ *ibid* 127–128.

Jonathan Ives and Heather Draper elaborate a response to the critique relayed by Hedgecoe and propose a methodology for integrating philosophical analysis and empirical work in bioethics.⁷⁷ Subsequent work by Ives is also important to the way I approached my research project. Consequently, I will follow closely the reasons Ives and Draper offer in support of combining empirical data with normative reflection. I will, however, also indicate points of convergence with other authors working in empirical ethics and identify another argument in favour of empirically informed normative analysis derived from their work.

The ultimate goal of my thesis is to contribute to improving the process of handling difficult decisions concerning WLST for young children. This objective fits squarely within the category of normative policy and practice-oriented bioethics, which, as described by Ives and Draper, 'engages in normative theorizing about what policy and practice should be'.⁷⁸ It is opposed, on one hand, to 'philosophical bioethics' which aims at conceptual elucidation; and on the other, to 'descriptive policy and practice-oriented bioethics' which is 'more like a sociology of bioethics, describing how bioethical reasoning actually takes place in various contexts'.⁷⁹ Ives and Draper write:

Normative policy and practice-oriented bioethics], which seeks to make normative judgements, requires the incorporation of moral theory and philosophical reasoning to produce rigorous and consistent ethical analysis, and yet it also requires empirical work so that the theorist can gain a practical understanding of the issues.⁸⁰

Further, Ives and Draper identify two main contributions of empirical data to this endeavour: 'to achieve a contextual understanding' and 'to understand meaning'.⁸¹ I will discuss each in turn and will extract a third theme from their analysis, namely the

⁷⁷ Ives and Draper (n 13) 250.

⁷⁸ *ibid* 251.

⁷⁹ *ibid*.

⁸⁰ *ibid*.

⁸¹ *ibid*.

expansion of the set of relevant intuitions.

1.1.1 'Achieving contextual understanding'

Essentially, 'achieving contextual understanding' means identifying and constructing issues from the bottom-up – from the actual social situations in which they arise – rather than superimposing theoretical concerns over them. The resulting normative solutions will thus be more attuned to the concrete situations from which they emerged. Draper and Ives write:

Having “encounters with experience” simply means positioning oneself so that one can understand, as far as possible, how an ethical problem affects peoples’ lives, how the problem is constructed and negotiated, and how different resolutions might affect stakeholders in different ways. The advantage of this is that it contextualises a problem and sensitises one to the needs and experiences of those most affected by it.⁸²

Similarly, Michael Dunn and colleagues argue that the quality and persuasiveness of an ethical argument depends not only on it being rational but also on its contextual accuracy:

ethical arguments that ignore or distort the actual details of the relevant situations risk drawing conclusions that are epistemically wrong. Individuals embedded in practical contexts are unlikely to be convinced by arguments that twist or misrepresent the facts as they come to know, understand, or act on them.⁸³

Researchers working in the hermeneutic ethics tradition also share this attention to lived moral experience and contextual understanding. For instance, Guy Widdershoven and colleagues argue for understanding 'empirical ethics as dialogical practice'. They write:

A dialogical approach emphasizes that ethics is concrete and contextual. A dialogue is an interaction between people involved in real problems. This

⁸² *ibid.* See also, Jonathan Ives, ““Encounters with Experience”: Empirical Bioethics and the Future’ (2008) 16 *Health Care Anal* 1.

⁸³ Dunn and others (n 65) 469.

distinguishes a dialogue from a theoretical debate. A dialogical approach to ethics implies a crucial role for experience and learning. A dialogue presupposes that the participants already have some interest in and insight into the matter at hand. It also presupposes that the participants can elaborate their interest and knowledge through an exchange of perspectives. A dialogical approach to ethics can be regarded as empirical, in that it implies a process of contextual and practical learning.⁸⁴

Contextual understanding is also important regarding the legal dimension of my study. HCPs only bring a small fraction of cases concerning the determination of the best interests before the courts. The vast majority of cases would either appear not to raise any conflict or be resolved without recourse to a formal judicial process. Of course, a few cases are sufficient to offer legal guidance, so that the eventual response of the courts can be anticipated without repeatedly litigating the same issues. Nonetheless, it appears likely that the small fraction of cases that are reported are not sufficient to provide an accurate representation of the resolution of controversial cases in practice, even when legal principles are invoked.⁸⁵ Empirical data is therefore susceptible of providing crucial elements to complete that picture.

1.1.2 'Understanding meaning'

The potential for terminological confusion is high and a clarifying exercise should be helpful. Understanding meaning refers to the process of:

establish[ing] how concepts and meanings are used at "ground level". The purpose of this is to ensure that everyone is talking the same language, and that the theorist is using terminology and concepts that are commensurate with the usage of the stakeholders.⁸⁶

Furthermore, qualitative empirical work goes beyond preparing an inventory of the different uses and definitions of a word or an expression. It can allow us to understand the role a concept plays in a practice, how it relates to other words, expressions and concepts. To paraphrase Ludwig Wittgenstein, it allows to witness

⁸⁴ Guy Widdershoven, Tineke Abma and Bert Molewijk, 'Empirical Ethics as Dialogical Practice' (2009) 23 *Bioethics* 236, 237. See also Matthew R Hunt and Franco A Carnevale, 'Moral Experience: A Framework for Bioethics Research' (2011) 37 *JME* 658.

⁸⁵ Ménard (n 11) 2–3.

⁸⁶ Ives and Draper (n 13) 251.

the 'language-game[s]' of which these words and concepts are a part and to attempt to reconstruct their inner logic and their rules.⁸⁷

1.1.3 Expanding the intuition set

Empirical research is relevant to normative endeavours in that it allows to move from the subjective experience of an individual reflecting on problems he or she has identified as raising ethical issues to an intersubjective understanding of the circumstances giving rise to ethical questioning or malaise, and to the ethical responses they elicit. This allows, at least in part, to overcome the charge of subjectivity that unavoidably follows any normative proposition in fraught moral debates. Indeed the researcher is forced to consider and accommodate perspectives or intuitions with which he or she initially disagrees.⁸⁸ Matthew Hunt and Franco Carnevale, two authors working within the tradition of hermeneutics and phenomenology formulate the idea of expanding the intuition set as follows:

Indeed, the scope of bioethics and the ambit of bioethics scholarship encompasses more than the processes of evaluating options and enacting choices in response to one's understanding of a contentious or vexing situation. This reality has implications for both empirical and theoretical approaches to bioethics. Drawing attention to a broader array of moral experience can lead to better understanding and richer analysis of topics of concern in bioethics.⁸⁹

Ives and Draper, whose philosophical point of reference is closer to the Anglo-American tradition of analytical moral philosophy, make a similar point when they suggest that empirical fieldwork allows expanding the set of intuitions that are used to construct and evaluate moral theories. They write:

[o]ne way, then, that empirical data can appropriately be combined with moral theory is to replace the individual philosophers' moral intuitions with the intuitions of the relevant stakeholder population.⁹⁰

⁸⁷ Ludwig Wittgenstein, *Philosophical Investigations* (Wiley-Blackwell 2009) para 23.

⁸⁸ Ives and Draper (n 13) 256.

⁸⁹ Hunt and Carnevale (n 84) 658.

⁹⁰ Ives and Draper (n 13) 255.

In this section, I identified the main justification for embarking in an empirical investigation of the topic of WLST. Empirical ethics provide a good model for anchoring our research in a practical context. In this regard, empirical data can serve three main functions, namely (1) to connect a normative inquiry with the concerns of a social context; (2) to clarify and explore the meaning of certain key terms and (3) to broaden the scope of relevant intuitions in approaching normative questions.

Having presented the case for empirically informed law and ethics, I can now turn to introducing grounded normative theory, the methodology I have devised to conduct my inquiry into the normativity of WLST.

2. Toward Grounded Normative Theory

An empirical methodology for exploring normative processes should retain a strong critical dimension, but it requires adaptations for integrating intersubjective and empirical dimensions and generating valid and relevant normative results. Michael Dunn and colleagues argue that such methods should be recast into new methodologies:

[e]mpirical ethics needs its own distinctive methodological repertoire that borrows from, and builds on, contemporary thinking about empirical data collection and analysis within the social sciences. Empirical ethics methodologies should be characterized not as toolboxes for extracting facts that can be fed unproblematically into normative reasoning, but rather as flexible and practice-orientated spaces within which ethics researchers and practitioners can offer explanations, engage in critical reasoning, come to understand one another, and codevelop relevant arguments.⁹¹

Ives and Draper provide an illustration of such a reconfiguration, noting that their project on paternal rights relied on a modified version of the focus group method, where, instead of only eliciting and recording the views of the participants, they also engaged in respectful debates with the participants to clarify their views and moral commitments and to uncover the premises of such views and commitments.⁹² Both Dunn and colleagues and Ives and Draper would agree that this flows from ‘the

⁹¹ Dunn and others (n 65) 473.

⁹² Ives and Draper (n 13) 255; Carter (n 55) 557.

constructivist foundations of contemporary social sciences, in which it is firmly acknowledged that meaning is coproduced during the research encounter'.⁹³

In this section, I introduce *grounded normative theory*, a research methodology I developed in response to this call for methodological renewal. I built primarily on grounded theory, an established qualitative research methodology in social science and, from empirical bioethics, on the work of Dunn and colleagues, Ives and Draper and Ives alone. I must also acknowledge the recent work published by Stacy M. Carter to highlight the lines of convergence between grounded theory and empirical ethics from the perspective of the former.⁹⁴

I begin by outlining what is grounded theory and what I took from it to devise an original research methodology for my project. I then move on to discuss salient methodological contributions from empirical bioethics to justifying the choices I have made in devising my methodology.

2.1 What is Grounded Theory?

Grounded theory is the main building block for grounded normative theory. It provides a set of structured methods for the analysis of qualitative data and the elaboration of theories grounded in that data.⁹⁵ Its key feature is its 'bottom-up' approach to the elaboration of theory. As such, it answers the need for connecting the inquiry to the social context. Grounded theory's founders, Anselm Strauss and Barney Glaser, described it as 'the discovery of theory from data systematically obtained from social research'.⁹⁶ Later, Glaser added that grounded theory is a methodology aimed to 'get through and beyond conjecture and preconception to exactly the underlying processes of what is going on, so that professionals and

⁹³ Dunn and others (n 65) 472. See also Dunn and Ives (n 20).

⁹⁴ Carter (n 55).

⁹⁵ Juliet M Corbin and Anselm L Strauss, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (SAGE 2008) 53–6.

⁹⁶ Barney G Glaser and Anselm L Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Aldine 1967) 2.

laymen alike can intervene with confidence to help resolve the participant's main concerns'.⁹⁷

Here, I will expose the principles of the methodology. In line with the social constructivist epistemological commitment discussed in the introduction, I follow the constructivist reinterpretation proposed by Kathy Charmaz in her book 'Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis'.⁹⁸

Through Glaser and Strauss, grounded theory inherited theoretical underpinnings in both social science positivism and pragmatism.⁹⁹ I do not subscribe to the positivist ideal of identifying objective truths through qualitative research. Yet, grounded theory, with its 'dispassionate empiricism, rigorous codified methods, emphasis on emergent discoveries, and its somewhat ambiguous specialized language that echoes quantitative methods'¹⁰⁰ nonetheless appears worthy as 'a strategy for research rather than as method to generate more positivist findings'.¹⁰¹ The methods of grounded theory contribute to streamlining the research by dividing it up into interlinked and yet discrete steps. Moreover, each of these steps leaves a written trace, thereby facilitating communication between researchers and allowing the steps leading to a conclusion to be retraced and evaluated. Consequently, when correctly applied, the methods of grounded theory contribute to the trustworthiness of the research findings.¹⁰²

On the other hand, the link between grounded theory and pragmatism, notably through its sociological interpretation as 'symbolic interactionism' is much more in line with the theoretical assumptions I have outlined above.¹⁰³ Charmaz summarises symbolic interactionism as follows:

⁹⁷ Barney G Glaser, *Doing Grounded Theory: Issues and Discussions* (Sociology Press 1998) 4–5.

⁹⁸ Charmaz (n 6).

⁹⁹ *ibid* 9; Stübing (n 15) 595.

¹⁰⁰ Charmaz (n 6) 9.

¹⁰¹ Lisa Webley, 'Qualitative Approaches to Empirical Legal Research' in Peter Cane and Herbert Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (OUP 2010) 945.

¹⁰² Bryman (n 10) 390–393.

¹⁰³ Corbin and Strauss (n 95) 1–8.

Pragmatism informed symbolic interactionism, a theoretical perspective assuming society, reality, and self are constructed through interaction and thus rely on language and communication. This perspective assumes that interaction is inherently dynamic and interpretive and addresses how people create, enact, and change meanings and actions.¹⁰⁴

There is a strong connection with the thought of legal pluralists such as Macdonald and van der Burg who also give pride of place to interactions in interpreting the emergence and effectivity of legal norms.¹⁰⁵ Macdonald's focus on individuals and their agency is also reflected in symbolic interactionism.¹⁰⁶ In turn, this emphasis on agency makes symbolic interactionism particularly apt for studying ethical decision-making.¹⁰⁷

Grounded theory is characterised by a series of methods aimed at systemising the process of analysing qualitative data for generating theory from it. These techniques can be applied to analyse any kind of data, from interviews to participant observation and documents.¹⁰⁸ The data generated is analysed from the beginning of the research process through 'constant comparative analysis'.¹⁰⁹

Initially, analysis is conducted through successive layers of 'coding', the process of 'naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data'.¹¹⁰ Charmaz further explains that:

[c]oding is the pivotal link between collecting data and developing an

¹⁰⁴ Charmaz (n 6) 9. On the basic tenets of symbolic interactionism, see Herbert Blumer, *Symbolic Interactionism: Perspective and Method* (Prentice-Hall 1969).

¹⁰⁵ Van der Burg acknowledges his debt to pragmatism and symbolic interactionism, see Wibren van der Burg, 'A Pluralist Account of Legal Interactionism' (Social Science Research Network 2013) SSRN Scholarly Paper ID 2264108 11 <<http://papers.ssrn.com/abstract=2264108>> accessed 12 March 2014. Macdonald's relation to this intellectual current appears to be mediated through the influence it had on the work of Lon L. Fuller. On the influence of pragmatism on Fuller's thought, see Kenneth I Winston, 'Is/Ought Redux: The Pragmatist Context of Lon Fuller's Conception of Law' (1988) 8 *Oxf J Leg Stud* 329.

¹⁰⁶ Areewan Klunklin and Jennifer Greenwood, 'Symbolic Interactionism in Grounded Theory Studies: Women Surviving With HIV/AIDS in Rural Northern Thailand' (2006) 17 *Journal Assoc Nurses AIDS Care* 32, 33.

¹⁰⁷ Sabine Salloch and others, 'The Normative Background of Empirical-Ethical Research: First Steps towards a Transparent and Reasoned Approach in the Selection of an Ethical Theory' (2015) 16 *BMC Medical Ethics* 20, 7.

¹⁰⁸ Charmaz (n 6) ch 2.

¹⁰⁹ *ibid* 132.

¹¹⁰ *ibid* 111.

emergent theory to explain these data. Through coding, you define what is happening in the data and begin to grapple with what it means. The codes take form together as elements of a nascent theory that explains these data and directs further data-gathering. By careful attending to coding, you begin weaving two major threads in the fabric of grounded theory: generalizable theoretical statements that transcend specific times and places and contextual analyses of actions and events'.¹¹¹

Charmaz designates the first stage as 'initial coding'. It aims at staying as close as possible to the data.¹¹² At this stage, coding strategies include 'line-by-line coding'¹¹³ where documents and transcripts are meticulously analysed and broken down into small units of meaning and the use of 'in vivo codes'¹¹⁴, that is codes taken directly from the participants' way of formulating things. In the second stage, codes are used to navigate the data, they facilitate comparison between different incidents or different interviewees.¹¹⁵ The codes themselves are then analysed to identify those that require further exploration and elaboration and to develop categories that would be susceptible of bringing initial codes together and therefore 'synthesise and explain larger segments of data'.¹¹⁶ This is what Charmaz designates as 'focused coding'.¹¹⁷

Although grounded theory insists on staying as close as possible to the data in conducting the analysis and in constructing a theory from it, it nonetheless recognises that researchers do not approach their task without any preconception or with a blank slate. Researchers come to their research with '[g]uiding interests, sensitizing concepts, and disciplinary perspectives'.¹¹⁸ However, an important characteristic of grounded theory is the relatively low epistemic status that is conferred upon these 'points of the departure'.¹¹⁹ This leads Charmaz to state bluntly: '[i]f particular sensitizing concepts prove to be irrelevant, then we dispense with

¹¹¹ *ibid* 113.

¹¹² *ibid*.

¹¹³ *ibid* 121.

¹¹⁴ *ibid* 134.

¹¹⁵ *ibid* 138.

¹¹⁶ *ibid*.

¹¹⁷ *ibid*.

¹¹⁸ *ibid* 31.

¹¹⁹ *ibid*.

them'.¹²⁰ As long as they contribute to illuminating data, such sensitising concepts are useful, however care has to be taken not to let them obscure the data by superimposing an interpretation the data does not warrant.

The iterative interpretation of the data generated and the incremental development of a more general perspective on it continues by reflecting on emerging codes and categories through 'memo writing'. The production of memos throughout the research contributes to the reflexive nature of the process and documents the emergence of theoretical insights from the data.¹²¹ Charmaz writes: [b]y writing memos on your focused codes, you build and clarify your category by examining all the data it covers and by identifying variations within it and between other categories. You also become aware of gaps in your analysis'.¹²²

As constant analysis of data guides the data generating process, sampling decisions, such as who to interview next, what questions to ask, or which situations to observe, are guided by the need to flesh out emerging insights or to rule out hypotheses.¹²³ The purpose of sampling is not therefore, as with quantitative studies, to achieve statistical significance, but rather theoretical relevance. Hence, this approach to sampling is labelled '*theoretical sampling*, which means seeking and collecting pertinent data to elaborate and refine categories in your emerging theory'.¹²⁴ The aim of theoretical sampling is ultimately to reach 'theoretical saturation'. Corbin and Strauss describe it as '[t]he point in analysis when all categories are well developed [...] Further data gathering and analysis add little conceptualization, though variations can always be discovered'.¹²⁵

2.2 Adapting grounded theory

Dunn and colleagues sketch out several methodologies they suggest could be used to conduct empirical ethics research. 'Grounded moral analysis' is one of those and,

¹²⁰ *ibid.*

¹²¹ Lora Bex Lempert, 'Asking Questions of the Data: Memo Writing in the Grounded Theory Tradition' in Antony Bryant and Kathy Charmaz (eds), *The SAGE Handbook of grounded theory* (SAGE 2012) 249.

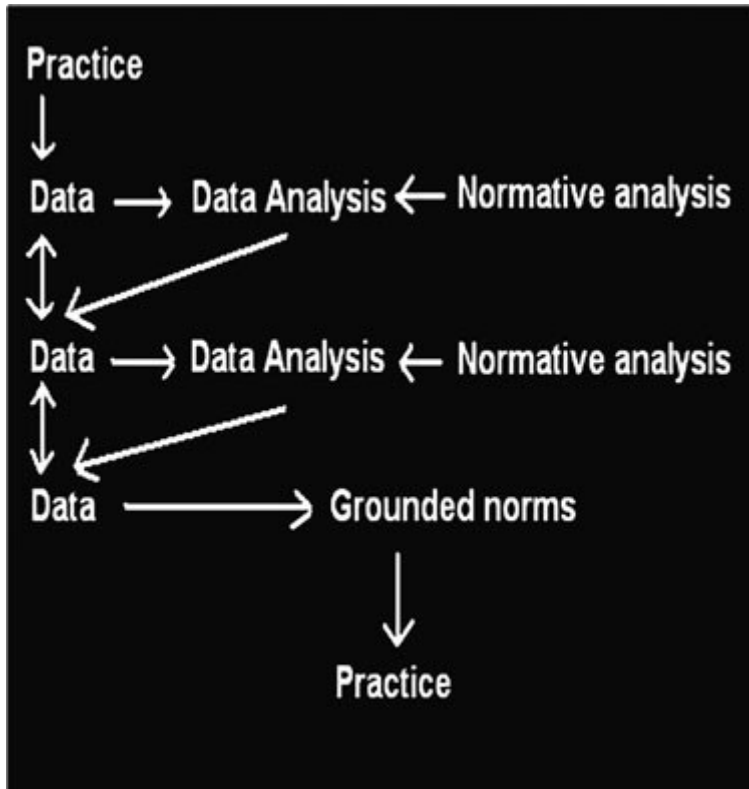
¹²² Charmaz (n 6) 190.

¹²³ *ibid* 204.

¹²⁴ *ibid* 192.

¹²⁵ Corbin and Strauss (n 95) 263.

as its name suggests, it is very close to grounded theory. It shares the latter's commitment for working from data to theory, rather than approaching data through a conceptual framework. The following figure summarises the research process envisioned by Dunn and colleagues.¹²⁶



As outlined above regarding grounded theory, ‘the research process is iterative and inductive’.¹²⁷ The generated data is continuously analysed and fed back into the data generating process, ‘directing the sampling frame and refining the interview guide so as to focus on particular targeted and active questioning that engages participants in reasoning through the relevant perspectives within the interactions that constitute the method’.¹²⁸

2.2.1 Grounded normative theory

A significant difference between Dunn and colleagues’ grounded moral analysis and

¹²⁶ Dunn and others (n 65) 474.

¹²⁷ *ibid* 473.

¹²⁸ *ibid* 474.

grounded theory is the inclusion of a further step of normative analysis in the analysis of the data gathered followed by the re-introduction of the results of this analysis in the research process. Such interplay between the normative and the empirical is obviously what characterises empirical bioethics. However, a crucial challenge in devising a research methodology in this area is that of achieving the right balance between these two elements.

The normative implications of the understanding emerging from fieldwork have to be worked out continuously. As such, the analysis process, both in terms of coding and memos and in terms of directing theoretical sampling should pay attention to the normative dimensions of the phenomena. It is thus important to identify and to probe the legal and ethical justifications evoked by participants in their activities, in written documents or in interviews and to assist them in developing them as much as possible.¹²⁹

However, too much insistence on the justification of normative claims early in the research process might contribute to weakening the link between the norms identified and the socially embedded practice they are meant to reflect. By combining the discovery of the normativity in the setting under study with its transformation right away, I would have run the risk of producing norms that are less 'grounded' than Dunn and colleagues suggest they would be by following their suggested method. One of the reasons for this difference lies in the fact that Dunn and colleagues adopt a conception of normativity that, as Macdonald would put it, is mostly explicit and formulaic.¹³⁰ They do not seem to accord much weight to the implicit, inferential and interactive dimensions of the normativity of practices. Indeed, as the name they give to their methodological sketch implies, they are strictly interested in the justification of moral norms, notwithstanding their insistence on the importance of context and local understandings in achieving this. My focus is broader and seeks to encompass both what is traditionally known as, respectively, legal norms and ethical norms. The

¹²⁹ Carter (n 55) 551.

¹³⁰ Roderick A Macdonald, 'Pour la reconnaissance d'une normativité juridique implicite et « inférentielle »' (1986) 18 *Sociol Soc* 47, 53.

name I have chosen for my methodology reflects this. I prefer 'normative theory' to 'moral analysis' because I want to stress that I seek to reflect both legal and ethical ideas, conceptions and representations in my theoretical constructions.

Similarly, as to the place to be afforded to dogmatic legal analysis, for instance, as to whether to inform participants that a view they express or endorse would seem to be contrary to positive law, I was mindful that such active intervention on the reasoning of participants early in the process would be likely to distort the normative account of their practice. I therefore took the view that first establishing a rich representation of their normative practices, then using ethical and legal arguments to problematise empirical findings and narrow down on the task of normative discussion would better serve my purpose.

This is why I proceeded in two stages. The first phase of my research design is concerned with the elaboration of a theoretical model of the normative landscape in the London NICU. I stayed close to grounded theory methodology as described above, except for the fact that I paid close attention to the normative dimension of the data in the analysis.¹³¹ This is what I call an 'emerging normative model'. In the terminology suggested by Draper and Ives, on its own, this would qualify as an exercise in 'descriptive policy or practice-oriented bioethics' whose purpose is 'more like a sociology of bioethics, describing how bioethical reasoning actually takes place in various contexts'.¹³²

The second phase builds on the findings of the first phase and proposes to bring together the empirical and the normative in a dialectical way.¹³³ Once I had been able to elaborate a convincing picture of the normative landscape, I presented the emerging normative model to participants in modified focus-group sessions.

¹³¹ Carter (n 55) 258–259.

¹³² Ives and Draper (n 13) 251.

¹³³ Reiter-Theil (n 69) 432.

2.2.2 Modified focus groups aimed at reflexive balancing

In developing the focus group element, I started from Ives and Draper's modified focus group method¹³⁴ and coupled it with the reflexive balancing method proposed by Ives in a later article.¹³⁵ According to Ives and Draper, the main difference between their approach and typical focus group research is that they

decided to challenge participants' views, actively but unaggressively, by offering counterfactual cases and counter-arguments and allowing them to revise and rethink as the discussion progressed, to distilling the moral principles and conceptual understanding on which participants' views [...] were based.¹³⁶

Ives and Draper indicate that they drew the inspiration for the focus group format from Alderson and colleagues who conducted several ethics discussion groups with healthcare practitioners on themes previously identified in 'in-depth sociological interviews'¹³⁷ to identify and precisely delineate the normative dilemmas that these professionals confront in their practice.¹³⁸

The purpose of the focus groups was twofold. First, I sought to elicit the views of the participants on the emerging normative model to assess the extent to which the model reflected the understanding of the group of people whose normative practices I sought to represent. It provided an opportunity to fine-tune the emerging normative model and to validate the results of the first two phases.¹³⁹

Secondly, I sought the input of participants on whether the emerging normative

¹³⁴ Ives and Draper (n 13) 255.

¹³⁵ Ives, 'Reflexive Balancing' (n 18). It is important to note, however, that Ives does not make the connection between these two aspects of his work.

¹³⁶ Ives and Draper (n 13) 255.

¹³⁷ Priscilla Alderson, Bobbie Farsides and Clare Williams, 'Examining Ethics in Practice: Health Service Professionals' Evaluations of in-Hospital Ethics Seminars' (2002) 9 *Nurs Ethics* 508, 510.

¹³⁸ See Alderson, Farsides and Williams (n 137); Clare Williams, Priscilla Alderson and Bobbie Farsides, 'Dilemmas Encountered by Health Practitioners Offering Nuchal Translucency Screening: A Qualitative Case Study' (2002) 22 *Prenatal Diag* 216.

¹³⁹ Bryman (n 10) 391; Patricia Bazeley, *Qualitative Data Analysis: Practical Strategies* (SAGE 2013) 408.

model could be improved and, if so, how. As noted by Webley, ‘Focus groups (group interviews) are one of a range of qualitative data collection methods that may lead to both useful data and truly participatory interviewer-interviewee interaction. *Groups are not just a convenient way to accumulate the individual knowledge of their members. They give rise synergistically to insights and solutions that would not come about without them* (Brown et al. 1989:40)’.¹⁴⁰

I took some distance from grounded theory and started to integrate a more explicitly critical method to my research design. Ives argues for using a process he calls ‘reflexive balancing’. Reflexive balancing is an attempt to answer some defects of the methodology of reflective equilibrium advocated by John Rawls in *A Theory of Justice*.¹⁴¹ Norman Daniels summarises reflective equilibrium as follows:

reflective equilibrium consists in working back and forth among our considered judgements (some say our “intuitions”) about particular instances or cases, the principles or rules that we believe govern them, and the theoretical considerations that we believe bear on accepting these considered judgements, principles, or rules, revising any of these elements wherever necessary to achieve an acceptable coherence among them.¹⁴²

Coherence between considered judgements and theoretical principles is thus at the centre of reflective equilibrium. The main problem highlighted by Ives is that when considered judgements and principles conflict, it is difficult, if not impossible, to decide which one of the two should be modified to accommodate the other.¹⁴³ This results in the possibility of many different points of equilibrium without any principled way to discriminate between them.¹⁴⁴ This is why Ives resorts to ‘quasi-moral foundationalism’ where the ‘boundary principles’ identified in the empirical stage of an inquiry into a bioethical problem are presumed to be justified and represent what he describes as a ‘null hypothesis’ that gets the process going. Ives defines the

¹⁴⁰ Webley (n 101) 937. Emphasis in original.

¹⁴¹ John Rawls, *A Theory of Justice* (Belknap 2003).

¹⁴² Norman Daniels, ‘Reflective Equilibrium’ in Edward N Zalta (ed), *The Stanford Encyclopedia of Philosophy* (Spring 2011, 2011) <<http://plato.stanford.edu/archives/spr2011/entries/reflective-equilibrium/>> accessed 1 July 2013.

¹⁴³ Ives, ‘Reflexive Balancing’ (n 18) 305.

¹⁴⁴ *ibid.*

boundary principles in an initial stage of the research that precedes the crucial step of reflexive balancing. He labels this stage 'disciplinary naïve inquiry into the problem' and states two related goals for it.¹⁴⁵ The first goal is to draw an inventory of the 'values that operate on the problem, and attempt to find some basic value propositions, which can act as quasi-foundational boundary principles'.¹⁴⁶ The second goal is to achieve deep contextual understanding of the issues at stake.¹⁴⁷

Thus, reflexive balancing can combine a deep and rich grounded theory of normative practices with the reflexive potential of those actors from whose understandings and interactions this model emerged. In this regard, I diverge from Ives. Contrarily to his previous methodological propositions, in which participants were actively involved in the normative analysis phase,¹⁴⁸ participants are not called upon to contribute to reflexive balancing.

Although the exercise cannot be conducted in a relatively short discussion with the same level of precision and conceptual sophistication, which a researcher working in the calm of his or her study and with the benefit of the literature would apply, I take the view that reflexive balancing should nonetheless serve as a guiding objective, especially when they involve professionals for whom reflection constitutes part of their practice. The focus group discussions, once analysed and integrated into the emerging normative model took me closer to a grounded normative model of WLST processes in the London Unit. Obviously, the researcher has to conduct a significant part of the normative analysis and critique required by reflexive balancing. As they are only presumed to be foundational, the 'boundary principles' gathered in the field are then confronted with diverging views emerging from the literature or empirical data coming from other sources. Ives writes:

¹⁴⁵ *ibid* 311.

¹⁴⁶ *ibid*.

¹⁴⁷ *ibid*.

¹⁴⁸ Ives and Draper (n 13); Jonathan Ives, 'Becoming a Father / Refusing Fatherhood: How Paternal Responsibilities and Rights Are Generated' (PhD thesis, University of Birmingham 2007) <<http://etheses.bham.ac.uk/254/>>.

the boundary principles are [...] systematically challenged by confronting these principles with the recalcitrant experience that generated the problem, alternative theoretical perspectives, potentially disconfirming data, etc. With each new confrontation, an attempt to find coherence with the boundary principles must be made, and the reason for either accepting or rejecting the new addition made explicit and justified in terms of its overall coherence.¹⁴⁹

This is why, once I finished constructing the GNM, I delved into a broad range of critical and theoretical literature to criticise and challenge some elements that struck me as potentially problematic or requiring further justification. As observed by Stacy M. Carter:

[t]he grounded theory tradition of focusing on concepts and exploring what they mean to people in the contexts of their lives can thus contribute significantly to ethical conceptual development.¹⁵⁰

A deep understanding of the context of the London NICU thus grounds the critique I articulated over the last two chapters. This, I argue, lends additional practical relevance to my analysis and credibility to the suggestions for improvement that I make there.

So far, I have discussed my research methodology at a rather abstract level. In the next section, I turn to detailing the way in which it was operationalised to conduct my research.

3. An exemplifying case study of WLST in a NICU

I conducted the fieldwork for this study in the NICU of a paediatric hospital in London, United Kingdom. In this section, I detail how I designed and conducted it. First, I introduce the London paediatric hospital and the NICU. I then turn to how I conducted the empirical component of the study. This will lead me to discuss both data generating processes, including research ethics considerations and the analysis processes that guided me in the realisation of this study.

The hospital where I conducted the London case study is one of a few hospitals

¹⁴⁹ Ives, 'Reflexive Balancing' (n 18) 311.

¹⁵⁰ Carter (n 55) 552.

providing tertiary specialised care and quaternary highly specialised care to children in the Metropolitan London area.¹⁵¹ The hospital is also a teaching and research hospital and is part of an Academic Health Science Partnership linking it with a university and other hospitals in London. Because of its university affiliation, many of the healthcare professionals working for the hospital, notably some consultants, also hold either primary or honorary academic appointments. As I explain more fully in the subsection on research ethics, to add a further layer of protection to the anonymity of the study's participants, I will not reveal the name of the hospital here.

The hospital is part of an NHS Foundation Trust and, as such, is primarily government-funded through NHS England and commissioning contracts with Clinical Commissioning Groups. An active charity also funds its activities and investments in various ways. Like all such centres in London, the hospital has an excellent reputation, both nationally and internationally, for the cutting-edge and innovative care it provides to its patients and the quality of the training offered to aspiring healthcare professionals.

For its part, the NICU is a relatively small unit, catering to babies with a need for the highest level of critical care support. The NHS London Neonatal Operational Delivery Network, which coordinates the operations of the 28 hospitals offering care to neonates in the Metropolitan London area lists the NICU as a level-3 unit, based on its capacity to care 'for babies who need:

respiratory support (ventilation)'; 'additional support due to weighing less than 1,000 g'; 'CPAP and are born at less than 28 weeks gestation'; 'support due to severe respiratory disease'; or 'surgery'.¹⁵²

The babies hospitalised in this unit are often referred to the NICU from the secondary care local hospital where they were born. Many were born prematurely, but not all of them. Some conditions or illnesses are treated primarily by the NICU

¹⁵¹ The information for this section has been gathered from public sources including the websites for the London Hospital and the NHS Foundation Trust of which it is part. To avoid identifying the Hospital, references to these materials are not included herein.

¹⁵² NHS London Neonatal Operational Delivery Network, 'About Us' (*London Neonatal Operational Delivery Network*) <<http://www.londonneonatalnetwork.org.uk/about-us/>> accessed 28 November 2017.

team. These include complications of prematurity, such as necrotising enterocolitis ('NEC'), and conditions also affecting term babies, such as persistent pulmonary hypertension of the newborn or congenital malformations. However, a significant number of patients are admitted to the NICU while remaining under the care of other specialists. For example, babies recovering from or getting ready to undergo surgery form an important part of that latter group.

My research design is essentially a case study.¹⁵³ My initial goal was to produce an 'emergent normative model' of the processes relating to WLST in the London NICU then to refine it to generate a 'grounded normative model'. As noted by Eisenhardt, 'the case study is a research strategy which focusses on understanding the dynamics present within single settings'.¹⁵⁴ In choosing the London NICU, my purpose was to select an 'exemplifying case'. As explained by Alan Bryman:

the notion of exemplification implies that cases are often chosen not because they are extreme or unusual in some way but because either they epitomize a broader category of cases or they will provide a suitable context for certain research questions to be answered.¹⁵⁵

The unit of analysis for my case study is not the formal legal jurisdiction of England and Wales, although the London NICU is subject to it. As I am adopting a qualitative methodology coupled with a legal pluralist approach, my focus is much narrower. It is more appropriate to say that I studied the normativity of WLST in an urban English paediatric hospital, rather than the law of England and Wales in the abstract. Furthermore, describing the research site primarily in geographical terms is, at best, shorthand. I treated the London NICU as a focal point for the multitude of normative orders hypothesised by legal pluralism.

I directed my research primarily at the context of the London NICU to contribute to the improvement of practices in that site. However, to the extent that London NICU is

¹⁵³ Bryman (n 10) 67–70.

¹⁵⁴ Kathleen M Eisenhardt, 'Building Theories from Case Study Research' (1989) 14 *Acad Manage Rev* 532, 534.

¹⁵⁵ Bryman (n 10) 70.

indeed an exemplifying case, my findings should also be transferable to other settings. In that sense, they also form the basis of a more general understanding of the law and ethics of WLST in neonatal care.¹⁵⁶

3.1 Overview of the data generation process

I generated the data for the case study over a period of 27 months between, September 2014 – when I first followed the morning rounds in the NICU, to December 2016, when I ran the last focus group discussion session with HCPs.

I generated the bulk of the data underpinning the GNM through interviews and focus group discussions with healthcare professionals, either directly involved in the care and support of severely disabled neonates and infants and their family, or indirectly through their involvement in the clinical ethics committee and the process leading to a court application. I will further describe the participants in the study in what follows. However, before doing so, I would like to sketch out the logistics of the fieldwork I conducted for the London case study.

3.1.1 Contextualising and orienting the data generating process through ethnographic observation

My fieldwork began with ethnographic observation of the London NICU. Undoubtedly, ethnographic observation was second to in-depth interviews and group discussions for generating data. Nonetheless, it was an important method and forms an integral part of my research design.¹⁵⁷ The time I spent observing the NICU and the clinical ethics committee would not be sufficient to form the basis of a convincing and reliable grounded normative model. Yet, my regular visits to the hospital generally and to the NICU allowed me to acquire contextual understanding of their inner workings and dynamics, and identifying potential interviewees and issues to address in interviews.¹⁵⁸ Relatedly, in analysing the data, the knowledge of the site I thus acquired also contributed to the triangulation and questioning of findings

¹⁵⁶ Keith Taber, *Classroom-Based Research and Evidence-Based Practice : An Introduction* (2nd edition, SAGE 2013) 127.

¹⁵⁷ Charmaz (n 6) 85.

¹⁵⁸ Jane Ritchie and others (eds), *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (SAGE 2014) 249–250.

emerging from in-depth interviews.¹⁵⁹

After meeting with the consultant who was my key informant in their office to discuss my project and request their collaboration, and once I had obtained the necessary research credentials, I attended the morning rounds in the London NICU for the first time. Every time I visited the hospital, I sought to focus my observation on the normative dimension of the role of HCPs going about their daily duties, notably to identify instances where they were recognising a normative dilemma or expressing a value judgement. Most of the interviews I conducted with HCPs working in the NICU took place on the unit, therefore affording me several shorter visits to the unit. Concretely, I took notes every time I visited the hospital and prepared fieldnotes whenever I spent a substantial amount of time at the London Hospital.¹⁶⁰

My continued observation of the functioning of the hospital allowed me to bring together some intuitions arising out of the interviews I conducted to test hypotheses in real time, thereby contributing to the constant analysis of the data I was generating. It allowed me to develop interstitial knowledge about the unit and the hospital's ethos that I could then use to fill some gaps between the perspectives of the different HCPs I interviewed. It is also in the context of the observations that I conducted in the early days of the data generating process that I could identify a case that I followed for several weeks and on which I based the first set of interviews that I conducted.¹⁶¹

Although I was a frequent visitor, I was not embedded in the NICU. My lack of clinical training prevented me from taking on any kind of clinical role that would have led me to be more involved.¹⁶² My access to the site was largely mediated by one consultant

¹⁵⁹ Jane Lewis and others, 'Generalising from Qualitative Research' in Jane Ritchie and others (eds), *Qualitative research practice: a guide for social science students and researchers* (SAGE 2014) 358; Bazeley (n 139) 406.

¹⁶⁰ Karen O'Reilly, *Ethnographic Methods* (Routledge 2005) 91.

¹⁶¹ Ritchie and others (n 158) 250–251.

¹⁶² Andrew Bengry, 'Accessing the Research Field' in Uwe Flick (ed), *The SAGE Handbook of Qualitative Data Collection* (SAGE 2018) 101.

who played the roles of sponsor, key informant and gatekeeper, inviting me to events of interest, introducing me to potential interviewees and taking me along to meetings.¹⁶³ I was also overt as to the purpose of my presence. I explained my research project to those who asked and to anyone with whom I interacted.¹⁶⁴

I was unable to establish a similarly close relationship with anyone else working on this fast-paced unit; therefore my access was more limited when the consultant was not on service. Had the data generating design of the case study been limited to observation, this would undoubtedly have been a serious limitation but was not an impediment considering my research design, which added both in-depth interviews and focus groups group discussions to observation.

Consequently, I can describe my involvement with the NICU and its staff, following Bryman's typology of roles in ethnographic research, as that of a 'non-participant observer with interactions', meaning that my main interactions with the healthcare professionals were through the interviews and focus group discussions I conducted with them, rather than through embedded observation.¹⁶⁵

3.1.2 Generating rich data through in-depth interviews and focus groups discussions

The lion's share of the data I generated for this study came from the in-depth interviews I conducted with HCPs involved with the London NICU. I relied on theoretical sampling to identify healthcare professionals to interview and situations to observe that could contribute relevant data.¹⁶⁶ I did not attempt to achieve probability sampling. 'Healthcare professionals'/HCPs include medical professionals (physicians and surgeons), but not exclusively. The main inclusion criterion was not medical expertise but rather professional involvement in the neonatal legal and ethical decision-making process. For instance, a hospital-based social worker involved in ethical discussions or a lay member of an ethics committee would both have been

¹⁶³ Bryman (n 10) 433–440. O'Reilly (n 160) 91. Bengry (n 162) 106–107.

¹⁶⁴ O'Reilly (n 160) 87.

¹⁶⁵ Bryman (n 10) 444.

¹⁶⁶ *ibid* 418–422; Charmaz (n 6) 192.

eligible to take part in the study. More specifically, in terms of recruitment strategy, I used snowball sampling to recruit interviewees, building on the relationships established with previous participants, and on introductions by the consultant who was my main contact and gatekeeper. One consultant surgeon and one consultant intensivist did not answer my emails asking them whether they would agree to allow me to interview them.

I conducted 16 in-depth interviews of approximately 60 minutes each. I interviewed four consultant intensivists, four nurses, two consultant surgeons, two allied professionals, two solicitors, one intensive care fellow and one lay member of the Clinical Ethics Committee.

Logistically, the interviews were arranged in collaboration with my key informant who either introduced me and my research project to potential interviewees – personally or through email – or provided me with their professional email addresses. All interviews took place in the hospital itself or in a neighbouring building belonging to the Trust. I generally met with consultants and allied professionals in their office, but also at least once in a room designed for meeting with parents on a nearby unit. Initially, when I interviewed nurses, I booked a room away from the NICU in the neighbouring building. However, I rapidly realised that nurses found it more convenient to be interviewed in the unit where they worked. For this reason, I discontinued the practice of booking a separate room and conducted the remaining interviews in meeting rooms on the unit. Unfortunately, these meeting rooms were all situated on a side of the hospital building where construction work was underway and construction noises slightly disturbed several interviews and discussion groups.

The initial observation I conducted in the autumn of 2014, along with informal discussions with my key informant led me to identifying a recent situation that appeared to have been experienced as particularly difficult and as raising significant ethical issues by the staff of the NICU. As I was still familiarising myself with the hospital and the NICU at that time but nonetheless wanted to start generating data

through interviewing, targeting HCPs who had been involved in the care of that baby allowed for a reasonably smooth transition from observation to interviewing.

Consequently, the first five interviews I conducted all included a portion where I asked the interviewee to share his or her views on the time that child had spent in the unit up until their death, the ethical and legal issues that the child's situation raised, the way the situation was handled and so on. As it became more difficult to identify potential participants who had been involved directly in the care of that child and because preliminary analysis suggested that I had gained a good understanding of that case, I stopped using that case as a prompt for interviews and transitioned to more general interview questions. However, a few subsequent participants also evoked that case in interviews, thereby confirming its relevance and importance and thus contributing to refining my understanding of it.

Once I had completed interviews and a preliminary analysis of the data generated up to that point through observation and interviews, I turned to organising focus group discussions. In January 2016, the first of these took a hybrid format because it consisted in a presentation of preliminary findings to the Clinical Ethics Committee followed by a discussion with the members of the committee. That presentation provided a first opportunity to crystallise the initial findings emerging from the fieldwork. The discussion with the members of the committee confirmed the plausibility of certain of these findings, while also generating interesting insights to push the analysis further. The summary of findings I presented then is at Appendix D.

I then conducted four focus group discussions with nurses, in groups ranging from two to five participants. Almost a year passed before I could return to the London Hospital to conduct my last focus group discussion. During that time, I continued to analyse the data generated thus far, including that of the first focus group discussions. When I returned to London in December 2016, I also conducted one focus group with a group of six NICU consultants. Of the six who took part in the

focus group discussion, three had already participated in the data generating process, including my key informant.

In setting up focus group discussions with nurses, a senior nurse assisted me, she informed the nurses on the ward of when I would be there and ensured to cover their work while they participated in the discussion. I held the discussions in one of the meeting rooms on the unit I had used previously for interviews. With regards to the consultant discussion group, my key informant advised me of the best moment to hold such discussion and relayed my invitation to colleagues. The discussion was also held on the unit, after a consultants' meeting.

3.1.2.1 Topic guides

Before conducting the first interview, I prepared a draft topic guide which I revised throughout the data generating process. Especially in the early interviews, I was interested in discovering what elements and issues HCPs perceived to be important and relevant. I thus let the interview unfold without seeking to direct it too much and did not seek to cover all the points in my topic guide. Later in the process, as I had identified emerging recurrent elements in the interviews, and issues that I wanted to explore with the participants, the topic guides became more stable. Nonetheless, I have always sought to use the topic guide more as a tool to guide and structure the interview than as a constraining list of questions to ask.¹⁶⁷

The first topic guide I designed, which then served as a template for all subsequent versions, adopted the structure proposed by Arthur et al.¹⁶⁸ Having presented to participants the measures taken to protect their confidentiality and anonymity, I ensured that they confirmed they had read, understood and signed the consent form, reminded them they could skip questions or stop the interview at any time if they so wished and gave them an overview of the structure and scope of the interview. Once the interview had properly begun, I endeavoured to put the interviewee at ease and

¹⁶⁷ Sue Arthur and others, 'Designing Fieldwork' in Jane Ritchie and others (eds), *Qualitative research practice: a guide for social science students and researchers* (SAGE 2014) p.149.

¹⁶⁸ *ibid* 150–152.

collected biographical and demographic information about themselves. The core of the interview was then dedicated to exploring their view on cases they perceived as raising difficult ethical issues, from the perspective of both substance and process. Finally, the last part of the topic guide led to ideas for potential improvements.

The process of elaborating and revising the topic guide was iterative. I periodically revised the topic guides considering the preliminary analysis of the data previously generated. The topic guide entitled *Specific case* went through two versions. The last version of that guide then became the template for the main version of the topic guide I used for general interviews of professionals directly associated with the NICU, essentially the consultant intensivists and the nurses working in the unit, but also those allied professionals who were affected in whole or in part to the NICU. That topic guide entitled *Topic guide – HCP* went through three versions.

In parallel to this, I created more versions of the topic guide for each of the other broadly defined categories of people I interviewed, using the current version of the main topic guide as a template. I therefore created one topic guide for surgeons (two versions), one for solicitors, and one to interview a lay member of the CEC.

Once I had completed all interviews, I used the third and final version of the *HCP* topic guide as the basis for the focus group discussion topic guides. I prepared one version for focus-group discussions with nurses and one for the focus group I conducted with consultant intensivists. All the topic guides that were developed for this case study are reproduced at Appendix C.

3.2.1.2 Transcription of audio recording of interviews

All interviews and focus groups discussions were recorded digitally and professionally transcribed within weeks of conducting. I instructed the transcriber to avoid ‘tidying’ the transcripts and to leave them as unedited as possible. She noted pauses and some basic emotional responses. For example, the transcriber inserted the word ‘smile’ in brackets when a participant spoke in a noticeably cheerful tone. I

reviewed the first two transcriptions for accuracy then only reviewed passages highlighted as 'inaudible' by the transcriber although I only rarely managed to achieve a better transcription than the transcriber. I also corrected obvious errors in the transcription of specialised technical terms.

3.1.3 Research ethics considerations

Following extensive consultations with the Health Research Authority, the UCL Joint Research Office ('JRO') and the Vice Dean (Research) of the UCL Faculty of Laws and both my supervisors, it was concluded that because this study was non-interventional, did not involve a vulnerable population and protected the anonymity of participants, it did not need to be reviewed and approved by a research ethics committee.

I registered the study with the UCL JRO for Research and Development (R&D) and insurance purposes. The study was attributed an R&D registration ID: 14/0195. I also registered it with the R&D office of the London Hospital.¹⁶⁹

Although the study did not need to be reviewed and approved by an ethics committee, I nonetheless sought to abide by recognised research ethics standards in designing and conducting it. I prepared and used a participant information sheet (PIS) and a consent form about the study following the guidelines of the Health Research Authority. The final versions of the PIS and the consent form are at Appendix B.

I also sought to provide a summary of the ethical implications and of the protections in place for participants in the study at the beginning of each interview and focus group discussion. I usually recorded this summary. As such, it is illustrated at the beginning of the interview and focus group discussion transcripts reproduced, respectively, at Appendix E and F.

¹⁶⁹ Evidence of this registration is on file with the author.

Legal and ethical issues surrounding withdrawal and withholding of care from children can be emotional and divisive. As I began to approach people in the London Hospital to arrange fieldwork, and when I started spending time in the hospital and with the clinical ethics committee, I realised that the HCPs were often worried about media coverage and that many of them wanted to avoid media attention as much as possible. Consequently, to reduce the risk of adverse consequences to participants by adding a further barrier of protection against re-identification, I decided to withhold the name of the hospital where I conducted the research from reports about it, including in this thesis.¹⁷⁰

Similarly, I sought to modulate the way I described and referred to participants to enhance the protection of participants' confidentiality.¹⁷¹ For example, whenever I have used a quote from a previous interview or paraphrased the views of a participant in another interview or of a focus group discussion, I would use the broadest category possible, referring to 'people here' or 'some of your colleagues' and only occasionally mentioned more defined occupational categories such as 'consultants' or 'nurses'. The fact that the NICU and the hospital are relatively small work environments where it is easy to attribute – rightly or wrongly – a view to a particular individual motivated this choice.

Here, however, I describe people in slightly more details, specifying their occupation and in the case of nurses, their level of seniority. I have nonetheless been careful to lump together certain occupations where being more specific would have facilitated the identification of an individual. For example, the senior intensive care fellow I interviewed is presented as one of the physicians, although all physicians, except that fellow, were consultants. Similarly, I avoided quoting certain details, such as references to their gender, national or cultural origins, previous employment, or the date when they joined the hospital. In certain cases, I removed potentially identifying

¹⁷⁰ Stephen Webster, Jane Lewis and Ashley Brown, 'Ethical Considerations in Qualitative Research' in Jane Ritchie and others (eds), *Qualitative research practice: a guide for social science students and researchers* (SAGE 2014) 92.

¹⁷¹ *ibid* 94.

information from the quotes I used. Moreover, I have favoured the use of they, their, themselves and them as gender-neutral singular pronouns to avoid specifying the gender of the person I referred to. However, in the case of the nurses who participated in my study, as they were all identifying as women, I used feminine pronouns.

3.2 Analysing data to construct a grounded normative model

Following the precepts of grounded theory, I analysed the data I generated through a series of iterative processes. This section gives an overview of these processes. I do not have the space here to cover in detail a process spanning several years. Yet, in keeping with my constructivist and reflexive perspective, I wish to make it as transparent as possible.¹⁷² My goal is thus to give a glimpse of the way in which I analysed my data and highlight, notwithstanding the subjective nature of qualitative data analysis, the methodological rigour that I applied throughout. I will pay attention to the main methods supporting analysis in grounded theory: coding and memo writing.

3.2.1. Seeing connections in data through coding

Throughout the data analysis process, I coded my field notes, transcriptions and memos using the NVivo computer assisted qualitative data analysis software package.¹⁷³ I began with line-by-line coding, and applied several coding strategies. First, I used gerunds as codes to highlight the actions and processes in the data.¹⁷⁴ Hence, I created codes such as ‘asking why we carry on treatment’, ‘being out of the loop’ and ‘managing the patient’s death’. Being mindful of the normative orientation of my research, I paid attention to evaluative language, and to mentions of the considerations likely to be invoked in deciding which direction to give to a child’s treatment. I thus created codes to organise mentions such as ‘the best interests of the child’, ‘official guidance’ or ‘worrying that the child is in pain’. Finally, I sought to capture particularly vivid images used by participants as they might have formed the

¹⁷² Bazeley (n 139) 407. Charmaz (n 6) 227.

¹⁷³ Patricia Bazeley and Kristi Jackson, *Qualitative Data Analysis with NVivo* (2nd edn, SAGE 2013) 5.

¹⁷⁴ Charmaz (n 6) 124.

basis of an in vivo code.¹⁷⁵ Very early in initial coding sessions, I extracted phrases such as ‘parents are not there at all’ and ‘get there with this family’ to use as codes to label fragments of data. These codes eventually became central to my analysis of the perspective of HCPs and through multiple iterations, they came to constitute the core category of the GNM.

Once I had coded my first round of interviews line-by-line, essentially the five interviews focusing on a recent case perceived as having been particularly difficult to resolve, I had accumulated a significant number of codes. Some of them were repetitive or very similar (e.g. ‘asking questions’, ‘asking curious questions’ and ‘asking is it reasonable’) and I had not yet started to establish relationships between them. Hence, at that point my coding structure was entirely flat. To transition between initial coding and focused coding, I developed a coding tree to group the codes I had generated in the initial coding phase. I reviewed my list of codes to identify potential groupings. I then completed the groupings with some elements from the coding structure proposed by Pat Bazeley.¹⁷⁶ My coding tree thus comprised the following ‘code groups’¹⁷⁷:

- Actors
- Actions
- Instances
- Strategies
- Norms, Principles, Beliefs, Values
- Information & Knowledge
- Work Organisation
- Relationships
- Timing
- Places
- Issues

¹⁷⁵ *ibid* 134.

¹⁷⁶ Bazeley (n 139) 181–182.

¹⁷⁷ *ibid* 182.

I then classified my codes into the coding tree, therefore introducing a flexible organisation to my coding that facilitated code retrieval and the process of comparing and contrasting codes. I continued to code the next round of interviews line-by-line, but I was also increasingly attentive to whether I needed to create a new code. I therefore started to explore the relationship between codes, to identify potential overlaps or distinctions emerging from codes. Hence, I started more actively to organise my codes, merging, breaking-down, moving and renaming some of them.¹⁷⁸

At this stage, which corresponds to what Charmaz describes as 'focused coding', I left some of my initial codes as they were and developed others.¹⁷⁹ For instance, under the heading 'Actions' I had over 40 verbs and gerunds, such as 'understanding', 'planning', 'communicate', 'decide', etc. The code 'treat' grouped five other codes: 'caring for the family', 'keeping alive', 'treatment options', and 'life support'. 'Treatment options' grouped another twenty other codes, including 'doing everything', 'withdraw', 'carrying on', and 'resuscitate'.

This very detailed coding allowed me to take advantage of NVivo to adopt a multitude of points of view on the data by juxtaposing extracts from different interviews, field notes and memos. By consulting the fragments gathered under each code, I saw my data from a slightly different angle. For example, the numerous codes under 'treat' and its sub-code, 'treatment options' which I just mentioned gave me a sense of the variety of options HCPs have in considering the direction to give to a child's treatment. Then, by cross-referencing these with the nuances of their perceptions of the child ('actors'/'baby') which range from 'corpse' to 'highly desired child' and 'decide for themselves', I saw the profile of the dramatis personae of the GNM emerge, namely the child for whom WLST appears imperative.

In turn, I explored the justifications offered by HCPs by studying the numerous data fragments coded under the code group 'norms, principles, beliefs, values'. For

¹⁷⁸ ibid 185.

¹⁷⁹ Linda Liska Belgrave and Kapriskie Seide, 'Coding for Grounded Theory' in Antony Bryant and Kathy Charmaz (eds), *The SAGE Handbook of Current Developments in Grounded Theory* (SAGE 2019) 176.

instance, under the subheading 'principles', 'best interests' was broken down into 21 sub-codes to account for its complex and multifaceted role in the normativity of the London NICU. These sub-codes (e.g. 'looking at the big picture', 'future of the child', 'family's best interests', 'consciousness') were instructive in that I could toggle between a large vista on best interests and a smaller scale perspective on a specific dimension. In coding, I also chose to distinguish 'best interests' from other closely related evaluative notions, such as 'avoidance of pain and suffering'. I eventually came to include 'avoidance of pain and suffering' as a major component of 'medical best interests' in JIC, but I only made this connection later in the analysis process as I was trying to relate my emerging understanding of the role of best interests and its relations to other notions evoked by HCPs. Distinguishing these two notions at that early stage helped me in assessing their relationship later in the analysis.

Indeed, coding is only one half of the analytical journey in grounded theory. Early on, most of the time I spent analysing data was devoted to it. Eventually, although I was still linking fragments by coding them, my use of codes changed as I increasingly used them to navigate the data as I was reflecting upon it. As my use of codes changed, I came to rely increasingly on research memos to advance the construction of the GNM.

3.2.2 Developing data analysis through memo writing

Writing memos about focused codes and the data more generally was how I moved from breaking down the data into smaller pieces through codes to integrating them in a theoretical model.¹⁸⁰ Through prolonged acquaintance with data, I came to see convincing patterns emerge from it.¹⁸¹ I spent more than two years interrogating the data, formulating ideas and confronting them to the hypotheses and intuitions encapsulated in my codes and memos before I began writing-up my results.

I wrote many memos directly in NVivo as I grappled with data, searching for the

¹⁸⁰ Judith A Holton, 'The Coding Process and Its Challenges' in Antony Bryant and Kathy Charmaz (eds), *The SAGE Handbook of Grounded Theory* (SAGE 2012) 266.

¹⁸¹ Bex Lempert (n 121) 245.

stories it was telling.¹⁸² They are thus recorded in my NVivo project. They are easily searchable and are milestones in the formation of the GNM, despite the many detours that I took before settling on the concepts forming its core. Yet, these are only the most obvious traces of my analytical process. Lora Bex Lempert describes memos as: ‘narrated records of a theorist’s analytical conversations with him/herself about the research data’¹⁸³. Many of the conversations I had with myself took place on the pages of the notebooks I filed with reflections, notes, lists, references, questions, sketches and diagrams.¹⁸⁴ I would also include conversations I had with others under the umbrella of memo writing. As I was drafting the GNM, I gave several oral presentations on my project, which gave me the opportunity to reflect on the articulation of the GNM rather than on its details. Each time, I prepared an outline to share with attendees, but also to record the state of my analysis.

To illustrate the progression of my analysis through coding and memo writing, I will now sketch out the trajectory I followed to elaborate GTWP, the second main process I constructed as part of the GNM. As mentioned above, it started with my picking up certain turn of phrases in early interviews and making in vivo codes out of them. However, it was only the beginning. First, I needed to elucidate what the conceptual destination euphemistically evoked as ‘there’ in ‘getting *there* with parents’ or in ‘clinicians get *there* first’ meant for HCPs. Once it became clear that it meant an agreed-upon WLST, I had to explore the means deployed by HCPs to achieve this agreement with parents, how they sought to *get* there.

I worked out these questions through many attempts and false starts that are documented in the memos I wrote. Yet, my understanding began to coalesce in a memo entitled ‘Normative tension in London Specific Case’ that I wrote a few weeks after I had finished coding the interviews focusing on a specific case. Having noted the tension between the *prima facie* authority of parents to determine the best interests of their child and the HCPs’ ‘sense that certain situations are not in the

¹⁸² *ibid* 251.

¹⁸³ *ibid* 247.

¹⁸⁴ *ibid* 249.

child's interest and therefore should not be allowed to continue', I tentatively wrote:

This normative principle is described as [sic] realist kind of way, it is described as a place, in the expression 'getting there with the parents'. In this sense it is seen as having a certain 'pull', or a dimension of inevitability. It is recognised that parents 'need more time to get there' but that most parents eventually get there and it is those who can't or won't get there, notably because of their spiritual and religious beliefs that are problematic. Could it be said that significant component of the support that is being offered to parents is geared toward helping them, on the way to 'there' i.e. acceptance of the fact that their child is suffering or is in pain for no recognised/legitimate reason. —'Getting there' is very likely to form the basis of a category/concept encompassing negotiation, support, interactions with the parents. [...] [Memo – Normative tension in London specific case - 15 April 2015]

Already, I could say that 'getting there with the parents' pointed toward an important interactional dynamic between HCPs and parents. I had a basic intuition, which obviously needed fleshing out. I kept wondering about the sense to give to getting there with parents as a process of influence throughout the time I spent working on the GNM. For instance, I wrote a memo in response to the following quote from Physician #4's interview:

Usually the decisions aren't difficult; it's actioning the decisions that is the difficult bit, I find. Because to me, I'm fairly sort of concrete really, so I find that deciding whether things are right or wrong is not an issue for me. But actually doing what you think is right or wrong – because there is not just the baby, there is the family. It's usually not so much what is happening to the baby that is the problem. It's what's happening with the family. And that's the tricky bit. [Physician #4]

In that memo, I started articulating the dilemma that I placed at the root of GTWP and connected it to some of my observations:

What do it mean to say that it is the tricky bit? —It is a salient problem, it could also mean that that it is the most difficult bit to navigate, the difficult part to implement, where you need a bit of craftiness, ingenuity, requires 'tactful handling' etc.

This points to a clear problem, to a problem that creates a lot of distress: what to do when you know what needs to be done but the parents do not agree that this is what should be done. This is the issue that has been discussed over and over in the course of these interviews. It has been characterised during the away day and at the conference. [Memo – It's actioning the decisions that is the difficult bit - 17 August 2015]

Specifying one of the issues to which GTWP provides an answer opened up to inquiring further into its realisation. 'Managing expectations' emerged as a central component of that process, first as a code, then in a memo:

Managing expectations is a component of getting there with the parents, it is about setting the frame of reference, the terms of the discussion, which in turn is a component of delineating the scope of parental discretion. Delineating the scope of parental discretion is also about defining the scope of agency for parents. What is it that they can control, what is it that they don't, for surely some things they don't control. [Memo–Managing expectations - 31 December 2015]

As I developed 'managing expectations', the question of the justification for attempting to steer parents toward the team's recommendation continued to bother me. An answer started to emerge when I brought together the doubts and attempted to classify and organise the doubts expressed by parents about the capacity of parents to consent to withdrawal of life-sustaining treatment. In the outline I prepared for my discussion with the London Hospital's Clinical Ethics Committee, I noted the following before presenting the evidence I had gathered:

E) Questioning the capacity of parents to assess the best interest of their child Another underlying trend in the interviews with HCPs is that many are uncomfortable with parental discretion/authority. Everyone agrees that taking parental views into account is crucial, but many questions are raised, challenging the authority of parental views: [...] [Outline CEC Discussion Group - 20 January 2016]

I could continue my description of the evolution of the categories forming GTWP, but my purpose is not to foreshadow the GNM in its entirety. Rather, I hope that in this section I could be as transparent as possible about the way in which I generated and analysed the data from which I built the GNM.

Conclusion

In this chapter, I considered the reasons for integrating empirical and normative research. In section 1, I identified three reasons to conduct qualitative empirical research about complex and normatively fraught issues such as WLST from neonates and infants: 1) to gain deeper understanding of the way normative issues are constructed, defined, experienced and resolved in relevant social contexts; 2) to clarify the meaning of certain key terms, expressions and concepts and the way they are deployed by their users; and, 3) to broaden our perspective in terms of relevant normative considerations for resolving the issues identified.

In section 2, I then built on a discussion of grounded theory and the methodological

work of Draper, Ives, and Dunn & colleagues to elaborate my methodology for integrating the empirical and the normative. Grounded normative theory proceeds in two main stages. The first stage aims at describing and theorising the normative practices found in a social context. Grounded normative theory achieves this by combining the methods associated with grounded theory with a particular attention to the normative dimension of practice. This first stage results in the elaboration of what I call an emerging normative model. The second stage aims at taking the emerging normative model back to participants from the site where it was developed to submit it to a critical discussion aimed at reflexive balancing. This results in a grounded normative model. Reflexive balancing then continues by opposing normative objections drawn from the literature to improve the GNM (section 2).

Finally, in section 3, I showed how I operationalised grounded normative theory in my case study. I selected the London NICU because it exemplifies intensive neonatal care in tertiary and quaternary university hospitals. I then presented the design of the study, presenting and illustrating both how I generated and how I analysed the data I generated (section 3).

The next three chapters, where I present the final version of the GNM, show how I answered the questions I asked myself, the data and the participants. Yet, I hope that this foray into the innards of the analytical process leading to the construction the GNM made clear that it is the result of an iterative and living process where rigorous methods framed intuition and serendipity.

Chapter III - Justifying intensive care

Introduction

HCPs working in the London Hospital's NICU acknowledge best interests as the main normative idea on which they rely in assessing the situation of a child and deciding whether to recommend WLST.

[...] the concept of best interests is a very useful one, and it is something that I think about quite a lot; but I struggle with, on an individual patient basis, where the responsibility for that decision rests ... about what that constitutes, about what that means. [London – Surgeon #1]

Consequently, in constructing a normative model for the NICU, the question of the understanding and operationalisation of the notion by HCPs imposed itself.

Initially, HCPs approach the interests of their patients from a medical and physiological perspective, excluding any other factors:

[...] best interests is only medical; there is no other social aspect. [...] [Physician #5]

HCPs explain the central reason for emphasising medical aspects is the critical condition patients find themselves in when they are admitted to the NICU, which primarily requires a technical intervention geared toward addressing the physiological issue that brought the child to the ICU:

You're on life support, you're on organ support – so you do make judgements based on the chance of a child physiologically recovering. [Physician #5]

Physician #5 concludes on the primacy of medical considerations, foreshadowing the distinction between medical and wider-best interests and the priority of the former on the latter:

But for us as clinicians, we tend to base best interests on the medical thoughts about the child in front of us, and the chance of surviving ICU, the chance of getting better and having a functional recovery. [Physician #5]

According to the surgeon consultant whose reflections are at the root of the distinction I draw between 'medical best interests' and 'wider best interests', often what is medically the right thing to do is also simply what is ethically right. In such cases, HCPs do not perceive a need to engage in a more elaborate analysis to identify the medical interventions with the most chance of leading to the child's recovery.

So there is interest, and there is wider best interests, and I think those are two slightly different concepts, aren't they?

A lot of the decision-making we make, the decisions we make are very straightforward ethically, actually. So if you've got a baby who has an oesophagus that is not in continuity, and they're not going to be able to eat unless you do an operation ... there is a risk of damaging the child by doing the operation, but actually the weight in favour of doing surgery is so overwhelming that it's almost not a discussion you need to have. Now clearly the parents can withhold consent for the operation, but I've never met anyone who would! [Laugh] [Surgeon #1]

Furthermore, often, babies do not spend enough time on the unit for the team to need or even have enough time to delve into appreciating other considerations. Such babies are admitted with a specific and often punctual need for critical care and they are discharged out of the unit very quickly:

Most of our children – over 95% – come in and go; so, three days is our median length of stay. Most children are gone within a week, and some stay within three or four weeks. [Physician #5]

It is more often when the NICU admission is prolonged, which necessarily implies that the child is in a more complex situation that the need for a broader assessment of that child's best interests arises. As noted by one of the allied professionals attached to the NICU:

And I think in ICU in itself, we are used to have a rapid turnover of patients. Things happen quickly, and when things don't happen quickly, that causes lots of anxiety. [Allied Professional #2]

In prolonged, complex situations, the process of establishing what is medically in the best interests of a baby reveals itself in its more elaborate form as one of consultation, deliberation and negotiation between the many HCPs involved in the care of the child. Considering the above qualification about the impact of the length

of the patient's stay, the process I am describing is likely always at play, albeit in an inchoate or sometimes truncated form, even when patients only stay on the unit for a short duration of time.

Over this chapter and the next, I elaborate a two-factor model of the determination of best interests in the NICU. HCPs follow a two-step sequence to construct a working hypothesis about a child's best interests. Initially, HCPs agree upon an interpretation of the child's 'medical best interests'. It is then presented to parents and revised according to a broader range of considerations, some of which are initially deemed of little relevance to the assessment, chief among them the views and circumstances of the child's parents and family. This second step allows to determine the 'wider best interests of the child'. I will show that medical considerations also drive this second step. The two-step model also explicitly excludes certain considerations, notably those related to resource allocation between patients and the protection of the reputation of the hospital.

My presentation of 'medical best interests' as the first set of factors proceeds in two main steps. First, in the section entitled 'A collegial and deliberative process', I highlight the emphasis put on medical knowledge and clinical evidence in the interactions that leads to the determination of medical best interests. I focus on the formal dimension of the process. I also sketch out the work organisation of the NICU and introduce some of its main actors. In the next section, entitled 'Balancing present and future, balancing life and death', I present the substantive considerations, values and principles deployed by HCPs in elaborating a hypothesis as to the medical best interests of the child. In the section entitled 'Normative implications', I spell out some normative conclusions derived from the unfolding of the process. Finally, I conclude with a vignette entitled 'nursing a corpse in the bed' which illustrates how the assessments of medical best interests can lead to a recommendation to withdraw or withhold life-sustaining treatment.

1. A collegial and deliberative process

First, I will present the two interlinked procedural norms, which coalesce to legitimise and lend normative weight to the position adopted about the appropriate direction to give to the care of a child. On one hand, all participants in the deliberation process share a commitment to medical evidence. On the other, HCPs display a widespread confidence in the medical expertise of colleagues, and in the superiority of collective deliberation to assess and interpret medical evidence. The authority of the group thus endows the resulting conclusion. I then move on to show that the process of establishing a consensus on the child's medical best interests is partially driven by the NICU consultants but is susceptible of involving many other medical specialists. Finally, I illustrate the deliberative nature of the process and highlight both formal and informal interactions between HCPs in forming conclusions about a child's best interests.

1.1 '[W]e are hugely swayed by medical things' [Physician #5] : medical evidence as a central norm

In the NICU, clinical evidence interpreted according to peer-reviewed medical knowledge is the epistemological gold standard. When questioned on their approach to decisions and recommendations for patients, physicians highlight the importance of clinical evidence and of establishing a consensus within the medical team on its meaning and impact on the treatment plan:

For many or the vast majority of our conversations with another speciality team or with the family, where you all look at the facts, and discuss what we think, and everybody can see a sensible path; and that path might be, I'm uncertain what this means but if things haven't changed in a day or two, or a week or something, they are going to change. So, a combination of information and time passing to firm up the information is often the easiest to get a consensus. [Physician #1]

Medical evidence is the touchstone of the whole discussion:

OK, so... Well, difficulties arise when some members of the team have a view that is so far outside of what the rest of the team thinks – and I'm including parents as a member of that team, or a speciality. The situations where the problem becomes intractable, when that opinion is not based on evidence, fact, reason, or whatever you want to call it... [Physician #1]

When discussing ways to get over disagreements, that same physician's deep commitment to the authority of medical evidence is unwavering, although the

physician recognises that it is not always shared by society, which often does not oblige individuals to conform their action to scientifically established facts:

So ... but society is very inconsistent about this. You know, we allow families not to immunise their children, which strikes me as absolute barking, when it has changed the world in terms of ... anyways! [Laugh] So there is an inconsistent message about the status of science versus individuality or professionalism, in all sorts of environments. We are relatively privileged, in that we often have lots of data, lots of investigation, lots of observational data, lots of speciality opinion, and it's usually very up to date, and it's changing constantly. [Physician #1]

1.2 Collegiality as a central norm

This commitment to medical evidence is not only an epistemological ideal. It also manifests itself as a strong belief in the capacity of the group to wield such evidence in a sophisticated way. HCPs display a high-level of confidence in their abilities, and in their colleagues'. Consequently, the members of the group perceive individual and collegial decisions as robust and trustworthy, notwithstanding occasional divergence of views. Thus, this is how one of the physicians describes the consultant team working in the NICU:

As a group of consultant colleagues, we are perceived as shit-hot; very, very good clinically, but a bit bonkers. A bit odd and full of personalities. And that's fine! That's exactly how we work. [Physician #5]

Yet, HCPs readily acknowledge the central role played by uncertainty in their work, the limits of medical knowledge and the need for further research, and the fact that they cannot always be right.

The level of trust that other healthcare professionals have in the expertise of the NICU team of consultants is also high. One allied professional insists on the quality and expertise of the clinicians in the hospital and notably those involved in the NICU:

... – particularly at a place like this, where you have such well trained and experienced ... and the best, among the best'. [Allied Professional #1]

Similarly, the surgeons I have interviewed insist on the importance and quality of the medical dialogue with their NICU colleagues.

I must say I feel very privileged to work here, because of the colleagues, first of all. You are surrounded by people who are considered to be the best in their field; so it's very unlikely that in a certain situation you don't find anyone that has expertise in that particular situation. So that is actually a very privileged point to work, because you feel always confident. If you get in trouble, you don't understand or you don't know, there is always somebody around who knows; and that is very, very good. [Surgeon #2]

Beyond trusting each other's expertise, HCPs also have confidence in the system of check and balances that they have in place to evaluate each other's decisions, fine-tune their practices, and develop a consensus.

There is also peer review through mortality and morbidity meetings, etc. Practice does come into line from previous past experiences. So although something might happen to an individual, and several of the consultants might not agree with it, and they'll vocalise it in the context ... post-priori if you like, in a mortality-morbidity meeting. That means the next time a similar situation happens, that isolated consultant will try and work toward the viewpoint that actually... 'Seven of my colleagues didn't quite agree with me, and I will...'

And I think there is that reflection and learning, and over time people do follow similar sort of thought process, implicitly or explicitly. [Physician #2]

The diversity of opinion among the various actors who are involved in the deliberation process is also seen as contributing to the quality of the debate.

I don't see that on ICU in terms of religious faith, but there are different viewpoints about how much you should push children through among my colleagues, and around the country. I would try to be as objective as possible. We seek collegiality, we discuss things about patients and have peer review every day on our ward round, and every week in our consultant meeting. [Physician #5]

Collegiality is therefore highly valued in the determination of the medical best interests of the child, both within the NICU team and in relations with colleagues from other medical specialities.

I think the advantage of the model we have here, when it runs well, is that we're able to pool information. So rather than somebody getting some information and making it, coming to a view about what the best way forward is, in the absence of some of the facts that are known to the people, if you've got everybody in the same place then you can kind of get the facts down and come to a collective view which is based on the facts that you have available; or all the facts that are available. [Surgeon #1]

Furthermore, HCPs perceive purporting to take important decisions affecting the

future of a child alone as running against an important norm of collegiality, especially among consultants:

I think the worst thing is that you withdraw on a patient that has been looked after for ... say a bone marrow transplant patient, or an oncology patient who has been looked after by another team who knows the parents really well; and you don't even involve them in the discussion. That would be awful. I know that it has happened before, and I know a consultant surgeon who walked onto the unit to find that one of my colleagues was withdrawing on his patient, and he didn't even know. [...] [Laugh] [Physician #3]

Because of the group's allegiance to the procedural aspects of the decision-making process, once they reach a conclusion, it carries the much weightier authority of the group, rather than simply that of a single individual. Hence, it becomes onerous in terms of justification to depart from it. This is particularly relevant when the stakes are high, such as when WLST is one of the options considered.

Well it's always nice to run things past... I don't think it should be a decision that is made by an individual. We work so often in teams now, so you would want to... And also it's useful for the parents to know that it's not just you that thinks that everything is hopeless – you've come to that decision based on your experience, but also based on having had lots of discussions with colleagues and other teams, say the neurologist for example, or the surgeons. You've had those discussions, and they also think there is nothing else that can be offered. It's not just an individual decision. [Physician #3].

Thus far, I have focused on the collegiality among medical professionals, notably intensivists and surgeons. However, while nurses recognise the leading role of consultants in ascertaining medical best interests, they also value collegiality in making that assessment.

Nurse # 3: Yes. So it's kind of prediction and probabilities, and research and study...

Nurse #2: It's a group decision; it's not one single person's decision. It will be a group decision between the doctors, and nurses, and the family.

Nurse #1: That's the most important time I guess to support your team. Like, sometimes you're not going necessarily with the decision that you personally would think you'd make maybe, but it's important to back up and support those in your team as best as you possibly can. I guess also, sometimes, because we have people who are qualified in special and people who aren't and those sorts of things, sometimes you end up looking after the same patient over and over and over again; and sometimes it's good to bring in that fresh perspective of someone who hasn't been looking after that patient; kind of like an outside view – because I think it probably gets a little distorted.

Nurse #2: And I also think that being the nurses looking after that patient, we have a better

idea of how the patient are, the way should be. Our decision should be included within the discussions. And it is sometimes us that bring up, 'should we be doing this?' Because we are literally there 12 hours a day, with these patients and families. [Nurses Discussion Group #4]

This exchange illustrates the authority conferred upon a widely discussed position, although it might differ from the decision that individual nurses would have taken personally.

1.3 The process is partially driven by the NICU consultants

Each week, a different NICU consultant is in charge of the unit during the daytime, with another one on call during the night. The consultant in charge of the NICU for the week is the leader of the clinical team for that period. Yet, the position does not confer absolute decision-making authority over the treatment of the unit's patients.

Ascertaining the medical best interests of a child is a collegial and iterative process only partially driven by NICU consultants. The complex cases making up a large proportion of the work of the NICU necessitate significant input from consultants from several other medical specialities – besides that of other NICU consultants who might not be in charge that week but who have or will take charge of the child and are present in another capacity:

Physician: Yes. It would be very unusual, in the NICU in particular, to be less than two; there would be ourselves and at least one speciality. And if you have more than two, then you often have five or seven. Once you tip over from a single problem plus intensive care, support need is often multiple. [Physician #1]

This input has to be integrated to achieve an understanding of the condition of the child that goes beyond the mere addition of the status of the physiological systems making up the child's body. Both NICU consultants and surgeons acknowledge the need to integrate and contextualise the input of each consultant specialist involved:

Um... I think the thing that we have here is babies with a complex series of problems with all sorts of different specialities involved, and I think one of the things that's hard to do here is keep a sense of the whole picture – so you kind of think your bit's all right, and the renal team think their bit's all right, and the brain surgeons think their bit's OK, but actually if you put all of that together in one big package for the patient, it's not necessarily all that straightforward. [Surgeon #1]

NICU consultants are often saddled with the task of integrating specialist input.

JFM: Would it be fair to say that it sort of becomes the intensivist's responsibility to integrate?

Physician: Well I think ... to some extent, yes. Is that fair? Yes, I mean I think we often pride ourselves on being relatively generalists. You can take two approaches as an intensivist, it seems to me: you can be all diseases that are bad enough to need intensive care, or you can treat yourself as a technician if you like – an expert in the support mechanisms. And if you take the former example of, you know, a sick child specialist, then you are in a good position to integrate lots of information. [...] [Physician #1]

Surgeons also contribute to the integration of medical information and are often significant interlocutors for NICU consultants. The unit receives an important number of 'surgical babies', namely patients who are admitted for surgery or surgical evaluation. These patients are under the care of a surgeon for their whole stay in the hospital, including when they are discharged out of the NICU to another ward.

This consultation process is open-ended and iterative. The medical best interests of a critically ill neonate can fluctuate significantly day-to-day, even minute-to-minute, subject to the evolution of their underlying condition or possible complications. Until significant clinical milestones are attained, such that prognosis can be formulated with more certainty and contemplating a longer period of time, any conclusion will be tentative and subject to revision.

The difference between the rotational schedule of NICU consultants – humorously known as the 'consultant of the week model' [Surgeon #1] – and the work organisation of other specialities, notably surgeons but also nurses, is often cited as a challenge to achieving a consensus in the NICU. As the participants tend to change, even a relatively stable consensus reached previously is not immune from a challenge by someone joining the ongoing conversation. One of the NICU doctors explains the impact on the consensus-building process:

[...] one of the challenges for us is the fact that we work on a rotational system. And so to consistently have the same debates, the same words and the same people until we all understand each other can be a challenge. [Physician #1]

However, HCPs often perceive debate as improving the quality of the deliberation process. For one of the surgeons, as long as continuity in the care of patients is

maintained, variation in the make-up of the treating team has the potential to be beneficial:

I don't see that as a problem, because there is always continuity. So, we provide continuity in terms of that single problem to follow it up, and they provide continuity in the sense that they are looking at the whole patient—they do look with different eyes, but they have good communication between themselves so I don't see it as a problem. I mean, sometimes there is a discrepancy of thinking, but that is about medicine and I don't see it as a problem, because actually sometimes you can have a solution by looking at different perspectives. So I don't see that as a limitation. Some of my colleagues might see that as a limitation, yes. [Surgeon #2]

1.4 A process of formal and informal deliberation

The NICU team and the other specialist consultants involved reach major decisions concerning the care of a child, including eventually the conclusion that WLST would be in his or her interest, through elaborate and repeated interactions—both formal and informal.

Such interactions primarily revolve around the gathering and assessment of medical information, such that the group can agree to a treatment pathway. Clinicians use the term 'pathway' to signify a general orientation for children's care. It connotes the recognition of the possibility the direction of the care might change along the way considering the baby's response to treatments and the evolution of their condition.

In the organisation of the NICU and of the hospital more generally, physicians have several opportunities to discuss, test hypotheses, and review the assessments of their colleagues. Some are formally entrenched in the routine of the unit, such as ward rounds, consultants' meetings and mortality and morbidity rounds. Other formal occasions include the frequent multidisciplinary team meetings (MDT) that are convened to discussing a patient with as many of the HCPs involved as possible, and the more exceptional clinical ethics consultations.

Morning rounds provide a telling illustration of routine interactions in the context of which consensus on the medical best interests of the child is discussed and negotiated. They allow to assess and eventually re-orient the care of each patient for the next half-day or so. Ward rounds occur twice a day, in the morning and in the late

afternoon. During the time I spent observing the work of the NICU, I attended the morning ward rounds in the NICU on six occasions.

At the beginning of the working day, around 8:15 a.m., a group of approximately fifteen HCPs headed by the NICU consultant in charge of the unit that week and comprising of other consultants – notably other NICU consultants, surgeons, neurologists, nurses, junior doctors, and trainees – visit each patient on the unit. Parents, although they have otherwise unrestricted access to their child's bedside, are specifically asked to leave during morning rounds.

The discussion is quick-paced and full of medical abbreviations. It aims at updating everyone involved on the patient's current status and to agree on a plan for the day both on clinical management and whether further investigations are warranted. The nurses affected to the bedside care of patients do not follow the ward round. However, they actively take part in the discussion concerning the (usually two) patients they are responsible for that day.

Many of the patients in the NICU are 'surgical patients'. Surgeons 'own' the patients that they operate, meaning that they are responsible for following them before and after the surgical intervention. Often, the NICU consultant leading the round will ask one of the surgeons if he or she wants anything else done for that patient, therefore highlighting the 'ownership' or primary responsibility of the surgeon for that patient. When a child's hospitalisation goes beyond the usual short length of stay, the NICU consultant who initially admitted the child to the NICU also takes on the role of 'lead consultant' for that child. One NICU consultant explained to me what the role of the lead consultant implies:

For those who are here longer than four weeks, we have this system where the person who admitted them becomes their lead consultant to provide continuity in the care, but also continuity for the families. It's quite hard, because they see a different consultant every week, and maybe even more than that with on-call consultants changing. So it's meant to provide a point of contact [...] [Physician #5]

The bedside nurse concludes the discussion, summarising the main parameters of

the care and the child's resuscitation status, meaning whether all resuscitation interventions should be performed if necessary or if a limitation had been agreed. As with the surgeon, the consultant leading the round will often ask the bedside nurse about any other possible worries she might have.

The tone of the discussion noticeably changes and its pace slows down when someone raises an issues relating to the child's level of care. This mood change suggests that these discussions are of a different nature than the more technical discussions typically taking place during morning rounds. Such issues might be flagged during morning rounds, but they are usually not settled at the bedside. When a significant reorientation of a baby's care is contemplated, and when medical uncertainty is high, HCPs will set up an MDT to allow for a more systematic discussion.

The formal sit down meetings usually mean there is a problem. It's not on the established pathway. All it means is that we're considering a change in direction from what is the obvious. And the obvious track is always full treatment, trying to go for a cure, and so on. So I can't imagine a situation where we would deviate from full-cure conception without a sit-down to think it through and get this right type of conversation. [Physician #1]

One of the surgeons who frequently attends morning rounds expresses a similar view:

Quite often in the most complex patients there is a series of different issues that are all in play, and what you need to do is get everybody in a room. And sometimes they can be quite short those meetings, because everybody agrees, but you just need to check. And so, pulling all the different professionals involved in decision-making about a baby together in a kind of, we're sitting down and we're having a proper conversation about it, the ways I would handle difficulties with you know, the overarching care of the baby... [Surgeon #1]

However, not every step of the discussion necessarily happens within a formal framework such as rounds or MDTs. Physician #5 expresses the view that formal meetings are not always the ideal setting for having serious discussions with one's colleagues and that much can be achieved informally:

Having said that ... many, many discussions about these children are handled – and I would argue are better handled – with a quiet, informal discussion when teams come visit. 'How do you think this is going, what do you think about that?' If every meeting is a sit-down, formal, MDT, sometimes you don't get anywhere with those meetings; so I do think there's a balance

there about how you have meetings. [Physician #5]

Similarly, a surgeon insists on the importance of informal discussions with colleagues in forming an opinion on the best course of action for a patient:

So I think it's about, for me ... the positive thing is about having access to people to talk to, and who will genuinely help you. And a lot of that is very informal. It's going to find a colleague during the day and having a chat. Or getting them on the phone in the evening and saying, 'I'm not quite sure what to do with this baby, I'm thinking of doing this, does that sound reasonable?' [Surgeon #1]

In this section, I sought to present some salient formal aspects of the process leading to the determination of a child's 'medical best interests'. In doing so, I highlighted the influence and authority of physicians wielding medical knowledge and evidence, and the collegial and interactional nature of the process through which medical conclusions are elaborated and agreed upon.

I now turn to the discussion of the substantive considerations that enter into the first phase of that assessment which I have labelled 'medical best interests'.

2. Balancing the present and future of the child, balancing life and death

When prompted to explain how they interpret and apply best interests, HCPs often refer to the idea of balancing the burdens and benefits of treatment to determine whether it is justified. HCPs readily acknowledge that often what is ultimately at stake is whether it is in the interest of the child to survive or not.

I think it's a terrible test, but it's better than everything else we have. [Laugh] In the sense that we are obviously making a series of assessments of what would be an unpleasant experience, and what would be potentially a pleasant experience, and trying to balance them. And we try to be open and honest about whether that might be something that you can imagine someone wishing for rather than death—because that is often the balance. [Physician #1]

In this section, I unpack and detail such affirmations. By default, HCPs focus on the goal of curing the child. It is only when this goal seems to escape their reach that they entertain alternative outcomes. However, as this study is mainly concerned with circumstances where WLST is deemed to be in the best interests of a child, I will concentrate on the process leading to such conclusions.

I begin by showing that the timeframe in which it is cast influences the process of balancing the burdens and benefits of treatment. Generally, the child for whom the question whether to withdraw life-sustaining treatment is asked will be one whose illness trajectory escapes the usual short time cycle of the NICU. While the expected benefits of the treatment will manifest themselves mainly in the future and remain uncertain until then, the treatment itself carries significant burdens for the child that are readily observable in the present. In discussing how HCPs perceive the experience of their patients, I also outline the contours of the understanding of pleasure and pain that underlies that balancing exercise. I then restate these elements as two main normative implications emerging from this process of ascertaining the medical best interests of a child: i) intensive care treatment is a burden that must be justified and ii) the death of the child might be the most desirable outcome.

2.1 Point of departure: a presumption in favour of treatment

HCPs approach each patient with the assumption that the treatment they provide is in the child's best interests. This resonates with their understanding of their role as HCPs, but also with the fact that NICU consultants control admissions to the unit. A child who would not benefit from admission in the NICU, either because he or she does not need it or because it would not yield any improvement in the child's condition, would not be admitted to the NICU. Consequently, in deciding what is in the best interests of a child, the first factor considered is what treatment is likely to cure the child. Reaching such a conclusion constitutes the core of the role of the consultant-led medical team.

One nurse underlines this basic, yet fundamental, feature of the assessment of best interests:

Nurse #2: best interests of the child... Once they are admitted under our care, we make sure that we do give the management that is best for them. As nurses, we always discuss with the doctors the management of the patient. And the doctors will also refer them to other departments, or other teams who can help with the management of the child. [...] [Nurses discussion groups # 1]

The search for a curative treatment is the default position for all patients. Consequently, notwithstanding the complexity and the risks associated with certain treatments or interventions, HCPs see clinical indications and best interests as coinciding. As such, they do not view the ethical component of the decision-making process as particularly pressing. Likewise, disagreements with parents are unlikely to arise at that stage.

Yet, some situations are not as clear-cut medically. Clinical judgement then takes on an increased importance. Any change of direction in the treatment plan toward WLST is widely discussed and scrutinised before HCPs adopt it, let alone present it to parents.

The formal sit down meetings usually mean there is a problem. It's not on the established pathway. All it means is that we're considering a change in direction from what is the obvious. And the obvious track is always full treatment, trying to go for a cure, and so on. So I can't imagine a situation where we would deviate from full-cure conception without a sit-down to think it through and get this right type of conversation. [Physician #1]

One of the trust's solicitors echoes this view, also observing that HCPs do not easily abandon the goal of offering their patients a cure:

[...] obviously doctors are programmed to cure and maintain life at any expense. And to say 'no, we can't do anything' must be very, very difficult for them. 'We've come to the end of the road, we really cannot do anymore,' I think must be very difficult for them. [Legal Counsel #2]

Ultimately, the HCPs' strong presumption in favour of treating their patients, sometimes aggressively, is also a presumption in favour of keeping them alive. However, while for many people this idea appears as a firm principle, allowing for little or no exceptions, HCPs take a different view. Consequently, I now turn to the considerations that would lead to abandoning that presumption. As I demonstrate, the ethical questioning of a previously agreed-upon course of treatment often arises out of a change in the timeframe in which HCPs consider the medical situation and subjective experience of the child.

2.2 Extending and deepening the timeframe to appreciate the relationship between the burden of treatment and its projected outcome

First, I show the justification for continuing life-sustaining treatments can be

questioned when a child's prolonged stay in the NICU triggers an inquiry into their projected future. This first foray into the future is limited to considering the survival expectancy and the projected functional outcome of the current treatment. It nonetheless extends the timeframe in which HCPs initially situate their patients. That timeframe is also deepened to integrate a broader range of elements about the child's present experience of intensive care. Indeed, HCPs become more inclined to scrutinise the present experience of the child in the NICU. Hence, the burdens associated with hospitalisation increasingly appear as requiring justification. Again, HCPs mostly appreciate such burdens from a physiological standpoint in terms of pleasure and pain.

The NICU's timeframe involves a succession of short cycles. The focus is on the short-term: children admitted to the unit are in critical situations requiring swift interventions. For many, their stay in the NICU will be short. They will then be discharged to another ward of the London Hospital or sent back to the local hospital where they were born. The NICU's work organisation overlaps with such short cycles. Nursing care is organised around two 12-hour shifts, ensuring that the child is under the immediate care of only two nurses each day. Similarly, as they rotate weekly, the work schedule of consultants also reflects the typical course of a child to and out of the unit.

The description of the role of the consultant in charge of the unit by one of the intensivists illustrates this narrow timeframe, focusing on the most immediate issues concerning the care of the unit's children and their path toward recovery:

[...] But the rest of it is, as the senior doctor on service, for either 24 or 48 hours; and that involves two ward-rounds a day, predominantly planning the strategic direction for individual cases. There's often something a bit more operational about how you are going to get that strategy, and sometimes there's technical stuff about delivering those strategies. But most of the time it's trying to plan what's going to happen to this patient in the next 24 to 48 hours, with your team. [...] [Physician #2]

Subject to unusual circumstances, the ethical and legal issues relating to withdrawal or withholding of intensive care that are at the centre of this study are not congruent

with one of these short cycles. Rather, such ethical issues usually arise when the succession of short cycles does not yield a relatively definitive result – either positive or negative.

The sense of urgency created by an acute condition requiring a prompt response diminishes slightly if diagnostic uncertainty, a particularly complex condition, complications or the impossibility of weaning them off life-sustaining treatment prolong a child's stay on the unit. One intensivist identified cases where, as the time pressure eases off, the situation is more likely to degenerate to the point of making its way to court:

Physician #3: There is a special, unique combination of circumstances that ends up in court, slowly, which is the chronic, usually neurological [inaudible] condition. Because other things tend to be getting worse or are so unstable that actually there is never a sort of set point to stop and discuss. It's very rare for somebody with multiple organ failure to end up in court... I mean it has happened, but...

[...]

Physician #3: It's that unique bit of lack of time pressure, if you like. [Consultant discussion group]

Cases deviating from the expected trajectory of a NICU patient call for HCPs to change their perspective. When the dynamic of urgent care subsides, the question of the child's best interests comes into renewed focus as it is detached from more immediate medical imperatives. The timeline of the child's treatment is reframed in a way that makes room for more explicit and sophisticated ethical reflections.

On one hand, the time horizon of the child's treatment is extended beyond the most immediate management of the child hour to hour and day to day to introduce considerations about the child's future. On the other, this extension of the timeframe toward the future is associated with a deepened attention to the child's present experience. Concurrently to appraising the situation of the child over a longer timeframe, HCPs also increasingly scrutinise the present subjective experience of the child, primarily in search of evidence of pain and discomfort.

The combined effects of the future of the child and that child's actual experience coming into sharper contrast lead to cast the issue of the child's best interests to in terms of a balance between the expected benefits of treatment and the burdens associated with such treatment.

2.3 The future of the child

Regarding the future of the child, the balancing exercise relies on two main projections. The first concerns the child's survival expectancy and the second, the child's functional outcome.

[...] But for us as clinicians, we tend to base best interests on the medical thoughts about the child in front of us, and the chance of surviving ICU, the chance of getting better and having a functional recovery. [Physician #5]

HCPs often move seamlessly between the two projections in their account of what is relevant to the assessment of a child's best interests:

JFM: So if you're looking at a neonate and you're trying to assess best interests, what would be taken into account?

What the current situation is; how much support the child is needing; and whether it's something that's survivable, or whether the patient's life is going to be in such a serious, severe situation that life is going to be burdensome. [Physician #3]

And then I think the next discussion is ... well, there are a number of factors: there is prognosis in terms of just life lived, you know, today he's alive; there is the possible experience of what that life would be; and the two main parts of that are, is it likely it would include some sort of interaction with the world? Or, would it be a life that contains suffering or pleasure? [Physician #1]

Nonetheless, although they are intertwined, HCPs also treat them as entailing different normative conclusions. Consequently, I will now briefly elaborate on each of them separately.

2.3.1 Survival expectancy

Logically, if not always chronologically, the first question is whether the child will survive. Indeed, the possibility that the progression of the child's condition will lead to a point where the medical conclusion will be that they are unlikely to survive the disease that brought them to the NICU is always present. A senior nurse explains that this is a frequent outcome:

But I think in neonatal care in particular, we are dealing with a lot of patients that ... what's the best way to say this... I feel like recently in particular, we've had a lot of very premature infants who have come and basically ... oh, what am I trying to say ... who are not going to survive. Especially with things like NEC... [Senior Nurse #1]

Whether the child will survive can be further specified by ascertaining for how long it is forecast they will live. For some, the answer will be a matter of days, weeks or months, while for others it will be a matter of years or even decades.

The fact the care provided in the NICU is susceptible of keeping the child alive for a relatively long or undetermined period of time complicates the process of deriving ethical consequences from the conclusion that the child has little chance of surviving. By definition, intensive care entails providing life-sustaining therapies to the child. However, HCPs consider many of these treatments as inadequate over the long-term.

The medical assessment also necessitates appreciating the level of life support required and whether it will likely be possible to wean off the child from it or whether the child will remain chronically dependent on it. Although life-support dependency involves several issues regarding the provision and organisation of future care, this assessment is initially medical and focused on the current situation.

Explaining some of the considerations that are relevant to decisions to withdraw life-sustaining care, a surgeon stressed the combined role of the life-sustaining technology – both mechanical and pharmacological – in prolonging the life of children whose ultimate short-term outcome is forecasted to be death.

Well for example, one typical case of necrotizing enterocolitis, multiple organ failure, and the child is not responding. There is a lot of dead bowel, so ... no bowel that could make the child survive. He's on inotropes, and it's escalating the treatment. And there will be some point where not only is the child kept alive by the machine, but it's also that you cannot escalate it anymore, and ... it's just not responding. [Surgeon #2]

2.3.2 Functional outcome

The next question is the projected functional outcome of the treatment plan for the child. Functional outcome refers to a forecast of the level of physical and cognitive

impairment or disability that will affect the child over the long-term and how it will affect the child's day-to-day functioning.

At the stage of assessing medical best interests, the subjective dimension of the experience of disability does not have much weight. Rather the focus is on the more objectively measurable and foreseeable elements perceived as susceptible of influencing the child's overarching quality of life. For HCPs, such an assessment appears necessary considering the range of poor functional outcomes that can result from a prolonged stay in the NICU.

Such outcomes are never far from the mind of HCPs. Many openly express that, personally, they consider extreme outcomes undesirable or intolerable. However, they also widely acknowledge that objective medical facts translate into a child's subjective experience. The assessment of the quality of that experience poses an entirely different set of question that they cannot answer alone.

Oh, in other cases? Well there is the survivability, and then there is whether or not the existence is going to be so appalling, in terms of the tolerability of the life – which I guess to some extent is a personal decision, whether or not... Some might say that an existence is tolerable, and others might not, but we have to make those decisions as well, so... [Physician #4]

Especially at the initial stage, HCPs attempt to avoid formulating a judgement on a child's projected quality of life. For this reason, locating functional outcome in the normative model of the unit is delicate because it is closely associated with the concept of quality of life and projections related thereto. 'Quality of life' is a catch-all phrase used in many ways by HCPs on the unit and it permeates their perspective on the best interests of the child at every stage of the process. Invocations of quality of life may refer to the actual experience of the hospitalised child or a more holistic judgement about what the life experience of the child is likely to be.¹⁸⁵

2.4 Pain and pleasure: the present of the child in the NICU

While questions about a child's survival expectancy and functional outcome point to

¹⁸⁵ I discuss quality of life in more detail in section 1 of Chapter IV.

the future, the balancing exercise conducted by HCPs to formulate a hypothesis about the child's best interests also relies on their appreciation of the burdens and benefits associated with the current experience of the child.

Just like their interpretation of functional outcome is constrained by a reluctance to judge the child's future quality of life, HCPs limit their appreciation of burdens and benefits to a basic, mainly physiological, understanding of pleasure and pain. This is congruent with the limited view of the situation of the child they adopt in restricting their assessment to the medical dimensions of the case.

HCPs do not all agree on the level of pain and discomfort experienced by the patients of the NICU. For at least one physician, pain management is so efficient that it almost entirely suppresses the symptoms of the stress and pain resulting from treatment in the NICU, to the point of misleading parents.

JFM: [...] What I'm getting at is, would it generally be because you feel that the child is in pain?

No, no, no. We can control pain so well now, and that is part of the problem. The parents don't see the stress and the pain, because they're on infusions or analgesia, so the child looks comfortable. And we can always control pain, even in the palliative care side when we withdraw treatment and take the tube out. [...] [Physician #3]

Similarly, the next section will show, some HCPs might perceive a baby's lack of physiological response to certain interventions and manipulations as evidencing the absence of a pain response, while others, notably nurses, disagree.

Those disagreements appear superficial. Independently of their view on exactly what makes it so, I have identified a widely shared belief among HCPs that undergoing a prolonged course of intensive care is extremely taxing for a newborn baby. This is a central assumption pervading the reflection of HCPs on the best interests of their patients. It weighs heavily on the burdens column of the balancing process.

Yet, all is not gloomy for neonates in the NICU. However difficult their present experience might be, it can often be relativised in light of the curative objective of the

treatment, in a balancing exercise of benefits and burdens. HCPs also identify outright benefits of the present experience of the child, notably in terms of their emerging relationships with family members.

I will now discuss successively the burdensome aspects of the experience of the child in the NICU and those aspects perceived as contributing to the welfare of the child.

2.4.1 Burdensome experiences: 'We put kids through horrendous stuff to get them better' [Physician #6]

HCPs see hospitalisation in the NICU as a terribly difficult experience for babies. Although they pay significant attention to ensuring children are handled delicately and that they receive appropriate analgesia and sedation, HCPs share a widespread understanding that their condition entails significant pain and discomfort. Most of the HCPs I interacted with insisted on that point.

JFM: You also mentioned that situation where it would be very burdensome for the child. Can you expand a bit on that? The kind of situation that would be too burdensome in your view?

Well, it's those examples I've given you, if they are not able to feed. They are completely not responsive to anything in the environment, any stimulation; and they are on a ventilator, and needing to be ventilated for 24 hours. You know, that sort of ... that is burdensome. It's not pleasant to have suction down your tube, your trachea regularly, because you can't breathe, you can't cough, you can't bring it up. That's not very nice. [Physician #3]

Nurses too see the NICU as a very stressful environment for patients:

... Because everything for these babies is stressful: the light is stressful, the sound is stressful. We are in a very loud unit. Most of the time it's very loud. Lights everywhere, beeping monitors everywhere; just that is so stressful. Coping with that, plus, people sticking needles on you... And sometimes it's two of them, one trying their arm, the other trying their leg. [...] [Nurses discussion group #2]

A group of three nurses explained in forceful details the observations upon which they base the claim that some of their patients are suffering. The following exchange between nurses is particularly instructive on the nurses' perception of the babies' experience. It develops and illustrates a broadly shared understanding of the burdens associated with the experience of neonates in the NICU.

First, Nurse #3 described a low birth weight premature child who is severely oedematous. Underlying her description is the observation that such children appear deformed by the accumulation of liquid in their tissues. She also raises frequently voiced doubts about the efficacy of analgesics over a long period of time.

Nurse #3: Well, if you were 500 grams, and you had fluid in your tissues that registered to 600 grams – that is double your body size that you actually are now. Do you think us being able to deliver pain relief for that would actually be effective, considering these babies have probably been on the same drug for quite a while, by the time they get to that stage... I don't know if your wife has ever had a baby and had swollen ankles, and she said, 'Oh my God, my feet are absolutely killing me.' Well, that is actually on a baby's body from head to toe. They are like Michelin. They are so swollen ... if you actually put a cannula in, they leak like a watering can. [Nurses discussion groups #2]

In response, one of her colleagues brings up the difficulties associated with finding a comfortable position for the child. When she concludes by suggesting that she sometimes perceives suffering in the eyes of her patients, her two colleagues concurred without hesitation.

Nurse #2: Yes. And even when you reposition them, they actually lie with their arms out like this. You can't put their arms anywhere. You can't roll them over, you can't do anything. And if they are awake and we haven't gotten them paralysed, they sometimes just look at you as if to say, 'What are you doing? Just leave me alone.'

Nurse #3: Yes.

Nurse #2: 'Go away.'

Nurse #1: You can tell by their eyes. You can see the suffering. Even with all the painkillers you can give... [Nurses discussion groups #2]

While the nurses acknowledge that their patients receive more appropriate sedation than in other contexts, notably the neonatal units of local hospitals, they nonetheless share the view that children in the NICU receive treatments that adults would find difficult to endure.

Nurse #1: We give sedation to intubate them and everything; but how many babies do you have that are intubated and awake? Whereas an adult, as soon as they wake up...

Nurse #3: Yes. They pull it...

Nurse #1: ... they pull out the tube, because it's unbearable to have it there. And we keep them like this for days if we need, awake with a tube down their throat.

[Nurses discussion group #2]

Still, HCPs also identify benefits to the experience of being in the NICU, to which I now turn.

2.4.2 Beneficial experiences

Two main elements are accounted for as benefits in appraising the child's experience of intensive care. The first is simply that of being alive and receiving top-quality care in a well-regarded institution. The second is the continued existence of the child and relates to the possibility of being cared for by close family – the child's parents mainly, but not exclusively – and the emerging relationships between the newborn and his or her family.

2.4.2.1 The benefits of being treated in a high-level unit

First, underlying HCPs' commitment to finding a pathway to a cure is a strong bias in favour of children being and remaining alive. This aspect is easy to neglect when the focus of the discussion is on situations where HCPs consider WLST. Yet, it lies beneath most treatment decisions in the NICU. Many HCPs are in awe of the power of the technology they wield and are sometimes critical of what comes out of its application. Yet, they strongly feel that treating children in one of the best-equipped and staffed NICUs in the country serves both the present and future interests of the child.

2.4.2.2 The benefits of relationships

Many HCPs stress the importance of affective relationships between newborn babies and their family, most importantly their parents. As relationships involve more than one party, it can be difficult to assess who benefits from them and to distinguish where the parents' interests converge with their child's and where they diverge. Indeed, the potential conflict between the interest of parents and that of their child is at forefront of many HCPs' reflections.

For instance, it would be possible to read the following quote from a surgeon suggesting that the right thing to do when it appears that the child will not survive is

'to allow the family [...] to have time to cuddle the child' as focusing primarily on doing what is in the interest of the child parents.

Because the machine can keep children alive for much longer than it used to be ten years ago. I mean now, you're very powerful with your drugs and your ... but what are you doing? You're just making this child suffer more. You know for sure that ... sometimes we open the abdomen, in NEC, and all the bowel is dead. So you know that the child is dead. You know that he cannot survive, and so you just close it, and you don't do anything.

So in those situations, you want to allow the family just to have the time to understand. So you could decide to stop the machine in the theatre, after you close. It's clear that that bowel is all dead, and it's just a matter of time before the heart stops beating. And so in these situations, you want to allow the family to adapt to that news, and to have the time to cuddle the child, or to... [Surgeon #2]

Some HCPs are critical of situations where they perceive the consequences of decisions made to accommodate a child's family are to the detriment of that child. Furthermore, they single out 'giving time to the family' as one of the main ways in which the interests of the family are placed above that of a child. I will return to in chapter IV.

Underlying the idea that the family and the child should be given some time together is a judgement about the value of that time spent together, independently of the projected outcome of the child's condition. HCPs mentioned that furthering the best interests of children means enabling the development of relationships between children and their family. Even when a consensus has emerged between a child's parents and the treating team that WLST would be in the child's best interests, HCPs will nonetheless see a benefit for the child in spending some more time with his or her parent, in being held by them or in hearing their voices.

Nurse #2: They [parents] always are given ... well, if they are presented that situation wherein we have given all the care and support, and there is nothing else that we can give, then most of the time they will always ask for some time within which the parents think about it, and then come back to us. And in my experience, most of the time they would give us... Like, when they wanted it to happen, a specific time, because they want other family members to come and visit first, before we actually stop any treatment. [Nurse discussion group #1]

3. Normative implications

Thus far, I have presented the main considerations in the process of balancing the benefits and burdens of treatment. I insisted on how the process involves increased scrutiny of the child's experience, both present and projected. The aim of this

balancing process is to recommend the option that offers the maximum benefits to the child. Other options that do not maximise net benefits might be considered at a later stage, as long as, on balance, the benefits outweigh the burdens. Options perceived to result in a net burden for the child would appear to be those for which HCPs might be willing to oppose the parents to ensure that they do not materialise.

At this point, I would like to bring the elements of the process together differently. I will highlight two of the normative implications at play in determining medical best interests. First, imposing pain and discomfort on a patient must be justified. Second, WLST treatment resulting in the death of the patient is morally acceptable and can, in certain circumstances, be in a child's best interests. These norms are so central to the ethos of the NICU that it is easy to lose sight of them and to assume everyone involved in the conversation shares them. I will briefly expand on each of these propositions.

3.1 'It's quite heart-breaking when you are inflicting pain for no sort of bigger gain' [Senior Nurse #1]: the burden of treatment must be justified

For HCPs, treatments provided to children in the NICU are burdensome. They describe the default treatment option as 'aggressive' or 'invasive', which means that no efforts are spared to try to improve the child's condition. A strong presumption in favour of pushing in that direction until signs accumulate suggesting that the expected results are not forthcoming abides. Although it is initially assumed, a net benefit must be identifiable to justify prolonged treatment in the NICU.

At the medical best interests stage, HCPs are particularly careful to identify situations where treatment does not lead toward a beneficial outcome and where the pain of treatment overcomes the balance of burdens and benefits. I asked nurses to describe their experience of caring for children when they have acquired 'the belief or the impression that there is no coming back'. Nurse #1's answer stresses the idea that there should be a *point* to the treatments, considering the burden they impose on the child.

Nurse #1: But it is very frustrating for us, I think. Because you know that ... you know that anything that you do is not going to change the baby's outcome. But we still do blood tests; we still have to prick their heel to do blood tests sometimes. We still have to do things that we know are going to be painful for them; and there is no point in doing that, because we are not going to change the situation. But because they are here, we need to do something, because we cannot be ... we can't not give them the care that they need. But we know ... and we give them the care to keep them alive; and so we control things and get on top of things; but we know that those bloods are not going to make any difference. You know that the treatment is not going to make any difference. So what is the point of making that baby suffer just a tiny bit more every day? [Nurses discussion group #2]

To the same effect, Surgeon #2, although acknowledging a tension with their religious faith, recognises treatment cannot continue if its net effect is suffering for the child:

Well, end of life is my biggest ethical challenge. That's certainly ... when we decide to withdraw care, I find it is very difficult, myself. I recognise that I'm biased; I'm [religious affiliation], a practising [religious affiliation], and I find it always difficult. I mean, in general doctors try to do this job to save lives, and you feel it as a personal failure when you cannot. I completely understand that at some point you just make these children suffer and that there must be an end; but personally I always find it very difficult to accept that.

Similarly, Physician #1 retrospectively describes as a tragedy the case of a child for which court authorisation had to be obtained before withdrawing life-sustaining treatments:

The tragedy of that is that it takes six months of the child's life for everything to come together, during which time he's had no pleasure, and significant suffering.

The balance of benefits and burdens points toward net burdens when no or little chance subsists that the child will survive. In such cases, no beneficial future for the child remains, only a present experience of pain and suffering. Similarly, if the predicted functional outcome is so catastrophic that a significant diminution of the present level of painful and burdensome treatment is unlikely, the current course of action appears difficult to justify.

3.2 Death might be the most desirable outcome

The norm that aggressive and invasive treatment must be justified is intimately linked to an almost unanimously shared understanding that it is entirely possible to conclude that the child's interest lies in WLST. Being alive is associated with little metaphysical value or meaning aside from the experiences it enables. As such, if the experiences are on balance valuable, life is beneficial. On the contrary, if life is only

the substrate for painful experiences, it is not beneficial.

As noted initially, assessing best interests is often perceived to be about balancing life and death.

[...] In the sense that we are obviously making a series of assessments of what would be an unpleasant experience, and what would be potentially a pleasant experience, and trying to balance them. And we try to be open and honest about whether that might be something that you can imagine someone wishing for rather than death – because that is often the balance.
[Physician #1]

3.2.1 A proximate relationship with death

HCPs working in the NICU have a particular relationship to death because of their proximity to it. This proximity has at least three facets. Firstly, while it is an unusual phenomenon outside medical settings, HCPs are temporally close to children dying because they experience it regularly. Secondly, they are physically close to those of their patients who die, spending their entire work-day by their side, especially nurses. Thirdly, they are technically close to the dying process as they are involved in the care of dying children even beyond their death. HCPs monitor every step of the way toward the death of a child. As a result, they find themselves with a precise understanding of the physiological processes leading to it.

Without entirely demystifying death or playing down its significance, this proximity results in a level of familiarity not shared by most of the population. Furthermore, it is even less common to find oneself faced with a situation where death appears to be the most desirable outcome for the child concerned. These counter-intuitive elements set the NICU apart from most other contexts in which children might find themselves at the beginning for their lives.

The consultants who participated in the discussion group observed that, although always tragic, children dying is part of their professional life.

Physician #5: But that's the point: that the normality of death is gone.

Physician #1: Yes. It's wrong to die.

Physician #5: [With emphasis] Everybody dies.

Physician #1: Yes, but in that documentary ... that [...] documentary showed 3 deaths [...]. And there was such a discussion about whether that was going to be possible. And there was quite a backlash, that it wasn't the 'dream alive' outcome; it was the real world that shows that sometimes with multiple pathologies, sometimes they don't survive. It shouldn't be a surprise to anyone. But actually saying it is a threat.

Initially, the discussion of that point seemed to focus on the perspective of parents, the lay public and of media. However, the consultants made it clear that even some of their colleagues, both within and outside the hospital, were not entirely attuned to the possibility of withdrawing or withholding treatment.

Physician #3: I had a consultant paediatrician on the phone. There was a child who had a long cardiac arrest in the hospital. There was no possible way they could survive. And I said, 'What you need to do is say, this is where we are, and we need to stop.' And she said, 'I've never told a family that their child is going to die, and I'm not going to start now.' And I'm a consultant paediatrician. I'm like... [Laugh]

3.2.2 A plausible conclusion

However implausible or remote it might appear to outsiders, the possibility that the child might not survive and that it might be the most desirable outcome for that child in the circumstances seems always to be present to HCPs working in the NICU. One of the allied professionals working with the team made the following observation:

I guess sometimes doctors and nurses think that it's not in a child's best interests to carry on treatment – which ultimately means that child will die. And I think it's very hard for parents to – especially initially – to remotely think that what is best for my child is letting them die. There is naturally a protective side, which thinks, 'Surely what is in my child's best interests is to keep trying everything possible in order for them to survive.' [Allied Professional #2]

Indeed, nurses do not shy away from reaching that conclusion:

Nurse #3: It can be. Because if sometimes the child is in a lot of pain, and the only way is passing away. [...] [Nurses discussion group # 4]

Similarly, Surgeon #1's comments highlight the fact that, although reaching a consensus among HCPs on whether it is appropriate to withdraw life-sustaining treatments might be difficult, such consensus is nonetheless reachable in the NICU:

I mean, you can be in a position where the feelings of the doctors looking after a child are pretty unanimously that withdrawal of care is the right thing to do. And that's a big statement in and of itself, because getting that unanimity is not always easy. [Surgeon #1]

3.2.3 The manifestation of a specific ethos

However, it is important to note that I am ascribing this norm to the NICU as a whole,

not to individual HCPs who may or may not adhere to it or may accept it without being willing to enforce it. Indeed, although nurses did not raise that aspect explicitly in interviews, consultants indicated that it is not adopted to the same degree by every doctor working in similar settings nor is it even adopted by every consultant working in the London Hospital's NICU.

Referring back to their time as a junior surgeon, Surgeon #1 suggested that consultants working in a unit can have diverging views.

So particularly in the context of neonatal units where I've worked, where withdrawal of care often happens—which it doesn't here, I think partly because of our patient population—you know that there are weeks where one of the consultants will come in and sort out all the long stay babies with a really poor prognosis, because their colleagues will never contemplate withdrawing care. And then in the next weeks someone else comes along, brings a completely different perspective, and by the end of the week three of the ventilators are shut off and the babies have been allowed to expire. [Surgeon #1]

One of the NICU's consultant intensivists indicated that the consultants of the unit did not all share the same views. Indeed that consultant referred to some colleagues as holding 'a pro-life viewpoint'. I understand that last expression to mean that, as evoked in the previous quote, some consultants do not adhere to the position that it can be in the interest of a child to die following WLST. However, that consultant also indicated that the norm held for the majority in the group of consultants:

It can make difficult conversations a little bit easier. But also, the divisions in the team, between very pro-life viewpoints—most of us being in the middle and rational, some people are at the other extreme of that. It's not anti-life, but people who think we should really be stopping on a lot of these children a lot sooner. There are always some ruptures about that. And that's ongoing. [Physician #5]

Another consultant insists on the convergence of views within the unit when describing 'the ethos' of the NICU in comparison with other settings where they have worked in the past. Again, the norm within the London Hospital's NICU is described to be that it can be in the interest of a child to die:

What you'll find is, as I'm sure you're looking into, is that different units will have very different views on that. [Other hospital #1] for instance, has a very strong Christian right to life ethos there, which I find difficult personally, which says that a person—they are much less likely to withdraw in various situations. Whereas at [Other hospital #2], we had a very sort of—I wouldn't say we were overly enthusiastic, but we would come to these decisions, and we

would generally agree. I can't think of any times where we didn't feel that these withdrawals weren't the right thing to do. And it's always ... it's a personal decision as well. It's also to do with what the general culture is within that particular unit. And you will find great differences... Here, I'm much more familiar with the ethos here at [London NICU] than I am at [Other Hospital #1], which I find far too ... there's a right to life underlying thing there which I find difficult. [Physician #4]

3. Conclusion: 'Nursing a corpse in the bed'

I wish to conclude this chapter on medical best interests with an illustration of the type of situations where the conclusion would unequivocally be to recommend withdrawal of intensive care. Most of the elements of the determination of medical best interests that I have presented in this chapter are at play in the comments and observations that I brought together here as 'nursing a corpse in the bed', following the powerful and evocative expression of one of the nurses I interviewed.

The core of the narrative comes from the experience of HCPs caring for one child, whose trajectory I followed at the beginning of my fieldwork. This child was in the NICU when I first attended morning rounds and I could interview many of those who were involved in their care until the child passed away after a long and tumultuous stay in the NICU. I then attended the Coroner's Court hearing on the determination of the cause of death, as well an ethics training session structured as a debriefing on the case. However, similar experiences were also related to me, without mention of that patient. This leads me to conclude that although it was a difficult situation, it was not an exceptional one. Cases like this one constitute significant points of reference for HCPs when they approach difficult cases.

In presenting that child's case and others who inspired similar reactions, I would like to display some features of those cases described by Surgeon #1 as warranting doing everything to ensure withdrawal of treatment to allow the child to die:

And so I think that's really muddy; it's a really muddy place, because there are some babies whose outcome is looking to be so dire that you're prepared to take the parent to court not to treat their child, because it's going to be so awful. [Surgeon #1]

One of the senior nurses described the condition of the child toward the end of her life as follows:

We had gotten to the stage where all the treatments we had tried to give to [the child] had failed. [The child] was in multi-organ failure. I think ultimately as a team we knew that [the] prognosis was not going to be good. [The child] had been extremely sick [their] whole life; ventilated, with PD lines in; a whole host of drugs had been given to [the child]. [The child] not very responsive at all. [The child] hardly moved in the bed. [The child] was so [Inaudible] and fluid overloaded at all times, really. And with [their] renal machine [the child] wasn't clearing the sedations and [...] was sedated the majority of the time. [Senior Nurse #1]

The combination of a dire survival prognosis and a grimly rated present experience with powerful life-support technology gives rise to a class of patients considered by HCPs to be in a position where not only they cannot benefit from the care they receive but are directly harmed by it. HCPs are deeply worried because they consider that they are only bringing suffering or pain to the life of the patient by providing them with the full array of life-sustaining therapies. In this context, voices arise, asserting that such therapies should be withdrawn and the treatment plan reoriented toward palliative care.

I can hardly overstate the strength of that sentiment. HCPs use strong words to describe children who have reached such a stage in their illness. Some of them resort to the vocabulary of death, evoking the image of a corpse in a state of decomposition, although the child is still alive. Senior Nurse #1 continues her description of the child's situation and her reaction to it:

With this, and in view of [him or her] not progressing or getting better, I think we were effectively nursing a corpse in the bed, who was breaking down before our eyes. And I think as a nurse who is at the bedside 12 hours a day doing that, it's quite heart breaking when you're inflicting pain for no sort of bigger gain, if you like. [Senior Nurse #1]

Later in the interview, when asked whether the case we were discussing was an exceptional one, she drew a parallel with the situation of another of her former patients, again using language that suggested that the child was already dead:

So it's kind of clear that the treatment that we've done has failed, and they have however much power left and they're not going to survive. It's not viable with life. I'm talking about 24, 25, 26-weekers. I can think of one in particular where they had 2 cm of bowel left, and the parents had asked whether we could do a bowel transplant. We were having all these lengthy meetings about whether we were going to do a bowel transplant, and this child, in the meantime, is decomposing in the bed, if you like. For me, I just think that's hugely wrong. We shouldn't consider those kinds of things for that kind of clientele. [Senior Nurse #1]

The description of the harshness of the condition, the idea that the child was in such a debilitated state that they were already dead, and the distress it created for HCPs, are all echoed in the recollection of another senior nurse:

I was just heartbroken to see [the child] with... [The child] was so tiny, and [...] looked so pale, and almost grey. [His or her] skin started being already a bit kind of like ... not normal baby skin anymore. All these wires and tubes, and [they were] oedematous. I think [they] had several bruises from cannulations and things like that. [They] just looked bruised and battered, and [...] didn't even look alive to me anymore. [Senior Nurse #2]

Senior Nurse #2 expressed her sense that continuing to treat that child aggressively was going against her professional duties, going as far comparing what she was doing to torturing the child:

And I know that someone once said, 'That's what we do,' and I thought no, that's not what I do. I do not torture babies. I make them better, but I don't want to torture them. And that's what it felt like to me in the end. [Senior Nurse #2]

This perspective is not limited to nurses. A surgeon also described certain patients as 'dead':

Because the machine can keep children alive for much longer than it used to be ten years ago. I mean now, you're very powerful with your drugs and your ... but what are you doing? You're just making this child suffer more. You know for sure that ... sometimes we open the abdomen, in NEC, and all the bowel is dead. So you know that the child is dead. You know that he cannot survive, and so you just close it, and you don't do anything. [Surgeon #2]

The point of concluding with this vignette is to show that sometimes, a widely shared consensus exists among HCPs that the balance of burdens and benefits points toward a recommendation to withdraw life-sustaining care, even when such assessment is limited to medical considerations. Nonetheless, in other cases, this first assessment forms the basis of a second stage in the process in which a broader range of considerations are introduced. This will be the focus of the next chapter.

Chapter IV - Wider best interests

Introduction

Once HCPs agree on a firm hypothesis on the medical best interests of the child, they turn their attention to refining it, considering an added set of considerations in a secondary process I have labelled 'wider best interests'.

I lifted the expression 'wider best interests' from the reflections of Surgeon #1, who used the idea of 'wider best interests' to distinguish situations where what ought to be done appears medically straightforward and those where it is less so. It is in the latter case that non-medical considerations are deemed relevant and given more weight.

JFM: All right. Now I'd like to ask you about – again from the perspective of ethical decision-making... You know, in the ethics literature, something we see all over the place is best interests, best interests of the child. I'm wondering first, is it a concept that is of any use to you? Is it something that you use or that you think about? I don't know if you see what I mean...

Surgeon #1: Yes, I do see what you mean. And yes, it is. I think sometimes... So there is interest, and there is wider best interests, and I think those are two slightly different concepts, aren't they?

Later in the interview, Surgeon #1 went on to use this distinction to highlight how the medical dimension of a child's situation can be interpreted differently once it is apprehended in the broader context of the child's wider best interests and the difficulties inherent thereto:

I had a patient a few months ago who had just about every complication of prematurity that you could possibly think of; and I'm sure [the child's] chance of achieving what I would regard as a meaningful existence was very low; but there's a bit of me that thinks, well actually, why is my judgement of a meaningful existence the one that should be used? Because I have my own prejudices about things. Which is where you get into the wider best interests argument about how this child fits into their family, and their value to the parents, and you know ... actually within some families and cultural contexts perhaps it's perfectly appropriate to have a child who continues to have significant needs, if they are loved and looked after and they bring joy to the family ... then why actually is that wrong? It's really difficult. [Surgeon #1]

HCPs in the NICU do not explicitly use the distinction between medical and wider

best interests. However, it maps onto how HCPs approach the issue and how considerations concerning a child's situation are ranked and weighted. It also introduces a nuance in the appreciation of best interests that is present even for those HCPs who assert that best interests is only assessed medically.

The additional factors constituting 'wider best interests' arise against the backdrop of the hypothesis elaborated at the medical best interests stage. This is why I consider the factors introduced at that stage as secondary, meaning they do not carry the same weight as the primary factors considered at the first stage of the assessment. The determination of wider best interests entails another expansion of the perspective adopted by HCPs. While medical best interests is determined through close attention to the immediate dimensions of the situation and experience of the child, wider best interests seeks to situate this picture in the broader context of the child's family and the potential long-term clinical evolution of the child. At this stage, HCPs consider the question of the child's future quality of life more directly. HCPs also start to solicit, consider and integrate the preferences of the child's family.

In this chapter, I address these two factors, the future quality of life of the child and the preference of parents. I then conclude by discussing two further factors acknowledged by HCPs as potentially relevant but which they consciously set aside, namely the allocation of scarce resources and the protection of the reputation of the hospital.

1. Is future quality of life relevant to assessing wider best interest? Who gets to make that assessment?

At the wider best interests stage, the question of the relevance of projections about the subjective and embodied future experience of the child poses itself more acutely. While HCPs acknowledge the future quality of life of the child as relevant in assessing best interests, they display a broad range of views as to its meaning and as to who is responsible for assessing it. In this section, I insist on implicit tensions in the understanding and use of quality of life in the NICU. Throughout this discussion, I will also show that, notwithstanding the broad range of views expressed on the

matter, a common thread is a somewhat pessimistic attitude toward the quality of life of severely disabled neonates. I also argue that even if we were to conclude that a projection as to the future quality of life of a child only has a modest explicit influence on the assessment of that child's best interests, such an attitude colours the perspective of many HCPs, therefore implicitly influencing the assessment.

First, HCPs contest the role of future quality of life in the assessment of best interests. Paradoxically, for some it is the main and central issue to consider, while others tend to minimise its importance. For the former, as noted by Allied Professional #2, the question of appreciating the future quality of life of neonates is recurrent in HCPs' reflections and discussions about their patients.

'What's in the best interests of the child?' I think often people are worried about, you know, 'Just because we can get them through intensive care, what is their future going to look like?' And 'What is their quality of life going to be?' is one I hear an awful lot. And I find that one very interesting, because it's very subjective. We all have different views on quality of life. [Allied Professional #2]

Some HCPs, notably nurses, go as far as suggesting that quality of life can serve as a definition or as a synonym of best interests.

JFM: [...] Some people have described this as 'putting the child first', for instance. So I am interested in your perception and understanding of best interests of the child. Basically, what does it mean for you, and what goes into it?

Nurse #1: The thing I take into consideration, and that I think most people take into consideration, is quality of life. Like, at the end point – we're hoping it's a good end point, but that's something you always have to consider; every moment of the care, whether or not it's to do withdrawal or just treatment in general. It's that final outcome, and trying to get them the best possible solution and to the best possible end, I suppose. [Nurses discussion group #4]

On the other hand, according to other HCPs, among them several consultants, the exclusion of future quality of life that characterises medical best interests has an even further reach. For these HCPs, the future quality of life of a child is largely irrelevant to the determination they make of their patients' best interests.

JFM: [...] What comes into the best interests analysis?

Best interests to us aren't the best interests of the courts about the child's potential future options being university or state school... Or you know, are you going to make a decision to change inotropes based on how many brothers the kid has and how old they are? Not really.

The other, social aspects don't really come into it. [...] [Physician #5]

A surgeon gives an illustration of that position, explaining that the historical tendency of the NICU has been to operate on neonates suffering from NEC whenever such intervention appeared susceptible of successfully treating the child, although co-occurring diseases or complications might otherwise point to an unfavourable outcome. Surgeon #1 contrasts that approach with that of a comparable hospital, whereby, in that surgeon's view, considering the children neurological prognosis would lead to a more conservative approach in selecting who to treat surgically. With more weight given to bleak projections about quality of life resulting from neurological impairments, fewer children with NEC are operated on, although considered separately, the intervention might appear technically feasible.

And so for example, it has historically been the case that mortality from surgically treated NEC in this unit has been very high, and... [Inaudible, few words] and then now at [Other Hospital] it has been quite low. Part of the reason for that is that the rate of surgery in really sick children there is lower than the rate of surgery here; because the prevailing view has been, we should offer this child all the treatment we can for their problem, and if they die, they die. And you know, it's not up to us to think too much about long-term outcome for them. You know, 'there is a child with a treatable problem here, we should treat it.'

There are other places where the view might be taken, 'we think this child's chance of achieving a reasonable quality of life is so low that we shouldn't intervene.' And then you're in this discussion about what constitutes a reasonable quality of life. [Surgeon #1]

However, it does not mean that this latter group of HCPs entirely rejects considering projected quality of life as a factor in assessing best interests. First, it must be reiterated that the appreciation of medical best interests includes a substantial dimension of quality of life under the heading of the future of the child, most notably as a prediction as to the functional outcome of the child. Granted, this prediction appears largely clinical and purports to exclude subjective elements that are more difficult to grasp adopting a strictly medical perspective. Yet, as I will explain shortly, a widespread implicit understanding prevails among HCPs as to many of the subjective dimensions of the experience of those children whose quality of life might be questioned.

The issue is not therefore exactly whether quality of life projections are relevant to

the determination of wider best interests. Rather, the more important controversy concerns the question as to who is responsible for making such assessments. Those who minimise the impact of projections about quality of life at this stage usually also mention that parents should make that assessment in contemplating whether to consent or not to the treatment plan that is presented to them. Although not all explicitly acknowledge it as a direct component of best interests, it contributes to its construction, notably through the type and tone of the information presented to parents in the consent process, through the factors HCPs encourage parents to consider in their assessment.

Thus, to the extent my inquiry reveals a disagreement among HCPs concerning quality of life, it is mainly as to its precise place in the process. For some, HCPs must address considerations relating to the future quality of life of the child in determining their patient's best interests. Those who disagree, do not deny its relevance. Rather they will stop short of integrating these considerations in their final recommendation and defer to the assessment made by the child's parents, according to their own beliefs and values. However, the pessimistic views held in the NICU about the future quality of life of neonates who go on to live with severe disability risk influencing the process of presenting and explaining the child's situation to parents.

In practice, the difference between the two approaches is subtler than it might appear at first sight. Both groups acknowledge that the preference of the child's parents is the other main factor modulating medical best interests and that the next step in the process is to engage with parents in the consent process. Although the path each group takes appears slightly different, they will most often end up reaching similar conclusions. Since the holders of each view interact with one another in determining a child's best interests, the concrete method used on the ground is likely to be a hybrid between the two types I presented here.

Having set out the controversial place that quality of life plays in the assessment of wider best interests, I will delve into its meaning and function for HCPs working in the

NICU and explain why I perceive pessimism about the future of severely disabled children as a broadly shared attitude within the unit.

1.1 Quality of life as a euphemistic placeholder for severe disability

Quality of life is an inherently evaluative notion. In the discourse of HCPs, it functions as a euphemism because it provides a somewhat positive, or at least neutral, way to capture the pessimistic view that many HCPs have of the experience of severely disabled children and their family. One of the symbolic roles of quality of life in determining a patient's best interests is that of a euphemistic placeholder for the web of issues related to the subjective impact of projected disability, first on children themselves, but also on the parents and family of those children. Often, HCPs use quality of life as a tactful label to put on the complex and controversial issues surrounding the status of severely disabled neonates. Chief among them are whether they can enjoy a meaningful life, how they relate to the members of their immediate and extended families and to what extent the heavy responsibilities associated with caring for a severely disabled child might impact the child's parents and siblings.

Yet, no euphemism can entirely obscure the fact that certain patients who survive their stay in the NICU will go on to live with severe disability. It is therefore important to first outline the profile of the children HCPs contemplate when they reflect on the future quality of life of severely disabled children and their families. I then turn to the way HCPs approach quality of life and highlight the pessimistic thread in that process.

1.1.1 Severely disabled children

Not all children in the NICU face the risk of severe disability. For those who do not, the previously discussed default position in favour of doing everything to ensure the survival of the child will apply without much debate, if at all. Similarly, if the assessment of a child's best interests reaches the stage where wider best interests is considered, arguably it means that the child is not in the excruciatingly painful and hopeless situation I described above as 'nursing a corpse in the bed'. However, even

notwithstanding such extreme situations, the projected functional outcome of a child can be one of severe disability. The following discussion applies to this subset of children, for whom the experience of the NICU is not so negative as to entail that persisting with treatments goes against their best interests, but for whom the projected long-term outcome appears sufficiently burdensome as to warrant questioning whether it would be in their best interests to survive.

HCPs have a widely shared conception of the disabilities susceptible of greatly impacting a child's quality of life. The NICU admits patients with a broad range of conditions, some of them much less frequent than others. However, the paradigmatic example repeatedly invoked is that of a premature neonate suffering from necrotising enterocolitis and requiring a surgical intervention.

I mean, the whole process of decision-making within neonatal care is interesting, particularly when you start talking about premature infants who have surgically ... particularly if you start talking about premature infants who have surgically managed necrotising enterocolitis, because we know that those who survive that illness and live on to become children will have an extremely high rate of very significant neurological handicap. [Surgeon #1]

The interview excerpts below, each taken from different interviews or discussion groups, attest that when different HCPs evoke severely disabled children, they generally agree as to what is at stake. Most frequently, the example HCPs provide when discussing the impact of projected disability on the best interests analysis is that of a child who incurred significant brain damage resulting in severe cerebral palsy and multiple associated impairments such as sight and hearing loss, incontinence, and severe difficulties to communicate.

You know, we have lots who have quite extreme forms of cerebral palsy, and can't walk, can't look after themselves, can't do their day-to-day, going to the toilet and feed themselves. [Legal Counsel #2]

Nurse #1: [...] 'If your child survived, you will probably end up with a child that is never going to walk, never going to talk; he is going to be in bed [...]' [Nurses discussion groups #2]

So you have to think, is not being able to feed yourself, and being a double incontinent, and being in a wheelchair is that something that is a tolerable thing for a human being to have? [Physician #4]

[...] Is it in this child's best interests to be treated aggressively, such that they end up in a wheelchair with no communication, with hearing and visual impairment, being fed with a tube,

question mark? I don't know the answer to that. [...] [Surgeon #1]

These descriptions of severely disabled children are often, although not always, accompanied by the expression of an opinion to the effect that such children will have a poor quality of life.

1.1.2 A pessimistic view of life with severe disability

Indeed, in this subsection, I wish to insist on the idea that pessimistic judgements on the future quality of life of severely disabled neonates are widespread among HCPs working in the NICU.

First, the choice of the qualifier 'pessimistic' requires explanation. I did not directly ask the participants in the study whether they would describe their take on the future quality of life of their patients as pessimistic or not. Often, such views are offered as a *realist* view derived from professional experience. Yet, even accepting such a characterisation at face value, the fact that it is realism about negative aspects of a child's future experience still makes it appropriate to describe them as pessimistic.

For HCPs, contemplating the worst possible outcome, or being cautious as to the likeliest outcome is an antidote against unfounded optimism. Many HCPs display a certain wariness against what they perceive to be unjustified or unreasonable hopes and expectations on the part of parents. As such, HCPs' interpretation of parents' perceptions as overly optimistic appears to warrant them to emphasise potentially negative aspects in their appraisal of a child's situation.

JFM: So if I understand correctly, you're saying that in your discussions with the parents, sometimes you're able to identify that maybe they don't necessarily understand – or to put it bluntly, that they have more hope than they should? Can I put it like that?

Nurse #2: Yes. Yes. Sometimes we ... sometimes it's the parents that are trying to say, but because we still are not discussing this information to them, it's like ... maybe there is still a lot of treatment out there that they can give to their child; that's why they're living it. Not until it has been properly discussed ... and a meeting has been made, and then they have been informed that we have done everything. That's when they start planning and saying...

Nurse #1: They hold on to every bit of hope ... like, if they...

Nurse #2: That's what we had recently...

Nurse #1: Yes. When they have a few things, a few illnesses as well, and then one looks like it's getting a bit better, they kind of forget about the other ones. And it doesn't necessarily mean that one part of the illness has gotten better forever. It just has gotten better for now. And then because that's a bit of hope, it looks like they are improving, then they think it's going to be fine. Whereas the reality is totally different; because they have whole other conditions and whole other problems, that they kind of forget about and just think, 'there is a little bit of improvement, so they are going to be fine'. [Nurses' discussion group #1]

Not only are HCPs theoretically aware of the worst possible outcomes in terms of disability, but they also occasionally encounter children for whom such outcomes have materialised, for example when the child comes back to the hospital for a courtesy visit or treatment in a different part of the London Hospital. Concerning the latter, the NICU is physically close to the paediatric intensive care unit (the 'PICU'), where older children requiring intensive care are treated and the majority of intensivists also work in the PICU. PICU patients offer anecdotal evidence of the extreme disabilities that can afflict a child. Such outcomes are therefore never far from HCPs, both in the concrete physical organisation of the London Hospital and in how they envision the future of their patients.

The reflections and observations of one physician lend support to the idea that a certain level of pessimism pervades the approach of some members of the NICU. While denying sharing this attitude, Physician #3 suggested that colleagues from other departments of the London Hospital perceive a tendency within the group of NICU consultants to base some of their decisions to recommend withdrawal of life-sustaining care on the hypothesis of a negative outcome in terms of quality of life.

JFM: [...] You mention that some of your colleagues from other departments think that sometimes you're a bit too quick [to withdraw life-sustaining treatment]?

Not me personally.

JFM: As a group, yes.

They do think that. As a group. Because they know... You see, we only see the bad cases, and we remember the bad cases. Whereas say for the haematology or oncology patients, they also see a lot of patients who get better with their treatment. And sometimes they think that we don't give the patient enough of a chance. And you know, we are too quick to judge that their life isn't worth living. So ... they have made those comments. And the neurologists as well have said that; the haematologists have said that.

JFM: Do you feel it's a fair comment?

Yeah. Yeah, I feel it's a fair comment, but sometimes I also think that some of my colleagues are a little bit too aggressive. Some are reasonable, but there are some who ... they only remember the bad cases, but they don't remember the ones who have gotten better.
[Physician #3]

Not everyone approaches the burdens associated with severe disability from the same standpoint nor accounts for them in the same way. In what follows, I wish to continue to illustrate the views that HCPs take on the future quality of life of their patient. To do so, I start with the views I consider to be the most pessimistic about future quality of life and tease out the commonalities in their normative assumptions. I will then present an alternative approach to the pessimistic take on quality of life that also has currency in the NICU. In doing so, I will also suggest that whether the appreciation of quality of life is conceived of in terms of a comparison between a disabled child and a non-disabled child or whether only the experience of the child is considered has a direct impact on the assessment of best interests.

At one end of the spectrum, I place one physician's categorical view that life with severe disability of the kind some NICU patients go on to live with is intolerable and should therefore be avoided.

So you have to think, is not being able to feed yourself, and being a double incontinent, and being in a wheelchair, is that something that is a tolerable thing for a human being to have? In my view not, whereas for others might say there would always be a quality of life there that is worth salvaging. [Physician #4]

Physician #4 is the HCP who displayed the most confidence in their judgement of the quality of life of a severely disabled child. Many other participants prefaced their opinion by expressing doubts in one way or another about the validity of their perception, notably evoking the impossibility to apprehend and evaluate the lived experience of a severely disabled child.

Physician #4 presents this view as resting on a clear moral vision as to what constitutes a life worth living and what does not. Physician #4 first explains that their position is founded at least in part on their personal cultural and familial background:

[...] ... it depends what your personal philosophy of life is as well. I mean, I come from a background where it was very clear what suffering is. I come from a [religious tradition] background; my family [contextual detail removed].

Physician #4 then goes on to explain that this background, along with their view of the moral ends of medicine, confer them with a sense of assurance as to the normative implications of suffering and their role toward it. The reasoning seems to be that a moral duty of a physician is to contribute to reducing the aggregate suffering in the world rather than adding to it.

I'm quite clear on what is right and what is wrong and that front, and there is a degree of suffering which I feel is not tolerable. And that there's too much unhappiness in the world as well, so to actually go into medicine and not take that into account, I find ridiculous. You know, we all come from somewhere. [Physician #4]

When prompted to expand on 'what is tolerable and what is not', Physician #4 relied on past experience and volunteered a comparison between twin siblings, one severely disabled since birth and the other not:

JF: You were talking about what is tolerable and what is not. Can you expand a little bit? You know, the kind of cases that you encounter.

Well, OK, for instance there was a child ... there was a set of twins, it must be 15 years ago. God, I'm getting old! One of the twins had a horrendous septicaemia. We desperately tried to get the parents to withdraw from this kid, because on the ultrasound scan, again, the brain was disintegrating. And they refused, they refused. I think I those days we were less into going to court. We were a bit wetter, I don't know. By the time we sort of thought about it we couldn't do it anymore, because the kid had gotten better; so it just wasn't possible anymore. And then I bumped into them seven years later. The child was in a wheelchair, and the other twin was completely normal. This child was obviously incredibly disabled, and the family ... well the family had disintegrated, really. So to my mind, that's intolerable. [Physician #4]

The comparison between the twins is telling. Indeed, comparing between able-bodied and disabled children is central to the approach of other HCPs, although they are less morally assured.

For instance, Nurse #1 insists on what a child ought 'normally' to be able to do.

JFM: OK. When you are talking about quality of life, can you expand a little bit on what you mean by that?

OK. Personally, like... Children should be able to play, go to school, eat normally, interact normally; and there are children with disability wherein their condition limits them in their movement, comprehension, understanding, and interaction, and social activities with other

children or the family itself. [Nurse #1]

Taking a typical able-bodied child as her point of departure leads Nurse #1 to wonder whether a severely disabled child enjoys the same quality of life as another child, who is not disabled and whether the child is happy with their situation.

I find it, um – like, you would see children in a wheelchair in a hospital – yes, they look very happy, but are we able to offer them a life wherein you would fully say that you've experienced a happy life, if they always come in the hospital and spend most of their time at the hospital? Yes, we do have play therapy, and we do everything they need and provide them with everything they need, food and everything; but we would never know how they actually feel, would we? I don't know; because it's difficult.

And they are attached to machines, or trapped in a wheelchair all their life. Well, most of the ones I see at the hospital. And sometimes you would just ask them if they are really happy with the life that they have, but obviously they cannot answer that. [Nurse #1]

A comparison of the child's situation with an ideal or idealised human life underlies the negative view of severe disability these two accounts evidence. Implicit in such views is the notion that able-bodied children enjoy a better quality of life than disabled children.

Next to the perspective comparing the life of a disabled child with that of an able-bodied one, I place those perspectives playing up the strains of the severely disabled child's existence. Among those, the duration and the frequency of hospitalisations are often highlighted. HCPs also identify dependency on life-support technology as a having a significant impact on quality of life:

It's probably very difficult to draw a line, but ... that's my personal opinion, but I think you should consider what will be the outcome ... if a patient has renal failure in that way, that the kidneys will never recover and the patient will need kidney transplant, but needs to reach 10 kilograms before it can have a kidney transplant, and the patient is 1.2 kilograms, how are you going to reach this? It's not reasonable to have this child in the hospital for what, two or three years before it can have its transplant? Is that fair for the baby, the child, and the family? And all the complications that would come with a hospital stay that long. Because we know that a lot of our babies get unwell because of being intubated, because of having lines inserted; they get infections because they have lines inserted, and then they get septic and it's all around septic, and not the initial NEC that was the problem or whatever they came for... PD ligation, and then they just got septic. And that's just because they are in the hospital. And then if they then have to stay in the hospital for another I don't know how many months or years to get to a certain point for a transplant or for another surgery, but they have to grow for another surgery, and they're in a situation where they are that unwell that they wouldn't survive without all the support... [Senior Nurse #2]

Another crucial aspect of the approach to future quality of life as part of the

assessment of wider best interests is the integration of considerations about the future quality of life of the child's parents and siblings. Again, in this regard, HCPs are painfully aware of potential negative outcomes. The quality of life of disabled children is dependent on their families' quality of life. Irrespective of the institutional support that can be offered, parents carry the responsibility of caring for a severely disabled child. This belief is connected to the conviction that the difficulties associated with raising a severely disabled child threaten the quality of life of all family members.

Nurse #4: In PICU or adults ... because you see them older, you see them getting to, like, 10-year-olds. And they are just so sick, they are really in PICU all the time and you see how their family struggles. So I think that helps me make my decision about quality of life. When I see the whole family struggle when they are older. And it affects the other siblings as well.

Nurse #1: Yes, desperately...

Nurse #4: They can't go out and play or anything, and all the attention is on the really sick one.

Nurse #3: They have to completely leave their homes, they have to adapt ... this helps you, not to come to a decision, but ... it helps you see them from when they are small. [Nurses' discussion groups #4]

One such threat frequently insisted upon is that of the family breaking up under the weight of the commitment to care for the disabled child. Many HCPs see that risk looming from the beginning of the child's life, although it might not materialise until later:

Nurse #3: And it's OK changing a nappy now on a baby who is 2, 3 or 4 kilos. It's a bit different changing a nappy on a child that is 12 years old and needing 24-hour care. And that, a lot of times, is not actually provided by the parents themselves. You'll be lucky if mum and dad actually even stay together; because there is such a high incidence of divorce rates for people who have handicapped children. [Discussion Group #2]

1.1.3 The optimistic counter-argument

I have argued that pessimism is widespread in how the prospect of severe disability is approached in the NICU. Yet, some HCPs hold more optimistic views. Indeed, at the other end of the spectrum of views, I found positions that focus on the specificity of a disabled child's context to put forward what makes such a life enjoyable and worthy. Nonetheless, they are less widely shared than their pessimistic counterpart or, at least, less spontaneously raised in discussions. This is why I treat them as a

minority current within the NICU. Moreover, as the most elaborate formulation of it comes from one of the Trust's in-house solicitors, that is from someone who is not involved day-to-day with the patient of the NICU, I can't take it to represent the prevailing view within the NICU.

Trust Solicitor #2's critique of quality of life as a component of best interests can also be related to the approach of one of the physicians, which means that it is nonetheless present in the NICU itself. The understanding of best interests offered by Physician #1 focuses on the experience of the child and foregrounds two elements: interaction with the world and suffering and pleasure.

[...] there is the possible experience of what that life would be; and the two main parts of that are, is it likely it would include some sort of interaction with the world? Or, would it be a life that contains suffering or pleasure?

So, both something about consciousness and something about experience, I think. I've probably never put it into those terms before we had that conversation, but that's how you think about it. [Laugh] [Physician #1]

So ... how long might they live for? And what would that look like, in terms of them as an individual? But also, their level of suffering or pleasure. And elements of that include how much time would they spend in hospital, how many operations they are likely to have – all of those discussions are part of your view about what their experiences would be. [...] [Physician #1]

The emphasis on the child's experience is susceptible of replacing or at least supplementing or reorienting the notion of quality of life. One of the features of this optimistic view is a certain caution toward the notion of quality of life itself. When I asked Solicitor #2 about the connection between best interests and quality of life, they prefaced their answer with a warning against the risk that relying on quality of life to assess the best interests of a child might detract from an analysis focusing on the child's own circumstances.

Quality of life is quite difficult to determine, because a lot of the children who come here have weird and wonderful diseases and disabilities, and stuff like that. To say, to have one standard, 'well this is quality of life', cannot necessarily be applied to each child. So what is quality of life for one child might not be quality of life for another. So you have to look at the child as an individual, and look at the starting premise of 'who is that child, what is their quality of life?'

Solicitor #2's argument is therefore a direct critique of the comparative approach to quality of life that I have outlined previously.

So it has to be tailor-made, I think, for each individual. That's why I tend to use 'best interests'. Because I think best interests does cover what is the best thing for that child; what will help that child's life as it is now, as opposed to what we're doing to that child. Will it improve how they are, or will it detract from who they are? Rather than using quality of life; I think that's such a nebulous term, which I know the courts have always found difficult to define as well. [Trust Solicitor #2]

The elements considered in both approaches are essentially the same: the pain associated with invasive treatments, the child's projected level of awareness of his or her surroundings, the relationships that the child might be able to develop with close ones, and the length and frequency of future hospitalisations. However, the difference is how these elements are evaluated. Trust Solicitor #2 suggests that the comparison with other children, especially those who do not suffer from disability is misleading, for it adds burdens that are irrelevant to the experience of the child. Each child's situation ought to be the point of departure of the analysis, so that each pleasurable experience and each meaningful relationship counts as a positive contribution to the life of the child. These elements should then be balanced against the burdens concretely associated with the child's experience, rather than counting each difference with the baseline of the able-bodied leading a 'normal' life child as a negative.

So it has to be attributed to that individual child; and I think sometimes people say, 'Well they have no quality of life, because they are wheelchair-bound, and they can't speak, and they only have one eye that works.' OK, maybe for an able-bodied person that is no quality of life, but for that child, it is their quality of life; they are loved by their parents, they are loved by their family. [...] [Trust Solicitor #2]

Besides relating potential burdens and limitations to how they are experienced by the child, this approach also tends to highlight and give significant weight to certain pleasures that might be taken for granted in the appreciation of a typical able-bodied child's experience of life.

[...] You know, we have lots who have quite extreme forms of cerebral palsy, and can't walk, can't look after themselves, can't do their day-to-day, going to the toilet and feed themselves. But that doesn't necessarily mean they don't have a quality of life for them. Being with family, looking at trees, looking at sensations, looking at lights, that's their quality of life. [Trust Solicitor #2]

The view that it is not for HCPs to decide whether such lives are worth living

counters the pessimistic assessment of the future quality of life of a severely disabled child. Most HCPs would argue that it is a judgement they should leave to parents. It is important to note that none of the proponents of such pessimistic views would suggest imposing them upon children and their family. They understand them to be personal positions. Yet, it would be misleading also to conclude that such opinions do not weigh on HCPs' views on the best interests of a given a child and do not influence their interactions with that child's family.

In this section, I grappled with the difficult task of situating projections about the future quality of life of neonates hospitalised in the NICU as part of the second stage of the process to assess best interests. I have shown that no consensus exists within the NICU on the meaning and relevance of future quality of life in that determination. Yet, I have also highlighted that even without consensus on the matter, there is nonetheless a shared underlying current of pessimism in how HCPs contemplate the future of severely disabled neonates. Finally, I also sought to nuance this point by presenting the minority counterpoint to the arguments supporting such pessimistic takes on future quality of life. The comparison between the pessimistic and the optimistic views shows that, essentially, their main difference lies in how the judgement is arrived at. Pessimistic judgements tend to focus on comparing the projected experience of the child to that of a typical able-bodied child while optimistic judgements concentrate on the experience of the child.

In the next section, I introduce the role of parental preferences, the other main constitutive element of the 'wider best interests' assessment. Like projections about the child's future quality of life, HCPs integrate the preferences expressed by parents in the process in two ways. At the wider best interests stage, they initially treat them as stable objective facts to be integrated in the assessment, while later in the process they are rather viewed as susceptible of evolving through repeated interactions between parents and HCPs. I now turn to the first aspect will consider the second in the next chapter.

2. The preferences of parents

Like future quality of life, the opinion of parents constitutes a secondary factor because it appears only susceptible of modulating the assessment arrived at the medical best interests stage.

[...] And in various conflicts such as that, you generally do what you think is right for the child, and the family's wishes become secondary. But where you can accommodate it without much disruption to treatment to the child, or what you think is in the best interests of the child, you will try and accommodate it. [...] [Physician #2]

As I have not interviewed nor interacted with parents in conducting this study, I do not purport to provide an inventory of the preferences, values and beliefs that parents express when they are consulted about the best interests of their children. Rather, I will pay attention to how HCPs receive and integrate such preferences, values and beliefs in their best interests assessment. This section might appear incomplete, for I will often refer and defer to the next chapter, in which I discuss at greater length the paradoxical status of parents in obtaining consent to withdraw life-sustaining treatment, whereby their preferences are at the same time highly valued procedurally, while often being considered with suspicion as to their substantive validity and grounding. In this section, I consider how the preferences of parents contributes to the formation of HCPs' own view as to best interests.

At the wider best interests stage, HCPs take parents' views to represent an objective factor in the appreciation of the child's situation, rather than as the expression of the parents' agency regarding their child's welfare. In that light, parental views may be crucial to determine the feasibility of a proposed course of treatment. For instance, as a severely disabled child often requires around-the-clock care, which cannot always be provided by the healthcare system. HCPs might consider the socio-economic situation of parents.

JFM: And what would be the relevance of the social situation of the family?

Wow... Um, gosh, what a good question... I mean, in many ways it shouldn't make a difference. It depends what you mean about the social situation. You know, you can go all the way from a very wealthy family for whom 24-hour care is not an issue, and the child will have whatever technology is available. So, of course, that makes a difference, and that is one end. And the other end is – because London, as mixed as it is, you sometimes have ... recently we

had some refugees from [a war-torn country]. And their residency links to the child being on [inaudible]. So there is a spectrum. So, of course, it's relevant. [Physician #1]

The commitment of parents and the resources available to them appear crucial in realising the full potential of a proposed treatment, for parents might be directly involved in implementing it.

HCPs report encountering a broad range of preferences, which can have a significant impact on the assessment of best interests.

[...] So the biggest determinant is the family's expectation and view of what is a good life. And the variance in that, you would not believe until you've been there. I've heard families say, 'If you can't guarantee he could go to university I think we should stop.' And I've had families say, 'we'll take him if he can breathe.' The absolute opposite ends of the spectrum. So that absolutely sets the frame of reference for the conversation. [...] [Physician #1]

Indeed, the level of tolerance or acceptance toward disability is one aspect where the opinions of parents seem to vary importantly.

In that case it was actually the parents, mainly the dad, who were actually kind of wanting to withdraw. They were like, 'We don't want our baby to suffer any more.' Also, the dad was saying, 'I don't want a disabled child.' So they were like ... they were not saying we don't want this baby, but we don't want him to go through all this, and we don't want this any more. [Senior nurse #2]

The views expressed by parents are often linked to their religious and cultural beliefs. HCPs mention two main types of religious arguments raised by parents. Firstly, HCPs identify the hope for a miracle as a religious argument they frequently encounter from parents who recoil from the suggestion to withdraw life-sustaining treatment.

Nurse #1: And some of them will come with a medical background, or something; that can be helpful, or it doesn't matter at times. Some people will come with really heavy religious views, and think that maybe God can fix it all. Their culture can be both a good and a bad thing, like in every circumstance.

Nurse #3: Some don't want to withdraw at all ... you just have to let them die naturally.

Nurse #1: Yes. I guess you always consider culture, even after withdrawal, making sure that you're doing everything appropriate for their family. Like, some patients need to be out very quickly, to be buried, or ... everyone has different... It's always considering things like that. [Nurses discussion groups #4]

Secondly, some parents will refuse withdrawal on the basis of a belief in the sanctity

of life, arguing that their religious duties forbid them from doing anything that would shorten the life of their child.

For example, one mum, it was because she felt if she said that the doctor should withdraw, that God would never forgive her. So that although her child would go to heaven, she would go to hell. So I mean, we're looking at this in very cosmic terms. [Allied professional #1]

However, these two types do not exhaustively describe religious arguments. In a discussion group, one nurse recounted a situation where the parents' religious beliefs were at the basis of a request to withdraw life-sustaining treatment.

Nurse #1: Well I had different situations; one where their parents were saying, from their religious beliefs, they think what we are doing is not in the best interests for the patient, and they wanted to stop. And the medical team was saying, 'No, we still carry on because it is in the best interests.' So we had an ethical meeting, and ... yes. And on the other side I had a patient where the parents were saying, 'No, we need to carry on,' and the medical were saying, 'No, there is nothing we can do.' [...]. [Nurses discussion group #3]

The variety of beliefs invoked should therefore not be underestimated. Depending on the preferences of parents, the same medical situation might lead to a different outcome or a different process leading to the same outcome. As noted by Physician #2, when life-sustaining treatments are concerned, the views of parents are afforded more weight than in less dramatic circumstances:

JFM: If we're talking about those higher stakes situations, withdrawal of care or an important change like a tracheostomy ... what would be the factors to take into account?

I think in those sorts of situations the family view probably has more ... well, it will have more say than it would otherwise; because the stakes are high obviously for the child, but I think the stakes are also high for the family. So thinking about—I suppose there are two separate things, or two separate ways of thinking about it. But the impact on the family of having a tracheostomy child who they are going to be caring for on a long-term basis is huge; and therefore their views are fairly important. Withdrawal of care has an impact, and it will have a long-term impact; but I suppose in terms of having to care for a child longer term, it's obviously the opposite, because they won't be having to care for the child longer term.

And I think the stakes in those situations, because they are higher, I think the family's viewpoint does become higher up in the scale of things, and you can't just think about the unit. But eventually, we are always trying, when the stakes are high, to focus on the child and what would be the best thing for them. [Physician #2]

Surgeon #1 discusses a case where the professional consensus is to withdraw life-sustaining treatment from a child who appears very unlikely to survive. In both scenarios envisioned, the patient dies in the NICU, but in very different

circumstances.

[...] And the parents have a profound influence over what happens. I mean, you can be in a position where the feelings of the doctors looking after a child are pretty unanimously that withdrawal of care is the right thing to do. And that's a big statement in and of itself, because getting that unanimity is not always easy. And the parents will say, 'yes, well it's absolutely our feeling too, please turn off the ventilator'. Six hours later you've reached the end of that child's life and everyone feels it's very appropriate and it's all a very happy coincidence of views. Although it's clearly an awful tragedy, everybody feels like it has been managed well.

And on the other end of the spectrum you could have the same child in the same situation with different parents, where you have a lengthy period of time with a child in the intensive care unit, and in the end the only way you get around it is to go to court. Or quite often circumstances intervene in the interim, and the child dies in a slightly different way. [...]

So I think the parental views and attitudes have a massive influence over what happens. It's very difficult. [...] [Surgeon #1]

As evidenced by the diverging views on what constitutes a meaningful human life already invoked, the difference could also be between WLST and survival with severe disability. Alternatively, considering the important dimension of uncertainty concerning the child's final outcome, the difference can also be between WLST and survival with no disability or with mild to moderate disability. Physician #4 illustrates this possibility with an example from the PICU:

Yeah... I remember very clearly one set of parents where the child had a very significant bleed in the head. And... I wasn't suggesting withdrawal as such; it was more just... I said to the parents, '[your child] is likely to be severely handicapped, [your child] might not ... [your child] definitely won't go back to normal'. Some parents might find that very difficult, very burdensome; and some parents do not want us to continue.

They said, '[This] is our child and we want you to do everything you can for [our child], and to get [our child] better and out of intensive care'. We spent quite a long time achieving that, but she did get discharged from ICU, and a few years later the parents emailed me and said, '[our child's] back at school and [...] doing really well'.

Sometimes I think if the parents had thought differently and wanted me to withdraw, I would have withdrawn. But because they said they love the child, and whatever [the child's] condition they would do everything for [the child]. And you know, that that they won't just give up on [the child], and put up with [the child], and that was fine.

Yet, HCPs reject preferences they consider to be too far removed from the child's best interests as determined according to other factors.

JFM: You also mention the parents. What's the role of the parents?

Um... I suppose, from a pure medical basis, you're trying to treat the child, and the child's best interests. Now, any child, if you think in terms of [inaudible] and parent ethics, is not

isolated; they are part of a family, and an interlinking web of society. And therefore you cannot completely ignore the wishes or the feelings of the family; and where possible you would try to accommodate it, but potentially there are times when the family's values or views or wishes aren't in line with what you think should happen, in the best interests. [Physician #2]

For instance, in the rare cases where parents request it, HCPs will refuse WLST from children whom they consider would benefit from continued treatment. Explaining 'the limits of parental discretion', Physician #1 evokes the case of a child born with a genetic syndrome involving several malformations. That syndrome is not 'particularly unusual' but is nonetheless 'complex' because it affects the child in several different ways. According to Physician #1, when the parents of the child asked for life-sustaining treatments to be withheld, the NICU team refused to abide by that request and a different plan had to be negotiated.

[...] And we had a family who said – it was an unexpected diagnosis – they saw the child, they did a bit of reading, they said, 'We want you not to feed the child. Let it die.' And that was outside of what the team felt it was OK to do. [...] [Physician #1]

The converse is also true. When confronted with a request to treat a child whom they believe would not benefit from such a treatment, HCPs will refuse to go ahead with the treatment.

So yes there are examples, both ways, but equally there are examples for ... requests for treatment would be completely beyond what any medical or nursing staff would feel is ... but it can go both ways, so... At one end, if you have performed resuscitation for 20 minutes or half an hour or whatever limit you want to apply, even if a family is screaming at me and insisting, I would not continue. [Physician #1]

Physicians explain that they do not consider themselves strictly bound by the views or preferences of the child's parent. However, as I will show in more details when discussing the consent process, they do consider that they must obtain the consent of parents to treat or to withdraw treatment for a child. Consequently, they also indicate that they are struggling to determine the limits of parental discretion.

Similarly, there are children I would not refer because ... so there are some extremes at one end that there is no parental discretion around. Where the bottom of that limit of that parental discretion is, is a subject of constant debate; and occasionally recourse to the law, as I'm sure you are aware. [Physician #1]

This tension about what constitutes the limits of parental discretion is one of the driving forces of the process of obtaining consent from parents to implement what is

in the best interests of the child, which I have labelled 'getting there with the parents'. Although they insist on the prerogative of parents, many HCPs concurrently doubt whether those parents who do not share their perspective are in a position to form an informed opinion. The idea that parents ought to determine acceptable quality of life is, in practice, undermined, for it conflicts with the beliefs HCPs derive from their professional experience.

I present this process in detail in the next chapter and I will return then on the conceptualisation and operationalisation of the limits of parental discretion. However, before doing so, I will present what HCPs explicitly purport to exclude in assessing best interests.

3. Resisting the pull: excluded factors

I proposed that the determination of the best interests of a child hospitalised in the NICU can be modelled as a two-factor process. Participants mentioned other factors, either spontaneously or in response to my questions. Two such considerations, both of which have featured importantly in my discussions with HCPs are resource allocation and protecting the reputation of the hospital. Yet, HCPs participating in this study also widely characterised these factors as irrelevant to the determination of best interests.

HCPs both feel and resist the pull of these considerations. They recognise their relevance, but they also refuse to incorporate them in their determination of best interests. I would therefore argue that these considerations have a different status than others that would be unidentified or unrecognised by HCPs. By explicitly excluding these aspects from the determination of best interests, HCPs implicitly recognise that they *could* be relevant to the recommendations they make. In stating that they ignore resource allocation and the reputation of the hospital in determining the best interests of a child, HCPs also indirectly respond to affirmations that they frequently encounter in their day-to-day experience, either from patients' families, from their own families and acquaintances or in the media, to the effect that these

considerations play a role in their decision-making.

The fact that the determination of a child's best interests excludes these considerations does not mean that they are not relevant elsewhere in the functioning of the NICU or of the London Hospital. While arguing that HCPs consciously resist the pull to include these considerations in their determination of best interests, I also briefly show when and why resource allocation and the protection of the reputation of the hospital come into play.

3.1 Ressource allocation

The NICU is an expensive medical setting. The 24-hour individual care, the high number of specialised HCPs involved, the sophisticated machinery, the drugs, and the tests all contribute to the cost of a day spent in the NICU. HCPs, however, do not seem to question that aspect very much. In a context of budget control, where healthcare funding is essentially a zero-sum game, it could be questioned whether such cost can be justified considering other needs within the healthcare system. Yet, none of the HCPs I have interacted with seemed to question whether providing neonatal intensive care was justified in the overall scheme of the healthcare system. Consequently, I did not explore this topic in my fieldwork in the NICU.

However, several participants raised the question of who should access this service. It is the set of distributive issues arising from the limited offer of neonatal intensive care in the London Hospital's NICU that I designate as 'resource allocation issues' and discuss in this subsection.

An opportunity cost is associated with attributing a NICU bed to a child, for it implies that another child might not be admitted. The NICU is constantly solicited to admit critically ill neonates. Often, fewer beds in the NICU are available than requested for transfer and admission.

So in those situations there is no real ... there is nothing that we can do, and we are keeping alive... Because now medicine has such powerful machines, that can keep children alive that have no chance of survival. And in those situations, you have to understand that by keeping

this child on this machine with no chance of surviving, you're probably not giving the chance to another child that is waiting somewhere to come, and it may survive. So I completely understand that we need to take that decision; but I find it very difficult to take. [Surgeon #1]

HCPs are acutely conscious of issues arising from the high demand for neonatal intensive care. Physician #1, for instance, explicitly recognises this as generating pressure on how they approach their professional duties.

OK, so, I feel pressure from outside to manage my resources to do the best for the most. That's perhaps a pressure I create, and create for myself, [withheld to protect confidentiality]. So I'm constantly aware of the number of referrals and how few actually make it in. And so one of the considerations I have – so maybe not the pressure that you might perceive behind your question – but I perceive a sort of utilitarian issue about, if that child can't survive, then actually they are doing harm by being here, in the sense that they are denying an opportunity to another child. [Physician #1]

Physician #1's intervention focuses on the 'child [who] can't survive'. In that case, it seems a child who cannot benefit from treatment in the NICU is consuming resources that would be more efficiently allocated to another child who would derive a greater benefit from treatment in the NICU.

Similarly, some nurses deplore such situations, hinting at the injustice they perceive when a patient uselessly receives care that could better benefit another child.

Nurse #2: And I think not just that, but it's quite frustrating as well, when you are in charge and you have children queueing up to come in, and you have a couple of babies on the unit that you know you are not going to be able to help; but you might be able to help these other two that are waiting to come in... It's also very frustrating from that point of view. It's like, well, we're stuck with these children, we can't help them, but they are here and we just have to keep going. But this one that needs this surgery that could save their lives, we can't do anything. We can't make them better, because we've got these babies here that ... are here.

Nurse #3: Well they're bed blockers, aren't they? [Nurses discussion groups #2]

It might be inferred from the strong evaluative language used in the quotes above that resource allocation plays an important role in how HCPs approach such patients. Physician #1 speaks of the 'pressure' these situations creates, while the nurses seem to challenge the allocation of scarce resources to certain children by calling them 'bed blockers', therefore implying that someone else would derive more benefits if they were allowed to take their place.

Yet, it is more precise to characterise resource allocation as an excluded factor in the

determination of best interests. First, while recognising resource allocation as a salient consideration, HCPs also explicitly reject it as a component of the assessment of best interests.

So yes, it's what's in the best interests of the child, knowing what the future is, but also considering what would be in the parents' best interests as well. But that shouldn't be predominant. It shouldn't be best interests of the doctor or of the hospital, in that, 'I don't have my bed, you are blocking a bed and therefore...'. So that shouldn't come into play, but some parents do sometimes think that we are... [...]. [Physician #3]

Parents worry that you want to get another kid in, but no. We put kids through horrendous stuff to get them better. It's always about whether you think it's the right thing to do, carrying on the treatment. [Physician #5]

Similarly, although the nurses cited above expressed the view that resource allocation ought to play a more important role in treatment decisions, when probed, they also indicated that this is not what happens in the NICU. They affirm the priority of the interests of the child as the central norm applicable to best interests determinations in the NICU.

JFM: And is there any way of addressing that? Would that ever be... How can I put it... Would people sort of do something about it, in a case like that? Do you feel that the consultant might want to push things a little more knowing that there is a queue for the bed?

Nurse #3: No...

Nurse #2: No.

JFM: No?

Nurse #2: They just go, 'Whoever is outside the hospital is not our concern. The babies here are our concern.' Which is true...

Nurse #3: Yes... [Nurses discussion groups #2]

When I presented the emerging normative model to the Clinical Ethics Committee, a lay member, whom I had regularly observed voicing concerns about the role that resource allocation might play in clinical decisions, seemed surprised by my suggestion that it did not contribute to the assessment of best interests by HCPs. In the discussion, two physicians, one of whom I have also interviewed individually, explained how they set distributive considerations aside in determining what is in the

best interests of a child:

Physician #2: The other point is, this is focused on your end-of-life issues.

Lay member #3: Yes.

Physician #2: So I think as a clinician I can recognise myself there. We ration all the time...

Lay member #3: Yes.

Physician #2: We think about in, out, whatever.

Lay member #3: Yes.

Physician #2: But you don't think about that when you're thinking about trying to pull the plug.

JFM: Yes, yes...

Physician #3: So I think if you... It's not 'not there,' but you don't let that dominate decisions on all [Inaudible] for each individual child. You do have to keep that barrier, however artificial it is.

Lay member #3: Well you say you don't think about it [Physician #2], but... If you've got somebody who could keep going indefinitely for reasons you consider to be futile...

Physician #3: Well then, that's the right reason for them to stop...

Lay member #3: ... are you really not thinking, 'Somebody else could make better use of this machine?'

Physician #2: But I'm not using that as my [Inaudible] somewhat prime directive. Why would you do that to that child?

Allied Professional #1: But it may influence your prime directive. Sorry, but...

Physician #2: Why?

Lay member #3: Well, because of what you are doing to another child.

Physician #2: But it's so small down there, because your focus is that child.

HCPs are far from oblivious to resource allocation. However, they make a conscious effort to prioritise the interests of the child in front of them. They acknowledge distributive reasons, but do not put them in the balance when deciding whether to recommend WLST because the balance concerns only one child.

3.1.1 A subordinated consideration

It is only once the latter process has yielded a conclusion that HCPs allow themselves to optimise the use of scarce resources. I draw a distinction between the

proposition that resource allocation is not relevant to the determination of the best interests of the child and the conclusion that it is not relevant at all to the functioning of the NICU.

Notwithstanding reporting to feel the pressure of resource allocation, Physician #1 also hastens to add that it does not contribute to the decision to recommend withdrawing intensive care from a child. Physician #1's reflections do suggest, however, that independently of the conclusion of the best interests assessment, it is more desirable to establish it sooner than later to favour an efficient allocation of resources.

Now, there is obviously huge leeway about that; it doesn't mean you stop on that child now, but it's one of the things that make you... If this can't work, it's better that it doesn't work today rather than it doesn't work in a month's time. [Physician #1]

At the most, HCPs consider resource allocation when two options are deemed equivalent. However, such a consideration only occurs after HCPs have concluded on best interests. It might then influence the modalities of a child's treatment. For instance, Physician #2 states that when the child is stabilised and the options are either transferring the child back to the local hospital or keeping the child for slightly longer, the question whether the bed is required by another child can become relevant to the implementations of the decision.

Now, the problems can arise I suppose when you both have the child's best interests in mind, but you've got other influences like unit factors directing your decision-making a little bit, versus the parents. I'm thinking of an example: say you've got a child who has come in for NEC to the neonatal unit here, and the child has just managed to get onto full feed for 24 hours, and you want to send the child back to local and such, and you're happy with that decision, but the family doesn't like the local and wants to stay here for another couple of days.

From our point of view we can't for the best interests of the child, and that's not a problem because he's going to be in a neonatal unit regardless of here or there. So it doesn't matter whether he stays or transfer, it'll be safe to watch him for another 48 hours or whatever. But from your point of having to make a decision for the whole population that you cater for, if you keep a child here who doesn't necessarily need our services, doesn't need surgical services, etc., and can be offered exactly the same sort of care at his local neonatal unit, then you have to think well, this child is therefore occupying a bed which somebody else might benefit from specifically. And that's where decision-making comes to lock heads with family. So, I think that's relatively important. At that point a distribution [inaudible] becomes primary concern in our minds; whereas in the family's mind that's different, they don't really think about it – rightly so. [Physician #2]

It is telling that Physician #2 uses the example of transferring a stabilised child back to the local hospital. As I highlighted several times already, HCPs never take a decision about WLST lightly, such that it is even less susceptible to be influenced by considerations relating to resource allocation than other decisions perceived to be critical.

Resource allocation is probably the consideration with the strongest pull on HCPs, for they are directly involved in managing scarce resources. When answering a call from a colleague inquiring about transferring a patient, they cannot ignore that the interests of that patient might conflict with those who are currently in the NICU. Consequently, it might be the most difficult consideration to resist. Yet, the attitude of HCPs in these situations converges with the overarching principle of prioritising the child. When conducting a best interests assessment, the interests of the child concerned are not balanced against those of another child.

This is not the only consideration HCPs identify as exercising a pull and which they consider irrelevant and endeavour to resist. They also recognise that the decisions they make, particularly regarding WLST, are susceptible of impacting the reputation of the London Hospital. However, as I will now show, although the risk is real, HCPs also explicitly deny that it plays a role in the assessment of best interests.

3.2 Protecting the reputation of the hospital

The London Hospital enjoys a good reputation from which it benefits. Like many British hospitals, it can rely on its charity's substantial fundraising to supplement public funding. As a respected public institution, it is also subject to significant attention and scrutiny on the part of the press, both in terms of accomplishments or missteps, so that both will inevitably receive extensive coverage and, in the case of the latter, severe criticism.

The desire to protect the reputation of the hospital and its fundraising capacity caught my attention following my observation of the London Hospital's CEC.

Observing the CEC, I noticed a significant apprehension that controversial decisions, including those to withdraw life-sustaining care, might cause a popular backlash led by the notoriously ferocious British tabloid press.¹⁸⁶ Early in my fieldwork, I attended the CEC annual study day and it struck me how often the members of the committee mentioned the *Daily Mail*, a conservative newspaper perceived to be likely to attack healthcare organisations and HCPs and to systematically side with parents in controversial disputes relating to the medical care of children. Throughout the time I observed the work of the CEC, I repeatedly heard its members wonder how the issues they were discussing would play out in the popular press. The British tabloid press, and more specifically that newspaper, was identified as creating a hostile environment for HCPs, including the risk that angry readers would picket consultants' houses. I raised the issue with one of the lay members of the CEC who agreed that it was a significant worry for the members of the committee, although that member also wondered whether it might be time to move on from such concerns.

JFM: There is something that has really struck me in the time I have spent in the committee. It's that... It's clear that this hospital here is very much in the public eye. But you know, there are countless mentions of the Daily Mail in your discussions, and I found that quite fascinating. I wonder if you have any thoughts on that.

Well, I think... I mean, that is partly why I was saying 'getting a bit of freshness in' might be a helpful thing to do. Because I think there has been a discourse for a number of years around the kind of Daily Mail issue; and I don't think it's necessarily all that helpful.

Certainly, the media in the UK is probably more poisonous than media almost anywhere else – and the Daily Mail is seen to epitomise that aspect. But it's also ... the media are also a way of telling the story, and engaging the media in thinking about some of the big issues of the day. So, we're going to have a couple of sessions on the media at our next conference. And it's a kind of unhelpful shorthand I think, that just occupies a position that maybe we could do without thinking in that kind of way. [CEC Lay Member]

In the summer of 2014, the controversy involving the young Ashya King, his parents and the Southampton General Hospital ('SGH') at least partially confirmed the concerns of the CEC members. As a major news story revolving around a disagreement between the parents of a sick child and his treating team, it was at the forefront of many HCPs' concerns and was much discussed across the London Hospital. A discussion of the legal aspects of that case is outside the remit of this

¹⁸⁶ Adrian Bingham and Martin Conboy, *Tabloid Century: The Popular Press in Britain, 1896 to the Present* (Peter Lang 2015) 195–197.

study, but it is worth summarising the controversy to contextualise the perspectives expressed by the members of the CEC about the influence of the tabloid press.

Ashya King was a young boy with a severe brain tumour. His parents disagreed with HCPs as to the best treatment following the removal of the tumour. The treating team at the SGH took the view that radiotherapy was most appropriate, and being the only one covered by the NHS, while the King family advocated for an experimental proton therapy on the basis that it would result in fewer side effects. The case took a dramatic turn when Ashya's parents surreptitiously removed him from the SGH against the advice of his treating team and took him out of the UK to receive proton therapy abroad. The SGH staff then alerted the police and the local authority of Ashya's disappearance. Following an application from the local authority alleging that Ashya was in danger, notably because he did not have a safe swallow and was still fed by nasogastric tube, he was made a ward of court. The police had a European arrest warrant issued against Ashya's parents. As a result, Ashya's parents were arrested in Spain and detained for several days pending their extradition to the United Kingdom, while Ashya was sent to a Spanish hospital. Ultimately, the arrest warrant against the parents was discharged and the High Court judge seized of the wardship proceedings endorsed an agreement negotiated between the parents and the SGH treating team permitting Ashya to be transferred from Spain to the Czech Republic to receive the experimental proton therapy his parents favoured.¹⁸⁷

The case was subject to intense media scrutiny. An elaborate presentation of the way the media framed the issue would detract me from the argument I am making here. However, I do wish to highlight how the CEC appeared particularly sensitive to the significant popular backlash against the SGH and the child's treating team specifically. This concern was discussed in a CEC meeting where the members watched a documentary entitled 'Ashya: the Untold Story' which had recently been broadcast on the BBC.

¹⁸⁷ *Re King (A Child)* [2014] EWHC 2694 (Fam).

In the documentary, it was reported that when the story broke out in the media, the SGH was bombarded with aggressive phone calls, voicemails, emails and letters. One of the consultants who was involved in Ashya's care is interviewed and makes the following declaration in the documentary: 'The overwhelming sentiment was one of just an absolute outpouring of hatred. One of the letters said they wished my children got cancer and died'.

Following these observations of the CEC, I sought to explore whether the risk of damaging the reputation of the London Hospital or the risk of being caught up in sensationalistic media coverage influenced HCPs' decisions.

However, the answers I received from HCPs working in the NICU did not cohere with the mood and the repeated concerns I observed at the level of the CEC. HCPs tended to reframe the issue slightly. For many of them, the main impact of the reputation of the London Hospital was to create expectations for the parents of children transferred there. As a tertiary centre, the London Hospital receives critically ill patients with complex or delicate conditions only few hospitals can treat. Being transferred to the NICU of the London Hospital signals the critical nature of the child's condition. Yet, HCPs observe that parents of children transferred to the London Hospital often get there with great expectations about their child receiving a cure.

Nurse #2: Yes, it has a prestige, and some parents come knowing that this is their last chance to come here and... [Overlap]

Nurse #1: They come for the [Hospital name] miracle.

JFM: For the [Hospital name] miracle?

Multiple: Yes.

Nurse #1: They really do.

Nurse #2: So, some of them are aware that this may be their last chance their child has got. And therefore, if this is the last chance and it doesn't work, some of them do have in the back of their mind that this may be an unhappy ending. [Nurses discussion groups #4]

HCPs perceive a tension between the positive public image of the London Hospital as an institution and the potentially tragic outcome of their patients' illnesses.

JFM: Does this make your job more difficult, this idea as you said of the [Hospital name] miracle? Because this place has a tremendous reputation...

Multiple: Yes. [Nurses discussion group #4]

The ethos of the unit embeds clinical excellence as a central aspiration. Indeed, the pressure it exerts on HCPs seems to converge with other principles I have already explored. It participates from the overarching principle of the priority of the child and its operationalisation in the presumption in favour of treatment, which is profoundly connected to the faith in medical evidence and clinical judgement that guides the determination of best interests by HCPs.

Nonetheless, HCPs sometimes worry that the protection the reputation of the hospital or of its fundraising capacity might explain certain decisions.

JFM: You mentioned keeping a good name for the hospital.

Yes. It's very important, given that a hospital lives on its reputation. Also, our charitable inputs pay for a third of the hospital. [Omitted to protect confidentiality] [T]here is always an undercurrent of that going on. [Physician #5]

As with resource allocation, it might be concluded that reputational considerations such as those I have outlined here are operative in HCPs' determination of the best interests of a child. Again, I would argue that although they feel such pressures, HCPs largely exclude or ignore them in determining best interests.

Rather, this influence arises later in the process, when HCPs find themselves unable to obtain the consent of parents for a treatment pathway they deem acceptable and start considering other options that will take the conversation to a forum outside the NICU itself. Such options include referring the case to the CEC and eventually filing a court application to be authorised to withdraw care life-sustaining treatments without the consent of the parents. In both these cases, the disagreement takes on a more public dimension than it previously had, which in turn entails an increased reputational risk for the London Hospital as a whole. HCPs argue that they do not

give any weight to reputational risk in best interests assessments but they do not deny that others might consider it at some point. The quote from Physician #5 above exemplifies the concern that other actors than HCPs working in the NICU might consider the reputation of the hospital and the fundraising potential attached to it. Physician #1 also shares that view:

The situation when you need to go to court is when that is combined with a child who is neither deteriorating nor improving. So you end up with an ongoing uncertainty about decision-making. And the next thing you have to factor in is how willing the institution is or isn't to go to court on such an issue; or whether they would fear ... so I think the institution fears the public opinion more than the individual doctors do. [Physician #1]

Conclusion

In chapter III, I have shown that the two-factor model of the determination of best interest follows a deliberative and collegial process. I have also described the significant weight that the medical expertise, knowledge, and evidence collectively wielded by HCPs is afforded in the process. The predominance of the medical paradigm in approaching best interests leads to the primacy of medical factors over those labelled as relating to 'wider best interest'.

In this chapter, I have shown that the opinion formed following the assessment of medical best interests is then reconsidered through the process of assessing the child's 'wider best interests'. This process is secondary to the assessment of medical best interests, for it aims at refining rather than questioning its result.

In section 1, I demonstrate that a wider range of considerations are examined before concluding, notably the projected quality of life of the child and the preferences of parents. Variability occurs among HCPs as to the precise weight they accord to these considerations. Regarding discussions concerning a child's projected quality of life, I have shown that the main issue is that of the impact of severe disability on a child and their family. For many HCPs, parents should appreciate that aspect, yet for some it is a central aspect of best interests. I also highlighted a pessimist streak in how the perception of severe disability by many HCPs working in the NICU, especially those who compare the life of a severely disabled child to that of a

hypothetical able-bodied counterpart. Nonetheless, I also presented a minority position which insists on using the experience of the child him or herself as the benchmark of their quality of life.

In section 2, I addressed the preferences of parents. I stressed that at the wider best interests stage of the process, HCPs treated them primarily as objective facts susceptible of impacting the experience of children and therefore their best interests. HCPs also insist they are confronted with many views coming from parents, from a strict adherence to the sanctity of life principle to the belief that disability is incompatible with quality of life. Parental preferences play a role in determining the range of options that can be envisioned for a child, notably by circumscribing what is feasible and what is not. I also foreshadowed the paradox that is at the centre of the next chapter, noting that HCPs are torn between their belief in the legitimate authority of parents to make decision for their child and their severe judgement of how parents appreciate their child's predicament.

In section 3, I completed my presentation by discussing two types of considerations present in HCPs' assessment of the best interests of their patient and yet specifically rejected by them. The first excluded consideration is the potential impact of decisions concerning a child hospitalised in the NICU on other children who might be waiting for admission. HCPs are conscious of these potential conflicts of interests, but they refuse to balance the interests of a patient against those of another child. Consequently, although the specialised care dispensed in the NICU is a scarce resource, the fairness of its distribution among children is not part of the assessment of the best interests of a child. However, it is not entirely neglected. Rather, it is subordinated to best interests. Once they establish what best interests requires, HCPs allow resource allocation to influence the way in which this decision is implemented.

The second consideration specifically rejected by HCPs is the protection of the excellent reputation of the London Hospital. HCPs recognise that controversial

decisions expose them or the London Hospital to a reputational risk, but they vigorously deny that this influences their assessment of best interests. Again, this does not mean that avoiding reputational risk never plays a role in any decision process. However, HCPs ascribe such worries to other instances within the Hospital. For instance, in my observation of the Clinical Ethics Committee, I witnessed the CEC's preoccupation with media coverage and how its members reacted to the Ashya King case, a controversial series of events and legal case surrounding the care of a young boy in an English general hospital.

JIC aims at modelling how HCPs conduct their assessment of best interests. It describes the interactive elaboration of a firm hypothesis through the integration of several considerations. However, once HCPs agree upon such a hypothesis, it cannot be immediately implemented. HCPs perceive the consent of the child's parents as a crucial requirement. However, the process of obtaining such consent is not always straightforward and it entails engaging the parents into a process of negotiation. I labelled this process 'Getting there with parents' and the third and final chapter dedicated to the presentation of the GNM is devoted to it.

Chapter V - Getting there with parents

Introduction

Once HCPs have agreed that the best interests of the child warrants withdrawing or withholding life-sustaining treatments, they face the task of obtaining consent from the child's parents to implement this decision. Sometimes, HCPs and parents will agree both on the factual elements of the child's situation and on their normative implications and parental consent will be forthcoming. However, obtaining parental consent to withdraw life-sustaining treatment also often requires a more elaborate process.

I call this second major process GTWP. 'Getting there with parents' was a recurring expression in the interviews, which I conducted with HCPs. It captures the nature and tone of the interactions between HCPs and parents once HCPs have reached a consensus that WLST is in the child's best interests. Here, I seek to model the interactions between HCPs and parents, as HCPs perceive and understand them. Thus, the account I present here might significantly differ from the experience of parents, which I have not studied.

GTWP is rooted in a dilemma between HCPs' belief in parental autonomy and the corollary obligation to obtain their consent to WLST and their view that often parents lack the capacity to fully appreciate the best interests of their child. GTWP is the pragmatic response adopted by HCPs to resolve this dilemma. The construction and management of a common frame of reference through interactions with parents are at the heart of the process. The encounter of the expectations of both parents and HCPs constructs this common frame of reference, which then serves as the backdrop for decision-making about the child's treatments.

Once they have a sense of 'where the parents are coming from', HCPs deploy various strategies in their interactions with them to steer the frame of reference toward a point where the expectations of parents converge with theirs. The whole NICU team is involved in this process of supporting parents along the way to integrating the factual and normative premises underlying the recommendation to withdraw life-sustaining treatment.

I conclude my presentation of GTWP by discussing how it sometimes fails to produce a workable consensus between HCPs and parents. HCPs invest deeply in the process and therefore are sometimes reluctant to admit that it will not yield the outcome they strive to achieve. This can result in a distortion of the process. Encouragement and support turn into pressure and can damage the relationship nurtured throughout the process. This in turn has the potential to impair the effectiveness of other processes in place to support HCPs in furthering the best interests of their patients.

1. A fundamental dilemma between the autonomy of parents and their capacity to assess best interests

GTWP is the response developed by HCPs to what I have identified as the fundamental dilemma they face in their relationship with parents. HCPs adhere to two potentially conflicting propositions. On one hand, HCPs insist that making important decisions about the child, such as those relating to WLST, is the parents' prerogative. On the other, HCPs entertain serious doubts as to the capacity of many parents to assess best interests adequately. As a result, HCPs frequently find themselves trying to reach a compromise between the two propositions, especially when WLST is contemplated. The various strategies, discourses and attitudes that are thus deployed come together in GTWP.

The clash between these two premises generates a palpable tension in the following interview excerpt. Senior Nurse #2 seems ambivalent between the two. She begins by reiterating the principle that parents ought to decide, yet she concludes by wondering how parents can adopt the right perspective to consent to withdrawal of

life-sustaining treatment.

JFM: In a situation like you describe, where there would seem to be a consensus between the nursing staff and the consultant that something ought to be done, or that in that case treatment should be withdrawn, do you feel it's right that parents have the last word?

At the end it's their child, isn't it? So, from my point of view, yes, but from a medical point of view, maybe no ... because I think parents are – they don't see the whole picture. They see that moment, but they maybe see that... We do try and treat the kidneys, but they don't see that. Yes, they might recover, but... I think they don't see the whole picture, and often don't understand the whole picture. And sometimes the questions parents ask, you just think... 'You do not really understand what's going on here right now, do you?' [Senior Nurse #2]

I will detail each premise separately before discussing how HCPs attempt to resolve the tension.

1.1 Parental consent is necessary for WLST

HCPs consider that WLST is always subject to the consent of the child's parents, unless a court of law grants them authorisation to overcome the refusal of parents. Physician #5 insists that the norm applicable to WLST in the London Hospital is unambiguous:

[...] this at least is very clear in our hospital, that you can't stop treatments without a family's agreement. [...] [Physician #5]

Physician #5 interprets this rule as in line with English law on the matter, as inferred from both published case law, such as the David Glass' case, and personal experience of going to court to seek authorisation to withdraw life-sustaining treatments from patients.

And that is the situation under law as far as the judiciary are concerned. [...] [C]ertainly in courts we've had that said to us. And if you read the case law about this, David Glass, and that sort of stuff, that's always the ... you should give parents the chance to discuss this and find out stuff. But most hospitals in this country would go to court to seek permission to withdraw treatment that they don't think is the right thing for the child. The courts have never suggested people shouldn't have taken those cases to court. [Physician #5]

Later in the interview, Physician #5 reiterates the notion that parental consent is a necessary condition to withdrawing treatments:

[...] Parents' views however do, of course, and they form part of our treating permissions here. They need to give consent to what we are doing. They also need to know about stuff, and give consent to stopping things as well. [...] [Physician #5]

Nurse #1 endorses a similar position:

But obviously, we cannot decide. It's the parents' decision on when to ... when not to escalate treatment, or when to withdraw care. Our doctors were very good to explain to them what's going on, but it's their decision on whether to continue or not the treatment for [patient]. [Nurse #1]

The same norm underlies Surgeon #1's contrasting depiction of the situation where the views of the family and of HCPs converge and the situation where the only way to obtain permission to withdraw life-sustaining care in the best interests of a child is to obtain a court order to allow for it:

With children and babies, you're dealing with the parents who have legal power over what happens, and so you can't treat the baby without the consent of the parents. [...]

And on the other end of the spectrum you could have the same child in the same situation with different parents, where you have a lengthy period of time with a child in the intensive care unit, and in the end the only way you get around it is to go to court. [...] [Surgeon #1]

HCPs therefore perceive obtaining consent from parents as a necessary condition for WLST. At the same time, it is experienced as challenging by HCPs for they have doubts as to the capacity of parents to exercise this decision-making authority in the best interests of their children.

1.2 Suspicions about the capacity of parents

The parental prerogative to consent appears to rest on shaky grounds. Thus, it is difficult for HCPs to give the view of parents a comparable weight to a WLST recommendation formed following the collegial process described in Chapter III. HCPs evoke two main reasons to explain their doubts about the capacity of parents to reach an informed view as to the best interests of their child. First, they suggest that having a child in the NICU makes it arduous to reach a proper understanding of the situation. Then, HCPs also tend to think that parents, by the mere fact of being parents, or because the child has just been born, are naturally incapable of concluding that WLST might be in their child's best interests. Finally, the suspicions HCPs entertain about the capacity of parents cover the whole range of

considerations they consider relevant for determining best interests.

1.2.1 A contextual incapacity

HCPs insist on the difficulties inherent to the parents' predicament and its impact on their capacity to consider WLST, notably upon first receiving such recommendation. According to them, the particularly trying circumstances of finding oneself abruptly thrown into the turmoil of having a critically ill child induce the incapacity they invoke.

JFM: Yes. I'm also interested to know: when we are confronted with decisions like that – obviously very difficult decisions – is it your perception, or ... based on your experience, do you think that parents come well equipped to make those decisions? Are they in a good position to make ... to consent, for instance, to withdrawal of care?

Nurse #2: Well, in my experience, in the first instance they would hear about the bad news, obviously, they cannot accept it. And they always would ask for some other treatments, or prolong the child's life because a new treatment may come along. And it's ... it's... I don't know, it's difficult, because ... sometimes, you think that they know there is no treatment; but they block, they just don't want to accept that. And they would want everything done – which most of the time is discussed between the team, and is being done anyway. But at the end of the day, it still is not ... like, the end result is still not good. [Nurses discussion groups #1]

[...] But they need things to be explained to them; but by the time some things get explained to them, they are at that blanket stage, where they can't take information in whatsoever. And unfortunately, that could have happened over a weekend, where you have one consultant over the weekend that can be fluffy, and then by the time Monday morning comes you have a consultant who can actually speak to them, but those shutters have already come down. [Nurses discussion groups #2]

One of the Trust's solicitors related their experience as the parent of a hospitalised child to their view of the capacity of parents to understand and make decisions based upon the information they receive while their child is in the NICU:

JFM: Oh, OK. And do you see an influence of that experience on the way you approach your work?

Um, yes. Because having been on the other side of the fence, it gives you a greater understanding into the anxiety, the anxieties of parents. And although you may have most intelligent parents, when they are stressed because their child is ill, they don't necessarily act in rational ways, or hear all the information; they'll pick up on certain pieces of information. So it has given me a better understanding. [Trust Solicitor #2]

Surgeon #1 voices the same concern about the impact of stress and the overwhelming nature of the experience:

And I think that's really hard, because when you say 'your child might have a severe

neurological impairment' to a parent, they don't always understand quite what you mean by that, and it's very difficult to frame that with upset traumatised people; to kind of get them to the place where they understand what that is like. You know, your child won't ever talk, won't ever walk, will be in a wheelchair, those kinds of things. [Surgeon #1]

The impact of having one's child hospitalised in the NICU is not the only basis for questioning the capacity of parents to appreciate the reasons put forward by HCPs to support their recommendation to withdraw life-sustaining treatment. HCPs also evoke a different basis for their suspicions about the capacity of parents to assess the best interests of their child.

1.2.2 An intrinsic incapacity

Besides contextual difficulties, some HCPs also suggest parents are biologically conditioned to reject a WLST recommendation. Physician #1 stated that 'every parent has a deep-rooted response to protect their child'. Likewise, Allied Professional #2 suggested that:

There is naturally a protective side, which thinks, 'Surely what is in my child's best interests is to keep trying everything possible in order for them to survive. [Allied Professional #2]

The lay member of the Clinical ethics committee also evokes a biological dimension to the parents' reactions:

JFM: What is the knowledge of the parents in a sense, or what knowledge do the parents bring to the table that is specific to them?

Well, it's knowledge of their child, but it's knowledge of what they can bear as parents; and parents raising this child.

Now, that might be ... they may have completely mistaken assumptions, because raising... I think that ... now this is a view that I'm not sure if there is research to back it up, but... When you've just had a baby, I think there is something chemical that happens, that you just want this baby to live. And I think that that gets in the way of thinking to the future. You know, 'can I really live with what this is going to entail, all the way through?' [CEC member]

According to HCPs, the perspective of parents may be skewed by an overestimation of the relevance of positively interpreted details or encouraging comments. HCPs portray parents as avid for anything that might give them hope their child's condition will improve.

Nurse #1: They hold on to every bit of hope ... like, if they...

Nurse #2: That's what we had recently...

Nurse #1: Yes. When they have a few things, a few illnesses as well, and then one looks like it's getting a bit better, they kind of forget about the other ones. And it doesn't necessarily mean that one part of the illness has gotten better forever. It just has gotten better for now. And then because that's a bit of hope, it looks like they are improving, then they think it's going to be fine. Whereas the reality is totally different; because they have whole other conditions and whole other problems, that they kind of forget about and just think, 'there is a little bit of improvement, so they are going to be fine. [Nurses discussion groups #1].

As a result, HCPs are careful in their interactions with parents, for even casual comments can be misinterpreted.

HCP are suspicious about the capacity of the parents to appreciate the reasons HCPs consider should go into a determination of best interests whether for contextual or intrinsic reasons.

1.2.3 A broad ranging incapacity

Independently of its underlying reasons, the suspicion toward parental capacity touches upon every aspect of the determination of best interests as discussed in the previous chapters. About medical best interests, HCPs worry that parents might have difficulty appreciating the severity of their child's condition and as a result overestimate the possibility of a meaningful recovery for their child:

I think sometimes they just don't see how severe the situation is. 'They think the baby can recover, they just need to start tolerating their feed; but they don't see that the kidneys are still not working. Or even ... they think if the kidneys start working again, that's fine. Yes, but your baby is still ventilated, and we haven't managed to get it off the ventilator. It's not tolerating its feed, and actually it also has a bleed in the brain. And we don't know what effect that will have on the later life. But you probably can't expect parents to see the whole picture and to look into the future as well [Senior Nurse #2]

Similarly, HCPs are concerned that parents may underestimate the burden of treatments on their child.

One of the issues is that... There is always anxiety on my part that if a family is for very active treatment in a situation where you feel that maybe average person wouldn't... I'm anxious that people could make that decision as informed as possible, because... I wonder if people really know what it means to be in tracheotomy through the night, or having a ventilator, or some of these more intensive interventions, until they do it. I'm not sure I do, you know, and I've done this for 20 years. I have a rough idea that it must be incredibly hard work ... but it would be all the time!

And you sometimes feel when people make requests, or seem to diminish or downplay that

part of the experience, assessing the quality of life thing... [...] [Physician #1]
A member of the CEC links this with the desire of parents to find reasons to remain hopeful that their child will survive:

So for example, the research would actually back me up that parents are in many [cases] and quite often more likely to underestimate the burden on a child, despite the fact that it's their child – because they are suffused with hope – than a clinician or the nursing staff [CEC lay member]

As I already explained in JIC, HCPs, notably nurses, take pride in their capacity to interpret the subtle clues neonates give of their experience of critical care. Conversely, some HCPs wonder whether parents can adequately interpret how their child subjectively experiences treatment.

JFM: I think you've already hinted at that, but what do you think about the parents' capacity and authority to make those decisions?

[Sigh] That is such a tough one, because... By the very love of your child, you're almost incapacitating yourself a bit. And yet at the same time, you are the real advocate for your child.

So, incapacity vs. advocacy, I don't know where they come in. I mean, you know, the things where somebody will say, 'Oh, but didn't you see them smile?' Well, it's something that people are kind of seeing, but which isn't really there, and shows a certain lack of capacity. Yet at the same time they're advocating for this child who they believe is doing this, and therefore needs to be given more time, and other chances, and everything. [Allied Professional #1]

Regarding wider best interests, HCPs also wonder whether parents might overestimate the future quality of life of their child:

And ... either they don't understand, they're not ready to understand the ramifications of 'if we do this, the life of your child would be mentally damaged. And you're going to have ... that child will grow, and you'll have a very disabled child.' And the future ... they don't look to the future; they just see this tiny teeny little baby, and want everything done for that child [Trust Solicitor #2]

Nurse #3: [Inaudible, low and noisy]. And I've had parents say to me, 'I don't care how [Inaudible] they are, as long as they are here.' And that's probably a big thing for withdrawals.

Nurse #2: But parents don't understand what the consequences are later. They only see their little baby that is absolutely lovely and beautiful, and they can cuddle it and pick it up; they don't see what it's going to be like in 12 months, 2 years, 6 years, 10 years' time. [Nurses discussion groups #4]

It is challenging for HCPs to reconcile the two propositions that I have presented here. On one hand, they perceive themselves as bound to obtain consent from

parents, while, on the other hand, they strongly suspect that parents are ill-equipped for the task of ascertaining the best interests of their child. To resolve this dilemma in practice, HCPs invest in their relationship with parents so that they can assist them in developing an appropriate decision-making capacity. This is achieved through the process that I have called GTWP, through which HCPs attempt to build a common frame of reference with parents to enable them to make difficult decisions about their child's care and future.

1.3 Resolving the dilemma: building a common frame of reference

The quality of the relationship between the clinical team and the parents is constantly monitored, as are the personal relationships constituting it. When the child is first admitted, physicians indicate that one of their first aims is to establish a relationship with parents. They considered it as a condition of the success of the care by enabling collaboration between them and the family. As far as possible, HCPs avoid mentioning the possibility of WLST to protect their emerging relationship with parents, unless it is immediately relevant to the child's situation.

Physician #5: Again, I think what [Physician #4] said is very important, because it's a series of conversations. So for me, it's like getting to know them and a very general feel of the situation.

Physician #5: But unfortunately, in the bigger part of the population, you don't always have the luxury of that.

Physician #2: Or even the neonatal population. I mean, quite frequently the first conversation I have with the family is, "I'm sorry, this is terrible news, we need to plan for what comes next." I mean, that's not uncommon actually. I think that's about a third of the conversations I have first up.

Physician #3: I mean, it's definitely also the meeting. Because if your first contact with us is saying, sort of "death and destruction", not infrequently the family starts hiding from you after that. But sometimes you can't avoid it, you know? [Consultants discussion group]

From the beginning of their interactions with parents, HCPs work on building a common frame of reference. It is within that frame of reference that the process of informing parents and obtaining consent for proposed treatments, investigations and care orientations will take place.

1.3.1 Expectations as building blocks of the frame of reference

As I will now explain, the common frame of reference emerges from the negotiation resulting from the encounter between the expectations of parents and those of HCPs. HCPs seek, on one hand, to understand parents' expectations in terms of the care that their child is susceptible of receiving in the NICU and the outcomes that would appear acceptable to them. On the other, they also share as much information as possible about the child's condition and its implications to shape their expectations.

I take expectations to be a function of knowledge, experiences, values, hopes and beliefs as applied to a future situation. Although the two aspects will often be intertwined, to understand how expectations are brought together to build a frame of reference, they can be viewed as either predominantly about facts or about norms. Factual expectations rest on a judgement on the likelihood or possibility of something happening. Factual expectations are likely to rest on beliefs about the natural world that can be proved either to be true or false or at least more or less probable. In the context of the NICU they will therefore primarily be about clinical or medical facts, for example when parents expect a short stay in the unit or that dialysis is possible for children of any age or weight.

Normative expectations are concerned with what ought to be done in response to a situation, for example when parents expect that cardiopulmonary resuscitation always ought to be performed on their child in the event of cardiac or respiratory arrest such that a chance of prolonging the life of the child is never intentionally denied. Normative expectations can apply to oneself or others: a nurse might have expectations as to the care children ought to receive or a parent might have expectations as to what is required to perform one's duties as a father adequately. Normative expectations are more difficult to assess as right or wrong for they largely rest on value judgements and ethical principles.

1.3.2 HCPs also have expectations

In constructing of a frame of reference as the encounter of expectations, HCPs also

bring their own expectations to the table, although they do not always entirely recognise it. First, their professional knowledge, training and experience are the source of many factual expectations. However, they also hold values and beliefs that are the source of normative expectations about how they ought to care for their patients or how parents ought to respond to certain situations. These normative expectations are often intertwined with factual expectations. HCPs displayed a varying level of reflexivity on that aspect of their experience. Some recognised it outright, while for others this recognition seemed more implicit. None of them went as far as denying it. Physician #5 provides a succinct illustration of an explicit recognition of the part that values play in defining the expectations of HCPs:

Our biggest issue – we have some colleagues in the team who have a very pro-life attitude; not many. There are other teams in the hospital – when you have shared care, you have an extremely pro-life attitude. And that does lead to some difficulties, insofar as ‘You must carry on’ ‘Why?’ ‘Well, because I think there needs to be another week.’ ‘Well, what is going to work in another week?’ ‘I need another week.’ ‘You need another week, or the child needs another week?’

Do you see what I mean, that kind of... So there are differences between different clinicians in this area, and that’s where so much of this isn’t about facts. No, it’s about values between individual people, and how they manifest this.

However, for some, professional expertise and scientific knowledge outweigh normative expectations in the way they approach their patients and interact with their parents. While also recognising wanting ‘the right thing to happen’, Physician #1 insists on the primacy of factual considerations in determining how the care of a child ought to be oriented, thereby downplaying the role of the normative expectations that HCPs bring to the relationship:

So there is an inconsistent message about the status of science versus individuality or professionalism, in all sorts of environments. We are relatively privileged, in that we often have lots of data, lots of investigation, lots of observational data, lots of specialty opinion, and it’s usually very up to date, and it’s changing constantly.

So the best way, in my view, to manage those kinds of disputes is to seek further evidence. And sometimes you’re wrong, and the further evidence pops something up that you are not expecting, and that’s helpful. And sometimes it just continues to confirm... But what is interesting is that there is an asymmetry in the kind of evidence that persuades non-clinicians. So often, visible evidence, maybe an X-ray or maybe how a child is behaving is much more powerful than laboratory evidence. [Physician #1]

Surgeon #1 also underlines the variations resulting from the different normative

expectations brought in determining the frame of reference by HCPs.

Is it in this child's best interests to be treated aggressively, such that they end up in a wheelchair with no communication, with hearing and visual impairment, being fed with a tube, question mark? I don't know the answer to that. And so by definition, because there is no clear answer to those questions, and we don't know where on the spectrum of badness this child will fall, you end up kind of negotiating it with your colleagues and the parents, and you can come up with a different answer depending on which parents you're dealing with, and which colleagues you're dealing with. [Surgeon #1]

Having identified the building blocks of the frame of reference, I can now turn to analysing more concretely how HCPs attempt to construct it with parents and how they go about managing it to get there with parents.

2. Getting there with parents: managing the frame of reference

Building the frame of reference does not take place over a single encounter. It is the result of the succession of interactions between HCPs and parents during the child's stay in the unit. New elements, both formal and informal, are added to the frame of reference as the condition of the child continues to evolve and as the process of formulating a hypothesis as to best interests progresses. Expectations are susceptible of evolving over time.

At its core, GTWP is about identifying, monitoring and steering the expectations of parents such that everyone can agree to a mutually acceptable course of action. To reach that point, parental expectations do not need to be entirely the same as that of HCPs. They only need to be sufficiently congruent or overlapping. The conceptual space at the intersection of the expectations of parents and of HCPs represents the extent to which the preferences of parents will be respected. One of the defining characteristics of the GTWP process is the endeavour by HCPs to adjust the frame of reference over time, such that it is congruent with their conception of the child's best interests. Another way, therefore, of understanding the nature of that process of constructing and adjusting the frame of reference is, as Physician #1 puts it, to characterise it as the process of delineating the scope of parental discretion.

And the skill perhaps is picking apart what's behind those requests. Is it a clear understanding of what's going on, with a different set of hopes or beliefs? Or is it a misunderstanding of the facts, or an over-emphasis on one fact that they perceive as positive compared to others that

they don't necessarily have the background to know how important those facts might be, for example? So we obviously spend a lot of time on trying to define that framing—the limits of the discretion, if you like. [Physician #1]

Ultimately, when WLST is proposed, GTWP aims at what Physician #3 describes as that 'swing' in the parents' view.

JFM: So I guess then we are talking about a situation where, from a medical point of view, the next thing or the next phase would be to go toward palliative care?

Yes. Yes. And I think it's important for parents to know that palliative care is also something that you can do for the child. It's not just that you're stopping everything and leaving the child to suffer. It's trying to get them around to a different focus of care now. It's not that we're withdrawing care; we're just withdrawing aggressive, invasive treatment. But then we can still continue with care and keep the child comfortable.

And it's that sort of swing in their view that you want to try and get. I think that the difficulty though is that it's not always easy with certain groups of patients. [Physician #3]

The two senior nurses I interviewed indicate that they see it as one of their responsibilities to reiterate and interpret what physicians tell parents, such that they can understand it, but also make progress toward accepting their recommendation.

JFM: You said it's usually to discuss or give an update. When you refer to difficult decisions that are made, are these decisions made in the meeting, or the question is introduced?

I guess it depends on the individual case, but generally, I would say we go in kind of knowing where we want to lead it, and sort of pitch it to the parents and see where they're at – if they're kind of getting there or if they're totally not where we are at yet. So I guess it's gauging where they are as well, and introducing it in a timely manner for them. [Senior nurse #1]

JFM: You suggested that perhaps it might be advisable to let her go. Do you see that as being part of your role, to have that kind of conversation or to raise that kind of point with the parents?

Not if it's the very first time, but if it has been... If the doctor has spoken to the parents already beforehand, and said, 'We are in a situation where we don't know where it's going, and if [the child] has an arrest again, we might not be able to resuscitate and get [the child] back,' then I feel it is my part, because I'm there the whole time, for 12 hours, whereas the doctor, especially the consultant who normally has the conversation, might not even be at the hospital at the time when it happens. [Senior nurse #2]

In this section, I first present one the premises of the GTWP process, namely that parents and HCPs do not share the same point of departure when they approach treatment options. I illustrate these different points of departure through a discussion of the imperative to *do everything* for a child. I then turn to introducing the two main

ways in ways in which HCPs endeavour to get there with parents. First, I will elaborate on the way HCPs seek to *inform* parents about their child's condition and how it connects with the purpose of steering their expectations toward accepting a recommendation to withdraw life-sustaining treatments. Secondly, I discuss another mode of interaction between HCPs and parents, that of psychological and emotional *support*.

2.1 Parents and HCPs come from a different place

Every patient and their parents literally come from elsewhere: the child will have been born in a different hospital then transferred to the NICU. Physicians are particularly careful to try to understand what expectations parents might have formed based on their interactions with the previous medical team they were involved with and what it means to them that their child's care is escalated to a more specialised clinical setting.

Physician #3: I guess because we're a receiving unit, the patients aren't becoming sick here very often, they are either in the ward upstairs, or more come from the neonatal unit, so... [Physician #2]'s point about finding out what they've been told up to now. And often they have had expectations they would have got from conversations about pushing somewhere else. So, some sort of feeling of what they understand, I would kind of start with that. Your first meeting is a bit about getting to know them as well. Trying to drop bombs like 'we might switch the machines off' the first time you meet someone, unless there is an imminent catastrophe going on, is not likely. [Consultants discussion group]

Expectations can vary, based on the way the previous team handled the situation:

Physician #2: Yes. And you have to information gather as well, because different places have different ethos. Depending where they come from, some places are much more likely to have been frank, and other places are much more likely to beat around the bush a bit more. [Consultants discussion group]

However, on a more fundamental level, the idea that parents have a different point of departure than HCPs is a defining feature of the process. Parents were not prepared for their child to require critical care so early in their life. Accepting the situation requires adjusting their expectations. As their relationship evolves, HCPs seek to gain a deeper understanding of the expectations of parents, both factual and normative. I have already indicated how HCPs consider the values and preferences of parents at the stage of wider best interests as an objective element susceptible of

modulating the best interests hypothesis. However, such preferences are also crucial components in elaborating the common frame of reference between HCPs and parents. The frame of reference is different for each patient. It varies depending on the values and beliefs brought to the conversation by the child's family, and those of the HCPs. Physician #1 insists on the variation resulting from the different expectations that parents can bring:

So the biggest determinant is the family's expectation and view of what is a good life. And the variance in that, you would not believe until you've been there. I've heard families say, 'If you can't guarantee he could go to university I think we should stop.' And I've had families say, 'we'll take him if he can breathe.' The absolute opposite ends of the spectrum. So that absolutely sets the frame of reference for the conversation. [...] But keeping in mind that the framing for those discussions can be as broad as I started with, it's a very exploratory discussion. [Physician #1]

The process is deployed to empower the parents, to assist them in becoming agents in both their lives and their child's.

Nurse #1: Yes, it's incorporating the parents and making them feel like experts; because the reality is that they are here every day, seeing their child, and seeing what does and doesn't react with them, and how they react to what in a situation. And it's using that information to help you make the decision as well – or to help everyone make that decision as well. But I guess at the end of the day you have to try to make them ... when they come to that decision, to try to make them as comfortable with their decision as you possibly can – which is easier said than done! [Laugh] [Nurses discussion groups #4]

The whole team of HCPs endeavours to build relationships so to assist parents in building the capacity to accept the outcome and live with their decision. They also encourage parents to activate their network of relationships to get the support they need in order to deal with the difficult situation they and their child are faced with.

2.2 HCPs get there first

One of the frequent consequences of the different points of departure of parents and HCPs is that the latter conclude that WLST is in a child's best interests before parents. This temporal difference frames the way HCPs approach the process of implementing the conclusion.

JFM: OK. Now can I ask, what would you see as being the most difficult issues or situations that would be arising on NICU, from the perspective of law and ethics? Or I guess mostly ethics...

I suppose it's the patients where you feel that there is not much more you can do for the

patient, and the parents are not on board with that yet, and there is then a conflict between your decisions, and what you want to do, and what the parents want to happen to their child. So that is the one that brings us the most issues, generally. [Physician #3]

And I think the problem is almost always a difference in perception, or a difference in understanding. And you can't expect a parent to suddenly have the same level or knowledge and expertise that you have, because we are trained to see a lot of children. [Physician #2]

The process of determining best interests I modelled in the previous two chapters can be interpreted as a journey HCPs go on together. Once they agree on a conclusion – on a destination if we keep to the metaphor – HCPs come back to meet the parents where they are to bring them along to that predetermined destination. Physician #5 explains how HCPs need to conclude before turning to parents and initiate GTWP.

So once you start – We might have had a conversation with the family earlier on, who had said they were a bit worried things weren't going well here. But when you start talking about withdrawing ICU, it's only because as a physician you've already been through the journey, and you come to the conclusion that you should be stopping. It's only then that you start having the discussion with the family and you negotiate. We don't go, 'Oh, if by tomorrow he's not better I think I might think about stopping.' We don't do that with families. Though you do sort of lay the ground of 'Things aren't going well.' So that's kind of it. You know, 'We think we ought to be stopping. [Physician #5]

Similarly, a nurse explains the connection between the two processes, outlining clearly how the process starts with HCPs agreeing between themselves before submitting that agreement to parents.

Nurse #1: There are so many different perspectives and opinions to consider at all times. You have ... however many consultants we have here, they all have their own views and opinions, and their own experience they bring into it. And the same with the nursing staff: you've got someone who is brand new to it, coming from a new perspective or newer training or something like that, that could ... and you have someone who has 20 years of experience, who has been there, done it, and brings in their experience as well. I don't think it's just... You've then got to incorporate the parents, and try to get them to wrap their head around whatever decision needs to be made. It's not an easy... [Nurses discussion groups #4]

The difference in expectations that HCPs and parents have when they approach a child's situation can have concrete consequences. For instance, it can even influence how a seemingly anodyne expression such as "doing everything" can be interpreted differently, sometimes leading to profound disagreement.

2.2.1 Doing everything: an illustration of the difference in points of departure

The default position of parents is generally the same as HCPs. Both expect that *everything* will be done to save the child. However, for HCPs, this position is tempered by the understanding, which I presented earlier, that aggressive treatment might cease to be in the child's best interest. HCPs worry that some parents do not recognise the existence of that limit. The distinction between these two perspectives underlies the perception HCPs have of what it means when a parent asks them to 'do everything'. '[T]he famous *everything*,' as Trust Solicitor #1 puts it, is a potential stumbling block along the way of GTWP, for it is often the expression of expectations perceived to be incompatible with those of the treating team.

The request to do everything implies the possibility that indeed HCPs could do something else or something more. For instance, Physician #5 related a conversation with a parent who insisted on their child receiving an inexistent treatment:

The second thing is, I want [my child] to go on a kidney machine.' 'There are no kidney machines for babies this small. They don't exist.' 'Find one.' [Physician #5]

For HCPs, the injunction to do everything can also reveal the parents' denial as to the possibility that their child's condition could be fatal. HCPs note that for people for whom death, and especially neonatal death, is not part of everyday experience, this possibility often appears as remote, if not impossible.

Physician #4: I think that's partly our own fault. As technology has developed, the media has portrayed this sort of image of, you know, you can't die. And therefore...

Physician #3: Well if you do, someone is to blame.

Physician #4: Yes. It's like there is something wrong; it's not the normal process. And you know, death is not a normal issue any more. You don't see people dying, whereas the generation before us did see people dying, and it was sort of a normal process that happened. That we're in a way making it ... that's what we've left them with, you know? And actually a lot of parents probably think it's a good idea that – not a good idea, but they think it's the right for their child to die; they just didn't know that that's possible. You know, can that really happen, without it being wrong? Do you see what I mean? It's ... the normality of death has gone. [Consultants discussion group]

For HCPs, getting there with parents therefore often means changing parental expectations as to what it means to *do everything* and when the situation is such that

they can do nothing else.

2.3 '[A] "disease that decides" [...] conversation': informing the parents

HCPs tread a fine line when they use medical information in GTWP, for they try to maintain a balance between the purported scientific objectivity of the information and the purpose to take the parents to a point where their expectations about their child's treatment options evolve. Physician #1 comments on the rhetorical stance HCPs should adopt in their interactions with parents.

[...] I'm not sure if this translates, but there is something slightly different between asking formally for consent, and just assenting to the information that we're sharing together. It's a 'disease that decides' sort of conversation. Do you follow my argument, rather than what do you think we should do now – which I think is an almost impossible question for most parents.
[Physician #1]

Ideally, the information presented to parents should bring them to the desired conclusion by leading them to accept its premises, without necessarily explicitly submitting the conclusion to them as such. '[A] "disease that decides" [...] conversation' is one where the conclusion seems irresistible because it follows from the unfolding of the disease, understood as a natural and objective process. The connection with the dilemma between parental autonomy and capacity I began this chapter with is clear here. GTWP aims at reaching the conclusion that HCPs consider to be the right one, without parents experiencing this conclusion being forced on them. The efforts of persuasion deployed by HCPs are, therefore, mostly indirect, especially early in the process.

Providing accurate and understandable clinical information to parents is one of the main ways in which HCPs seek to manage parents' expectations. Most acutely when the team takes the view that best interests requires WLST, the aim of the information process is to help parents accept that HCPs can't do anything more for their child. As its audience changes from HCPs to parents, so does the mode of the presentation of medical information. Although HCPs perceive the information shared as evidence-based and rational, it is not normatively neutral for it is also presented to guide and influence the parents in revising and adjusting their expectations, both factual and

normative. For instance, Physician #1 insists that providing contextualised and adapted information is one of the main ways to avoid or dissipate misunderstandings with parents. The information emphasised in conversations with parents is not only chosen for its scientific weight, but also for its potential to persuade the parents.

[...] But what is interesting is that there is an asymmetry in the kind of evidence that persuades non-clinicians. So often, visible evidence, maybe an X-ray or maybe how a child is behaving is much more powerful than laboratory evidence.

So you have to sort of build in how effective some of the evidence is, when you show it. So for example, if you are having trouble explaining to a family, or having trouble communicating with a family about severity of a brain injury, say, two things are often useful: sometimes looking at a scan is useful, and showing a normal scan next to the child in question's scan; but also, watching the child very carefully with the family, or comparing them to another child of a similar age is very powerful information. I think that's especially true in young children, where the whole development is going on. But if you as a parent are just focused on the child and it looks the same as yesterday and that's OK, you're missing the trajectory; you're missing important information. [Physician #1]

Nurses also reinforce the meaning of information provided by physicians to parents. Senior Nurse #2 sees it as part of her role to act as an intermediary between physicians and parents by providing additional explanations or reiterating the information, such that parents can integrate it.

I feel that it's my role to make the parents aware. Because I know that sometimes in the conversation with the doctors they are so shocked that the information might not sink in. I sometimes feel – and parents do ask, 'What did the doctor actually mean by this?' or 'What did the doctor mean by that?' or 'I don't understand what he's saying.' Sometimes they ask later on, way back after the conversation, what was actually said. Not just specifically in these cases but in other situations as well. For example for consent for a surgery, they'll say, 'What exactly did they mean by this, or what does that mean?' So I think it is part of my role to then tell the parents, 'This is what they mean,' or 'If this and this happens, then we probably have to do this and this. [Senior Nurse #2]

Nurses working at the bedside also highlight clinical details supporting the team's recommendation in their interactions with parents:

Nurse #1: And probably also what you are seeing clinically at any moment and across your shift that is making you think that that is the right decision. I guess it's education, like the scores we are [Inaudible] in – because we are used to interpreting when the drugs the patient is on are at the highest doses you can possibly do. And say you have a patient who is isolated and on everything under the sun, it's showing them and trying to explain to them, 'look, there is actually nowhere to go from here.' [Nurse discussion group #4]

Providing parents with relevant medical information and assistance in interpreting it is only one aspect of GTWP. HCPs apply significant efforts to support the parents in

integrating and processing that information and accepting the situation of their child. I now turn to this second aspect.

2.4 Supporting parents

Bringing parents to accept that WLST would be in their child's best interests is not only achieved through rational discussion. HCPs also insist on the importance that parents receive emotional, psychological and spiritual support. As I showed previously, in the NICU parents are perceived as 'upset traumatised people'. Their child's illness makes them vulnerable. A widespread worry is that they might not be capable of receiving and integrating the information presented to them. Thus, significant attention is devoted to monitoring and addressing the emotional, psychological and spiritual needs of parents. In this regard, the wellbeing of parents is the primary reason for providing such services. It would be reductive to claim that getting parents to accept WLST is the only goal of the support offered to them when it is deemed to be in their child's best interests. However, it would be equally reductive not to acknowledge that HCPs mobilise support to make parents more comfortable with that conclusion. Interactions with parents aimed at supporting them also contribute to the construction of the common frame of reference and its management by HCPs. Although HCPs pay attention to the mode of presentation of medical information, informing parents remains primarily geared toward the factual. By contrast, supporting parents is more concerned with the subjective reception, interpretation and integration of the information provided.

In this section, I address three ways to support parents articulated by HCPs. First, I present psychosocial support, which I take to be the central case of the category. I then discuss the adjustments to the standard of consent that HCPs make to accommodate the expectations of parents as to the role they want or can play in decision-making about their child. Finally, I show how managing the common frame of reference implies attending to its temporal dimension.

2.4.1 Being there for parents: psychosocial support

HCPs understand supporting parents as involving being emotionally available for

parents, listening to their concerns and counselling them. Another group of HCPs, whom I have described as allied professionals throughout my study, see it as central to their role. Allied professional #2 describes their role as follows:

As [an allied professional] across those two intensive care units, my role is to support primarily parents and family members when their child or baby is in the intensive care unit. Obviously on NICU it's parent work, on PICU it has some work with the children as well.

What that looks like is either having conversations with them by the bed space or in private about how they're coping, perhaps adjusting to new diagnosis, thinking about end-of-life, decision-making and supporting them through the general intensive care, and further to intensive care as well. [Allied Professional #2]

Several groups of professionals coordinate the formal aspect of supporting parents among themselves. Weekly, a 'psychosocial meeting' brings together the family liaison nurses, the units' social workers, the chaplains and the unit's psychologist to discuss the unit's patients. The meeting covers each patient, but in varying degrees of details, depending on the needs of their family. In certain cases, the emphasis is on the material or logistical aspects of the situation. For instance, whether the parents have accommodation near the hospital or whether they have access to childcare for their other children. Attendees also discuss parents' emotional states and attitudes. For example, in one of the meetings I attended, attendees described parents as 'appropriately anxious' about their child's situation. Allied Professional #2 describes the broad scope of those meetings as follows:

JFM: And is there any kind of coordination between these people?

The psychosocial people? Yes. We all work very closely.

We have a weekly psychosocial meeting where we discuss all the patients on the unit, and think about them holistically – which definitely covers ethical dilemmas. Not discussing the ethics dilemma, but having ... although, ethics will come up in those discussions. We're very coordinated and we support each other a lot in our roles as well, because obviously it can be tough on staff as well.

Again as I said before, it's about us helping with communication. That's a big part of what family liaison nurses do, because they meet with all families, whereas I tend to just meet with families who have requested [my services], or someone thought it would be helpful and has referred them.

So yes, there is quite a lot of coordination. There might sometimes be confusion, if perhaps I'm seeing them, and so is chaplaincy and family liaison, that might get a bit – there might be an overlap of what we do. But we tend to discuss that and think about what is most helpful.

[Allied Professional #2]

The process through which HCPs reiterate and explain the information already provided forms part of the general category of support. Supporting parents is not limited to the psychosocial team. Nurses, both those working at the bedside and those with more senior roles, report that supporting parents is an important part of their work. Physicians also insist both on their role in that regard and on their responsibility to direct parents to resources that could provide parents with the support they need in order 'to get there'.

Based on their understanding of the underlying justifications for the parents' position, the team can adjust to provide them with services or interlocutors to address their concerns. When parents raise religious arguments, HCPs might seek to involve the unit's chaplain. HCPs also acknowledge that the parents' interactions with other people influence their contribution to the frame of reference. If HCPs cannot personally influence the parent's perspective, some other people with whom the parents have significant relationships might be able to do so. HCPs thus encourage parents to go back to their friends, family or spiritual advisors to discuss the situation in the hope that it might help them see their child's situation differently.

JFM: Yes. And if we're talking about the more usual cases, like you mention, where there might be a bit of back and forth, or negotiation... If the parents come back to you and say, 'we don't agree with what you're suggesting,' what would be your next course of action?

Well usually what you'd say is 'I'm really sorry to hear that.' It's in steps, so there's never an end point to these conversations. You'd say 'OK, that's fine, we respect your views, and let's go away and think about it over the weekend,' or 'go and talk to whomever, the important people in your life.'

[...]And not infrequently then, especially if it's very young people having to make these terrible decisions, they've got to talk with their mum or dad, or if there's a strong grandmother, and they'll each come out and say 'yes, we've thought about it actually, and it's OK.' So it's not an end point. You do try and try and try. You try not to let the relations break down, and it's very rare ... it's very unusual for them to break down to such an extent as they had in this case. Because most parents want what's best for their child, and if you say to them, 'Look, there are some things worse than life,' a lot of that resonates with a lot of people. You know, probably 98% of people will recognise that, and will then come along to the right decision, as it were.
[Physician #4]

2.4.2 Easing the burden from the parents' shoulders: incorporating decision-

making role expectations

GTWP also involves determining with parents what role they expect to play in the decision-making process about their child's treatments. As parents come with different expectations, such negotiation constitutes another aspect of the construction and management of the common frame of reference. Some parents come to the NICU with the expectation that they can make all decisions concerning their child's care, independently of the professional opinions of HCPs. For instance, HCPs report that occasionally parents will come to the NICU expecting to be able to request certain treatments from the team. In such cases, HCPs will attempt to reinforce the notion that identifying and presenting treatment options are a prerogative of consultants and that, legally parents cannot force them to offer a treatment they consider inappropriate. Physician #5 relates doing that in a tense meeting with parents disagreeing with the team's assessment that they could not do anything more.

So I was very clear to them, I said, 'Just so you understand the law...' 'You're going to take this to court, aren't you?' 'I'm not taking anything to court, we've been...' [One of the parents] was being very inquisitional on what I was going to do. 'You're going to take us to court!' I said, 'Look, just help the situation, the way the law is,' looking at the solicitor, 'I don't have to do something that I don't think is right for [the child] [London – Physician #5].

Next to parents who want to take on a greater role than HCPs are willing to let them play, are those who want to exercise the full extent of their decisional prerogatives. HCPs do not perceive that as particularly difficult to accommodate. Within the unit, maximising parental autonomy is the default position.

However, at the other end of the spectrum, HCPs see some parents as refusing the burden of directly requesting WLST.

Nurse #1: I guess it's also ... it sounds weird, but you can't put a positive spin on withdrawal. It's not a nice thing. But it's trying to ease their shouldering the burden, and I don't think there is any way you can stop that; I don't think there is anything you can do. But it's trying to help them feel that...[Nurses discussion groups #4]

HCPs respond to such situations by adapting, often lowering their expectations as to the involvement of parents in decision-making. HCPs are mindful of the needs of parents who might be willing to go along with withdrawal as long as they do not

perceive themselves as having caused the withdrawal by explicitly consenting to it. Paradoxically, in such cases the requirement that parents consent and, therefore, take on part of the responsibility of the decision and its anticipated outcome becomes a stumbling-block along the way to realising what everyone tacitly agrees to.

And we've gotten to the stage where we're involving the parents so much that we ... sort of update them and inform them, and ask for their views. And sometimes they think that we're asking for their permission to stop or withdraw, and they can't take on that responsibility. And I think there are some families who feel that when we update them and ask for their opinions, we are asking for their permission to stop. And that is difficult for them. Because you know, they are left with the guilt and the long-term consequences of that decision, whereas we can just move on. And sometimes they are actually looking to us to actually say, 'This is what we feel,' rather than, 'What do you think we should do?' You know? And it's quite difficult then to balance as to how you put it across. [Physician #3]

Supporting the parents can therefore also take the form of a modification of the default standard of parental consent to adjust it to the expectation of parents. In some case, parents acquiescing or even not actively opposing WLST can be sufficient for HCPs to go ahead with that plan.

JFM: So in that case, is it ... could it be fair to say that in certain situations, it might be too much to ask parents to give an actual permission?

Physician #1: Well, this is ... we often talk about this, about whether the degree to which there is an open question or a closed question to the parents... Is it, 'What would you like us to do?' or is it, 'We have a very strong recommendation from the whole medical staff that we should do this. We might do it this afternoon, would you like to get your family around?'

Physician #4: You have to give them ... you have to ... so they have to be able to save face. It's a horrible thing to say, but to go back to the family, and 'Oh no, this is what they told us we have to do.' So it's a balancing act of making sure that they are... Is it complicit? So that they are working with you. But this was definitely your idea, not mine.

JFM: So they are rather assenting to what is going on?

Physician #5: Yes.

Physician #4: It's even more important for Muslim families. Because they can't be seen to tell you to stop.

Physician #1: Yes.

Physician #4: So you say, 'This is what we think is the right thing to be doing.'

Physician #1: It's a sort of up-down versus [inaudible] question.

JFM: Yes.

Physician #1: It's a strong [inaudible] in one direction.

Physician #4: Obviously if you don't... If you really object to this, then we all rethink how we think, but this is what we think we want to do. [Consultants discussion group]

As indicated in Physician #4's last intervention, HCPs are conscious that they tread a fine line when they purport to apply a different standard of consent. They will not sustain that approach if they perceive parents to be disagreeing with it.

2.4.3 Giving parents time to get there

GTWP also implies recognising and managing the temporal dimension of the process. Giving time to parents is an important tool used by HCPs in the GTWP process. However, as I will also show, HCPs use it with restraint, for they worry it risks setting aside the interests of the child.

Giving time to parents is the underlying condition and context for the whole process of GTWP. Without taking the time to do so, it would be impossible to get there with parents. The time given to parents is a processing time when parents can integrate the numerous inputs they receive and relate them to their frame of reference.

Well, I think once as a team we know what the outcome is going to be and we have had that discussion with the parents, I think you need to give them a little bit of time to get their head around that. Because on the whole, most parents do. They might be completely against it when you approach them, but given bit of time, they generally come around and they don't want to inflict any more suffering on their child. [Senior nurse #1]

Physician #3 insists on the importance of patient and repeated interaction with parents and on giving them the time they need to change their positions:

Um... I think the main thing that you can do as the medic is to try and spend time with the parents, explaining to them, and trying to get them to see what the issues are.

I think sometimes we jump in too quickly. You know, rather than trying to get the parents on board with you, we start labelling them as difficult parents, or start getting the legal team involved; whereas sometimes it's just a question of giving the parents a bit more time to come to terms with the problem. [Physician #3]

Because parents have a different starting point, HCPs acknowledge that parents cannot get there instantly.

I think it's natural that doctors and nurses get there sooner, because they have had more experience of this. I think it's perfectly understandable that parents want to keep going as long as they can, because they don't want to be seen as ... it's really hard for them, they can think they're giving up on their child. [Allied Professional #2]

However, giving time to parents to get there is not viewed as a neutral process and can be controversial within the NICU team. HCPs worry the time they give to parents to adjust their expectation imposes and prolongs a painful experience for the child. As I have argued throughout this thesis, when HCPs have reached a point where they recommend WLST, they are acutely concerned for the child's subjective experience.

And the nurses looking after that child – the longer things go on, they find it more and more difficult, because they're seeing a child deteriorating in the bed. So everyone has a different timeframe in their mind, and I think it's very hard to get that balance right. But I don't think we can ever expect a parent to be told very difficult news about us thinking their child is not going to survive, and then very quickly be expected to come around to the thought of turning off the machines.

So yes, there are just lots of different timeframes. And I think in ICU in itself, we are used to have a rapid turnover of patients. Things happen quickly, and when things don't happen quickly, that causes lots of anxiety. [Allied Professional #2]

HCPs see the child as bearing the cost of time given to parents. This can go as far as detracting from the priority of the child and amount to 'putting the parents first', a notion to which I will return in the next section. Physician #1 makes that point as follows:

But, you know, that's obviously the process. [The parent] pushed it as far as it could go, the law takes over and everybody can walk away satisfied. The tragedy of that is that it takes six months of the child's life for everything to come together, during which time [the child] had no pleasure, and significant suffering. [Physician #1]

HCPs are also mindful of the possibility that parents can use their willingness to give them time as 'a delaying tactic' along the way to WLST.

So, I was just saying... When a family feels that the arguments are building up – perhaps it is a technical opinion, perhaps it is specialty consensus – that there aren't any other options, one of the last strategies that you often hear from families that are resisting the message that it's futile and we shouldn't carry on, is 'not yet.'

So time is used as a delaying tactic, but also as a... So the medics often use it to try to increase the certainty of their case. 'I made this statement today, I'll make it again tomorrow, I'll make it again the day after that.' And if the picture is repeated, then clearly it has a greater certainty. That's often a very powerful tool. But when a family is in absolute dispute and isn't listening to you, the response is 'not yet.' It doesn't matter what you tell me, because maybe

tomorrow it will be different. Whichever day tomorrow is that we are talking about. And that's fascinating. [Physician #1]

This tension in how HCPs perceive the need to give parents time to get there points to a broader element. HCPs consider informing and supporting parents as the optimal pathway to realising the best interests of the child. However, the process is fraught with difficulties and does not always succeed. Some parents cannot get there. However HCPs put the issue to them, they cannot consent or assent to the conclusion that WLST is in the best interests of their child. When this happens, the process breaks down and some of its limitations are exposed. I now turn to discussing the eventuality that parents will not get there.

3. Not getting there

Numerous expectations can become stumbling blocks along the way to a mutually acceptable resolution. For instance, the parent's expectations of themselves can lead them to adopt the posture of advocates for their child against the medical establishment. However, HCPs worry parents are pushing this role to the extreme when they forcefully try to convince them that their child can be the exception, that a miracle can still happen or when they attempt to refute the medical views of the treating team.

Physician #5: Somewhere down the line that balance is a little bit off in some cases. They say, 'I know my child.' Yes, that is very true to a certain extent, but you know, your judgement may be clouded by a lot of other factors, and you've got objective medical evidence. So that comes into play quite a lot of times.

Physician #4: But again, if they recognised that death was a normal process that does happen, then they wouldn't... I think parents are in a very difficult position, because they seem to feel that they have to advocate for their children. That it's part of their role to do. Which it is, but they couldn't possibly allow their child to die. If they did, they would be a bad parent. And so they get into a position of having to go down a path, which I'm not sure they always want to do.

In other cases, parents might realise that HCPs' interactions with them aim at making them accept WLST would be in their child's best interests. This has the potential to create an impasse by undermining the parents' trust in the NICU team, leading them to refuse to engage in further discussions. Such situations are often associated with religious beliefs about the sanctity of life that are incompatible with

the idea that death might be in the child's interest. Sometimes, the mere fact of questioning or trying to distinguish a core belief can appear sacrilegious.

We had the discussion many times about withdrawing care, and that what we were doing was not in her best interests. However the parents were not there at all. I think the mum was a little bit more, but the dad was not there. I think, however, many conversations we would have had with him, he would not have gotten there. I think some of that was religious – their beliefs were that they could not say no or stop the treatments. [Senior nurse #1]

Physician #4 describes another situation where it seemed impossible to reach a common understanding with parents:

There was a... I can't remember the exact tipping point, but there is a point where I thought, there is no way we are going to be able to get around this. We talked ... and as a team, we sat ... it wasn't just me. It was a group, collegiate decision that this was the only way out. Because I think we had all had the same... Sometimes parents take sides, no matter what you say. Sometimes it's good cop bad cop, and they'll go along with something someone else says, but they hated all of us. So... And also they hated all the nurses. They hated everyone! So there was no way we were ever going to make any progress. [Physician #4]

For some parents, the deliberative and consensual model of GTWP is inherently inadequate. The components of the frame of reference HCPs attempt to construct with them are so deeply incompatible with their core beliefs and values they cannot integrate them.

Oh, interesting. So, um ... when does it feel like it, or when... OK, so, I think you can often spot the families quite early on in whom evidence is not relevant to the position they're in. OK? So, they didn't get to their position through reason, and therefore reason or time or evidence is not going to change their opinion. That's often clear early, you know, within a couple of weeks of admission. [Physician #1]

When the process stalls, reframing the debate in a different forum and using different tools will be the only way for HCPs to advance their view of best interests. For instance, HCPs perceive that, for certain parents, a court application seeking permission for WLST will be the final step toward 'getting there'.

JFM: And do you feel it's a good way of solving those disagreements?

Um... Often, yes. OK, I know I said earlier I think it's a mistake that we have taken away some of the paternalism. But there are other cases where there is genuine uncertainty about what should happen; when precedent isn't set or there is such strong objection that ... for example, we had a child a few years ago who had a [disease], and who nobody thought had a chance in the world, and nothing positive on the quality of life scale at all, but the family were very resistant to stopping. And actually the court application was to stop, and it was granted. And rather than any kind of upset at the process for the father, who was a very religious man, he was grateful. What it meant was that it allowed him to behave in a way that

consistent with his faith, and not make a decision that he would be criticised for; and yet also, what happened he knew inside was probably the best for his child, but he didn't have to make that decision. [Physician #1]

Trust Solicitor #1 echoes this point, noting that for some parents, withholding consent to WLST for as long as possible is a way of discharging their parental duty of protecting their child:

And we all came back [from the court]. Me and him came back and went up to the unit, and his parents had arrived. And interestingly, I think the thing that was the most—I mean from what I see, because at the end of that afternoon I sort of ducked out of it—but the thing that seemed to be most helpful to him was his father saying, 'You've done everything you can.' I think he took some comfort from that in a way that he hadn't from hearing that from other people. I think in the funniest of ways that let him off the hook, in terms of what he had expected his role as a father to be. You know, doing everything he could to support his son. I think that's quite a common narrative that I hear from parents. 'We wanted to be able to say we have done everything.' [Trust Solicitor #1]

Independently of the reasons why the process failed or stalled, there needs to be a next step, something that will set things in motion again. Several HCPs have indicated to me that they feel the courts ought to be involved earlier in the process when they detect indications that the parents will not get there. HCPs are aware that obtaining a court authorisation is an alternative to obtaining parental consent. The London Hospital as a whole regularly takes matters to court to decide according to best interests. Nonetheless, while applications to withdraw life-sustaining treatments are perhaps not so rare to be called exceptional, they are infrequent. Part of the explanation is that most situations that might give rise to an application to withdraw life-sustaining treatment resolve themselves either with parental consent to withdraw, following the above described process of GTWP, or with the child succumbing to their illness despite life support.

Another avenue usually considered before taking the matter to court is to bring the disagreement to the attention of the hospital's clinical ethics committee. However, as I will show, while they acknowledge the CEC as a useful forum for addressing certain types of questions, HCPs see it as limited in terms of what it can achieve when the disagreement is about WLST. HCPs are reluctant to abandon their efforts to get there with parents and move on to another strategy. In what follows, I explore the

reasons for that disinclination. I address in turn referrals to the clinical ethics committee and court applications.

When GTWP does not deliver the expected progress, the process becomes susceptible of being distorted. In the second part of this section, I will therefore examine two types of distortion that can affect the process identified by HCPs. On one hand, HCPs apply too much pressure on parents and efforts of persuasion might veer toward coercion or manipulation. On the other, HCPs might be wary to confront parents and the best interests of the child might be neglected in favour of preserving the relationship with parents.

3.1 HCPs are reluctant to abandon getting there with parents

HCPs are reluctant to abandon GTWP. As GTWP is premised on giving time to parents and on explaining and reiterating the reasons for recommending withdrawal, it can be difficult to ascertain precisely whether the process has irremediably failed or whether parents are nearly getting there. Moreover, as the process results from the combination of interactions between several actors, notwithstanding the team's coordination, no one has a complete picture of its progress. The iterative nature of the process is thus susceptible of inducing a reaction akin to the sunk-cost fallacy, whereby HCPs consider the collective investment in the process as justifying continuing with it just a little longer, in the hope of finally succeeding. In this subsection, I discuss the hesitations that HCPs entertain toward the two most obvious fora to which they could turn to when GTWP does not seem likely to succeed. First, I explore how HCPs consider the CEC to be of limited use to address difficulties with obtaining parental consent to WLST. Next, I will discuss the reluctance of HCPs to bring the disagreement to court for adjudication.

3.1.1 The clinical ethics committee is not the ideal forum to solve disagreements with parents

HCPs are reluctant to refer a matter to the CEC. Many think it does not contribute much when WLST is contemplated. Here, I am not concerned with describing the functioning of the CEC as whole, nor to appraise it. The scope of my discussion is

limited to disagreements between HCPs and parents whether WLST is in the best interests of a child. In this context, the CEC was only rarely mentioned as an option to help solve disagreement. Indeed, I was often the one to raise it in interviews. My starting hypothesis that it played an important role was largely disproved.

Consultants have the most direct access to the CEC, for they are the ones making the referral to it. They see little use for it when the issue at stake is disagreement between HCPs and parents.

[...] But I'm not sure when you have this sort of case that the ethics committee ... does it add a lot? Do the families ever say, 'You know what, we agree with you now that we heard the ethics committee, we figure we should stop.' Or do the clinicians say, 'Do you know, we agree with the family now, we should carry on now that we've heard this.' No. I don't think I've ever heard the ethics process mend that or alter things. Maybe that's what is wrong. [Physician #5]]

HCPs see referral to the CEC as a formal prerequisite to bringing the matter to court. As I will show next, HCPs have a negative view of the legal process, which might taint their perception of the CEC if they see the two processes as linked.

JFM: What about the ethics committee?

[...] My criticism of our committee would be that sometimes it feels like our legal team would state a step we have to go through ... does it actually provide a solution in these situations? Probably not. [Physician #5]

Well, I've been to one, because of the case that recently happened, and I went to the ethics committee there. Which is very interesting actually, but it felt of no use whatsoever. It didn't help in any way whatsoever to resolve the problem, which had to be decided by the courts. Because it was obvious what was right. But it's just that they needed a little bit more chat. [Physician #4]

This characterisation of the CEC's place in the process leading to a court application is at least partially accepted by the lay member of the committee whom I have interviewed.

JFM: One of the clinicians I was talking to told me that ... he was wondering if perhaps the cases that went to the ethics committee were perhaps not the right ones. Because they were, like ... by the time they thought of sending you a case, things were so advanced that it was almost a foregone conclusion; and so in a sense it was, you know, just on its way to court.

Well, this is where I come back to readiness. That is probably true; it would probably be really good to have cases come in a bit earlier. Quite often, I have looked at the cases and thought,

'Oh my goodness, they might as well just be going straight to the legal team.' But this is part of a process, and it's a process of disentangling a whole lot of considerations. So while there is an element of truth in that—and perhaps more than an element—I don't think it's unnecessary to have the consult. And I think it sometimes throws out issues that are ... you know, that haven't been considered. [CEC Lay Member]

Nonetheless, as the CEC member notes, a referral to the CEC can contribute to clarifying the views of each side of the disagreement.

JFM: In this specific case, what was the involvement of the ethics committee? What did they do?

They met the clinicians—it wasn't me, because I was away when they had the meeting. So my colleague [...] went. They met the family, and they certainly found out lots of things about the family being very unhappy, very accusatory which they hadn't been before.

So the family felt—maybe that was a good thing, because it let the family air their views where they either hadn't aired them before, or hadn't felt able to air them before. [Physician #5]

Despite the hesitations mentioned above, this points to a potentially productive use for a CEC referral. It might help to reactivate or reframe a stalled conversation between HCPs and parents by introducing new interlocutors, and enabling a last round of discussions between parents and HCPs before going to court.

I think it's much more difficult in that short period of time, but the feedback that we have had from parents who have been, is that they're glad to see the quality of thinking that goes into consideration of what is the right thing to do. They felt that they have had an opportunity to have their voice heard. And just yesterday, I was stopped by a parent who I didn't recognize in the reception, whose child... She came to the committee, and it was about whether her [child], who is quite profoundly disabled, should get TPN at home. Clinicians were very unkeen, and in the light of some of the discussion, it was decided to try to go ahead; because the reasoning that the clinicians were giving was that it's too much for this family to bear—which they are not necessarily in a position to come to a view on! And the woman stopped me and said, 'you probably don't remember me, but I just wanted to tell you that a year on she has never had another infection and it's really going well, her condition has improved. It's been a wonderful year for us.' [CEC Lay Member]

Referral to the CEC can thus be the last act in GTWP or the first step in the process of formalising the dispute with parents, which culminates with a court application. However, the latter is a decision HCPs do not take lightly. As I will now explain, HCPs are highly uncomfortable with the legal process. This might therefore partially explain why, despite the low level of confidence in the CEC displayed by HCPs in such circumstances, most cases where parents do not get there are nonetheless referred to the CEC, before going to court.

3.1.2 Going to court is not the preferred option

In this subsection, I explore HCPs' perspective on the possibility of making an application to the court to determine the child's best interests. HCPs support such applications, but they will only do so as a last resort. HCPs invoke several reasons to explain why they prefer avoiding the legal process. They see it as damaging the relationship they have with parents, as a failure on their part, which signals the fruitless end of GTWP. Besides, they perceive the legal process to be onerous on many fronts and as largely redundant.

3.1.2.1 Going to court means not getting there with parents

Once the disagreement is handed over to the courts for resolution, the informal and interactive processes taking place in the NICU appear to be neutralised. This creates an uncomfortable hiatus. The proximity between HCPs and the child and their family characterising treatment in the NICU remains, yet the underlying relationship of trust is damaged, sometimes beyond repair.

JFM: [...] I'm also interested in those cases where, you know... I was talking about 'getting there' with the parents. Those cases where the parents are not 'getting there'.

Nurse #1: That's the worst. [Smile] That's the worst-case scenario, pretty much. Because at that point, if medically there is nothing more you can do, the only thing you can do is then to get lawyers involved. I have personally never been involved in that process, touch wood...

Nurse #3: I've seen it twice...

Nurse #2: It's a very difficult situation for you. Because the parents lose that trust in you, and they can become very aggressive, which makes it difficult for the staff. It's a very difficult situation all around.

Nurse #3: And you see the children suffering as well. [Nurses discussion groups #4]

This perspective seems to encourage HCPs to continue with GTWP for as long as possible, in the hope that it will achieve its purpose.

JFM: OK. Now I would like to turn to the work of the legal team, and the run-up to court. Have you ever worked with the legal team on a situation or on a case? And at which point would you feel it's time to reach for the legal team?

It's not easy to say. And I've said earlier that sometimes I think we get them involved too early, and it gets the parents' hats up. And then they get into a defensive role. I think when you get the feeling that it's likely to end up in court because you're never going to be able to persuade

the parents to come around to your view, then the legal team does help, in terms of... You still have to get your second opinions, but in terms of advising what can or can't be done... And then they involve the trust solicitors, or the judges. [Physician #3]

For many HCPs, bringing a case to court means they have failed in their duty to reach an agreement with the family.

And the whole process is completely ridiculous. Days of going up to the court and not getting our case heard, or hanging around outside with barristers earning 300 pounds an hour, and then nothing happening – and then going away again, and coming back the next week. So there is a lot of time wasted. [Laugh] And it's a very inefficient system. And also, it's governed by this feeling of complete failure, because to have to go to court is really bad. It's really awful, for everyone concerned, really. And everyone feels like they are failed, because of the relationship that's broken down to such extent. [Physician #4]

Trust solicitor #2 acknowledges this sentiment, while trying to downplay the significance of bringing a court application.

JFM: And do you feel they come to see you at the right time?

Yes, they are beginning to come a little bit earlier. We're trying to persuade them that actually going to court is not a bad thing. I think they see going to court as – historically see it as a bad thing, or that they have failed.

JFM: Yes. Many of them have said that to me.

Yes... And actually, it's not. You know, if you had a disagreement with a friend outside about anything, you'd always ask another friend, 'Well what do you think?' Same-same; same sort of situation... Someone has one view, you have another view; OK, you cannot proceed any further because there really are [inaudible]. Let's go find somebody else who can make a decision. [Trust Solicitor #2]

Despite Trust solicitor #2's disagreement with their perspective on the legal process, HCPs tend to see going to court as involving a direct confrontation with the child's family:

But I think law becomes quite a deterrent because of the processes involved, and the long drawn-out procedures – or at least the perception of long drawn-out procedures. It shouldn't, and you almost wish that it doesn't, and often there is a stigma of going to court, which you wish wasn't there. The way I think about it is that it is a genuine 'I think this is the right thing to do,' and the parents are saying that this is the right thing to do. You have to both accept that we don't know what is the right thing to do, and therefore a third party should decide. So there shouldn't be animosity, it shouldn't be seen as a confrontational step; it should be seen as arbitration, which is what it's meant to be.

Unfortunately I don't think that perception is there, so there is always a deterrent – it always acts as a deterrent to [inaudible, mumbled]. [Physician #2]

This in turn contributes to the view that going to court is incompatible with HCPs'

commitment to GTWP. Moreover, the relationship with parents is not the only loss that HCPs associate with bringing the matter to court.

3.1.2.2 Going to court is an expensive process by all accounts

HCPs perceive the costs of going to court—personal, professional, and institutional—as steep. The process is described as emotionally draining, and necessitating a significant expense of time, efforts, professional capital and public resources. Physician #4 describes this perspective in unmistakable terms:

And also the judges hate making these decisions as well, because they always think we've been utterly useless. 'How could you not possibly come to a reasonable decision, isn't that your job?' I've had that said to me by a judge. So it's a horrible thing to have to do. And also, the money it costs, I feel bad about as well. I got sent the barrister's bill by mistake, that he had sent in, and it was just unbelievable. I think for three days of work it was something like 8000 quid or something. He'd done nothing, nothing at all, probably ten minutes in the court. So I had the feeling I was in the wrong career! [Laugh] [Physician #4]

Consultants also criticise the legal process for imposing an obligation on HCPs to support their position in a form departing from the expectations which prevail in the medical context. The pace at which legal decision-making unfolds is also seen to be much slower than its medical counterpart. In that regard, the example of second medical opinions was offered to me as particularly significant. In cases involving significant levels of uncertainty or when a serious and irreversible course of action such as WLST is contemplated, it is common to ask colleagues from a different hospital to examine the child and review the medical file. However, Physician #5 expresses frustration at the fact that second opinions requested and obtained in the course of a patient's care are not sufficiently formal to satisfy the requirements of the Court:

[...] And one of the problems there is that we thought that at this stage we really ought to be going to the courts and seeking permission to withdraw. But to do that, the second opinions need to be written down in blood, if you like.

We have been sent back from the courts. 'Well, we have second opinions...' 'Can I see them?' 'They're on our computer system.' 'Well, go get them to write them properly.' They need to see things properly written down. The courts will always take a long time over a decision that might result in death. They will defer that for a time and make sure you have all the information. We understand that. It's obviously a weighty thing that people are thinking about. [Physician #5]

This delays a process that is already time-consuming.

Second opinions are something that someone does in their spare time – and the people who did them were great; they were very quick second opinions. One took three days to come and the other took five days to come; but then reports took another three days from the first one, and seven days for the second one. And that's the problem. These things take from 10 days to two weeks. They don't take five minutes. And that's because these people go home, they want to make sure they spelled it properly, they write a letter, they have it checked out... I understand that, I've been on the other side. I do second opinions.

And the problem is that you know that it is likely to go in front of a court, so you want to do it properly. But you are a full-time clinician, working flat out already. So no one has – you know, you're not paid to do this; you don't get any reward for it. It's a kind of collegiate thing we do for other hospitals. [Physician #5]

HCPs also find the perspective of testifying in court unappealing. The angle from which their work and their interactions with the child and the parents are scrutinised often strikes them as unfair. The legal process appears to assume motivations opposed to those they hold and attribute to their colleagues.

Except, as I said ... it is hard, because of the adversarial nature of the court; when you have a staff member who really does want what's best for the child, and they're being grilled like they, you know, skewered some 71-year-old lady, it makes it a bit hard. [Allied Professional #1]

The legal process is perceived as hostile and potentially damaging to HCPs either personally or career-wise.

JFM: And ... one last question. What about going to court with these cases? Does that ever happen, is that an option? How does that play out?

Nurse #3: That is hard. It's really, really hard.

Nurse #2: Hard. Yes.

Nurse #3: It's very ... because I had to go to court with one of them a few years ago, and that was really hard; because I didn't even know why the parents wanted me to go there, apart from the fact that they get to look and everything that has ever been written on the child, they get to look at [Inaudible] of you. Lawyers get to look at it, and barristers, and they just literally plucked people out that had said something a little bit positive. And you have to go and sit on this stand, and... You haven't looked after them for months, but because you once said, 'The baby smiled at me,' or something like that...

Nurse #2: That is why the nurses' documentation is so crucial to being impartial; because what you put down as your possible interpretation of something, some of these girls, actually, their career was swiped through the floor, and they actually left.

Nurse #3: And as you know, being from a law background, it is really hard to be sat there and cross-examined on every little bit...

Nurse #2: You probably couldn't even remember...

Nurse #3: It was about a year since I had looked after the child. I had been around, but because I was in charge of doing various different things, I hadn't looked after that child for a long time since they were tiny. And yeah, that's really hard. Really hard.

Nurses who have been assigned to testify do not have positive memories of their time in the witness box. Consultants, for their part, have a mixed experience. One of them portrays their experience in the High Court as grim and upsetting:

It's very unpleasant. It's a very, very intimidating environment—even if you haven't done anything wrong. It's a very intimidating environment, with a judge sitting, and even if they aren't wearing their wigs ... it's a scary place, I think. And they've got very bright barristers who pick holes ... because remember, medical records are not legal records—or rather, they're not written as legal records, so they're often inaccurate and contradictory. And so they're picked apart, and the parents sit there, and it's just very unpleasant. And then the press got hold of it, and it just kind of escalated. It got very unpleasant. Anyway. The judge ruled in our favour in the end, but it was not a nice experience. [Physician #4]

Even providing a second opinion for colleagues at another hospital is 'the chance to put your head up on a parapet for someone to throw things at you occasionally in court' [Physician #5]. However, one consultant had a more positive opinion of the court process, having testified in various capacities and contexts.

JFM: OK. Can you tell me what you think of the court process, especially when it's your patient and you're going there asking for a specific order, or...

You know, much to my surprise I was impressed. The majority of the time, I think both the lawyers and especially the judges are able to distil an awful lot of information incredibly quickly, and come to the summary points. And ... the vast majority of times I have been—not all—I have thought, well, you know, these are smart people who are especially skilful with words and the way they express themselves, and often do a better job of describing the issues in a way that is relevant to society. You know, we are slightly nerdy scientists in comparison to these very literate, articulate people, and I think they often put it in a wider context much better than we do.

Having said that, there is ... the other priority of the court is clearly not to be too different to anything that has been said before; and so there is often a feeling of looking for compromise. And the more I do it, the more I understand that. I think generally there is a bit of a game in what the application consists of. You know ... if you need three things you ask for four or five, if you need two you ask for three, or whatever. [Laugh] So there is some sort of ... everybody can feel there is some sort of equity, but there is always a compromise, it seems to me, in the law. And as a scientist that just doesn't make sense to me. There are facts, there is a right and a wrong, and let's just get on with it. But as a person, I can understand that that's the way people communicate; I just find it a little strange. [Physician #1]

Yet, even Physician #1 sees the court process as being at odds with their reasoning 'as a scientist' and therefore requiring HCPs to do things that they would never do if it were not for that process.

3.1.2.3 Going to court is often redundant

A third and related set of reasons which explain HCPs' reluctance to file an application to the High Court is that they often experience it as redundant and less optimal than GTWP. The London Hospital was involved in several cases over the years and HCPs have access to quality legal advice, both in-house and from outside counsel. They know precisely what the courts are looking for in an application and they can meet these requirements, notwithstanding the efforts it requires of them. In their experience, the courts will almost always agree with the cases they bring.

[...] As long as you've done the process properly, there can't be a better recommendation than that done by a team of properly trained professionals with a second opinion. So the court is going to agree, unless there is something extraordinarily wrong with how you have come to that opinion.

So ... it doesn't make a lot of sense to me that we don't give professionals a little bit more decision-making... Or no, let me word this correctly: we already have a huge decision-making influence, but it's interesting that hospitals and society expect us to seek court support, given that when we go to court, it's deferent to professionals often. [...] [Physician #1]

For HCPs, the law is primarily seen through an objective lens. Their expectations about what will happen are largely factual. Most consultants have experienced the legal process before and many have studied the leading precedents in one capacity or another. Yet, despite being successful in court, HCPs have a hard time identifying the added value of the court process. As I described in the previous subsection, they perceive it to involve a broad range of efforts and expenses that are alien to the normal functioning of the NICU. Furthermore, because they see the legal process as leading to a foregone conclusion, some nurses note that it also has a negative impact on the mourning process of parents by adding the stress and acrimony of the legal dispute to their grief once the court decides that withdrawal of life-sustaining treatment is in the best interests of their child.

It's a really hard process, and it's really unfortunate for the parents that it has gotten to that, because I think ultimately in all of these situations the court has ruled in favour with the medical—so you have withdrawn care, and you are just going to have parents who are forever going to... I mean, maybe eventually they will come to terms with it, but they are going to be angry, and they are going to be upset. And I think that is really sad, that they are not going to have the opportunity to mourn their child in the same way they potentially could have. I mean, there is no way around it obviously, you don't go to court for no reason obviously, but I think it's quite sad and unfortunate for the families that... [Nurses discussion group #4]

Going to court is therefore perceived as imposing a toll on both HCPs and families and yet without yielding a different or better outcome than GTWP.

In this section, I have shown that HCPs do not regard the clinical ethics committee nor the court as attractive fora to resolve a disagreement with parents concerning WLST. HCPs are personally and professionally invested in GTWP. They see switching gears as onerous in many ways and often struggle to find what net benefits a court application can bring.

Given how unattractive the alternatives are, HCPs might double down on GTWP. Sometimes, that wager pays off and the issue will be resolved. However, in other cases, it might be argued that overreliance on the process will cause it to become distorted. I now turn to discussing the two main potential distortions of the GTWP emerging from this study.

3.2 Potential distortions of the process

GTWP is not always perfectly calibrated and does not always reach its proposed destination through the shortest possible path. In our conversations, HCPs have alerted me to two potential distortions of GTWP.

These distortions are largely symmetrical. They both involve situations where too much weight is put on one horn of the dilemma at the heart of GTWP over the other. Losing balance between the two opposed premises, the process becomes distorted and is susceptible of producing undesirable outcomes. On one hand, if HCPs put excessive weight on the agency of parents to take fundamental decisions concerning their child, the consent process will lean toward following the preferences of parents to the detriment of the best interests of the child. HCPs refer to this potential distortion of the process as 'putting the parents first'. On the other, if excessive weight is placed on getting the parents to consent to the HCPs' view of best interests, the process will lean toward forcing a conclusion on parents, such that it will no longer be appropriate to describe it as a consensual process. This is what I

labelled as 'pushing the parents to get there'. I will now briefly introduce some characteristics of each of these two potential distortions.

3.2.1 Putting parents first

One of the ways that GTWP can be distorted is when it turns into 'putting the parents first'. This is in direct opposition with the commitment to give priority to the child, which constitutes the foundations of the grounded normative model that I am describing here. As such, HCPs find it undesirable. HCPs do not see all consideration of the interests of parents, including their interest to be agents in the life of their child, as negative. They do, however, often claim that too much emphasis on parental needs and autonomy is detrimental to children's interests.

HCPs broadly agree that caring for a child in the NICU also involves caring for that child's family. They might therefore take some actions to promote the parents' welfare, especially if the consequences on the child are limited, either in intensity or in time. For instance, the family might be afforded some time to accept the situation, as I have already discussed. Although, from a strictly medical perspective, it appears that the child's condition will be fatal in the short term and involves significant suffering, the emotional needs of the child's family guide HCPs in the next steps of treatment. HCPs do not see such accommodations as raising any issue. Indeed, they can also be justifiable in terms of the interests of children to be integrated into loving relationships with their families, even if they will not survive.

However, in situations where the prognosis is unanimously considered to be bleak and the child is experiencing significant suffering, the time and efforts applied to obtaining the consent of parents to WLST may appear excessive.

Nurse #1: I do agree. I do think we sometimes prolong situations too much ... because we are thinking about the parents, and how the parents are going to deal with it, and then the child ends up suffering for days; because there is nothing else we can do for them. And we know that. But sometimes the decision ... we try to work as a team, but ultimately the decision is not ours. And sometimes I feel there is this idea that we want to put an end to that child's suffering, and we have the feeling that other members of the team are like, 'OK, but we need to give parents a chance to...' You know, talk with the parents and see how they feel about this. And sometimes we end up prolonging the child's suffering. [Nurses discussion

group #2]

Senior Nurse #1 provided an example where, in her view, GTWP went on for too long to the detriment of the child's best interests:

[...] However the parents were not there at all. I think the mum was a little bit more, but the dad was not there. I think however many conversations we would have had with him, he would not have gotten there. I think some of that was religious – their beliefs were that they could not say no or stop the treatments.

I think the real issue with me with this case was the time it took for us to intervene and say, actually, 'we need to act in the best interest of this child' rather than anything else. I think for me that was the biggest issue, because [the child] was literally breaking down in front of your eyes, and to nurse her was quite hard, actually. And also, having that constant discussion with the parents all the time, it's hard. [Senior Nurse #1]

GTWP becomes distorted and moves toward putting parents first when HCPs lose sight of the finality of the process and the process itself is inconspicuously allowed to become the finality. Allied Professional #1 uses a colourful image, speaking of the 'worship of informed consent'. From the most valuable means to achieve the best interests of the child, parental consent becomes an end in itself.

On the contrary, if the end of realising the best interests of the child takes over the process, parental consent becomes completely instrumentalised. The process turns into 'pushing the parents to get there'. This is the corresponding distortion of the consent process that I will now discuss.

3.2.2 Pushing the parents to get there

One of the risks associated with the GTWP approach to obtaining consent is that it might reach a point where HCPs impose their preferred interpretation to parents under the guise of obtaining their consent. Allied Professional #1 described that risk as follows:

[...] So... I think the only thing the professionals have available to them is trying to make parents aware of the seriousness of the situation; but at the same time, I think it must be frustrating for them, because they can't say, 'We think this is best.' And sometimes they do, when it gets to the very end.

But so I think it's necessary, because... But parents often perceive it – and again, because I work with both – as being pushed. As if people are harping at them to do this, that or the other. And also, it's interesting how the timeframes come about, how sometimes the lack of

consistency ... the whole nature of medicine is that we can't guarantee that a child is going to die at a certain time if something does or doesn't happen. And so we need to take that dynamic influence into account. So I feel for the professionals, but I don't know any other way to do what they do. [Allied Professional #1]

Allied Professional #1 used another powerful image to describe how the process can take a negative turn, describing interactions between parents and HCPs as a 'tug of war' between two teams of unequal strength. Tug of war is a game where two opposing teams pull on a rope. The winning team is the one that succeeds in bringing the centre of the rope over to their side. Representing the interactions between parents and HCPs as a tug of war points to the imbalance of power, knowledge and information that characterises their relationship and to the vulnerability inducing characteristics of the situation of parents.

Well, it's just that the parents hopefully have never seen anything like this before. The clinicians have—particularly at a place like this, where you have such well trained and experienced ... and the best, among the best. So, there's a huge gap there. And you can't drag the parents along; but at the same time, they can't drag the clinicians back. And so you get this tension, where it's almost like having a tug of war over a huge valley, and one of you is going to fall into it. And I think that... So there is the experiential issue of what these doctors have seen, what they know from the data, and all that. [Allied Professional #1]

Tug of war is sometimes played over a puddle of mud, adding the risk of a humiliating fall in the mud for the losing team. When Allied Professional #1 situates the contest over 'a huge valley' they evoke the risk that GTWP turn from a cooperative endeavour into an antagonistic process where the losers suffer more than the winners benefit.

Senior Nurse #2 gave an account of her interactions with the parents of one of the NICU's patient which illustrate the risk of pushing parents too much. She describes her first encounter with the father of a patient, for whom the consensus among HCPs was that WLST would be in the child's best interests. She indicated that the encounter took place after the child had been in the NICU for over 60 days.

My first close encounter with him was actually after a shift where his [child] had been very unwell, and actually had an arrest the day before. [The child] was still quite unwell and we weren't sure if [the child] was going to make it through the night. So I spoke to the parents about it and said that [the child] was still quite unwell and we didn't know if [the child] would make it. I can't remember exactly but I said something about—I think I said, 'Maybe we have to let [the child] go.' And the mum was like, 'What do you mean by that?' And I thought, 'Hmm,

she has been here quite a long while, she should know what that means.’ So I said, ‘Well maybe if [the child] arrests again, we might not be able to resuscitate [the child], and we would stop doing it.’ The mum didn’t say much, but the dad, when I spoke of [the child] being unwell, he almost shouted at me and said, ‘We don’t need to hear that any more. We’ve been told that enough. That’s not helping.’

He did apologise later, and I apologised as well. I said, ‘I know you’ve been hearing that, but we just want to make sure that you are aware.’ But yes, that was my first close encounter with the dad, him shouting at me. [Laughs] [Senior Nurse #2]

Nurse #2’s account suggests that significant pressure had been applied to make the father and the mother accept that withdrawal of life-sustaining treatment was in the best interests of their child.

[...] But yes, I think in their case, in that short period of time they were maybe told too often by the previous nurse, and then I started straight away in my shift saying again, ‘She might not make it through the night,’ so that that was maybe the reason why the dad... [Senior Nurse #2]

Thus, the process appears susceptible of leaving the realm of persuasion. As Nurse #2 indicates, this can result from the repetition of similar statements by different HCPs rather than from a concerted or conscious effort to impose a conclusion upon parents. Yet, repeating these upsetting statements is an important device for HCPs in managing the frame of reference. Again, according to Senior Nurse #2:

I feel that it’s my role to make the parents aware. Because I know that sometimes in the conversation with the doctors they are so shocked that the information might not sink in. I sometimes feel – and parents do ask, ‘What did the doctor actually mean by this?’ or ‘What did the doctor mean by that?’ or ‘I don’t understand what he’s saying.’ Sometimes they ask later on, way back after the conversation, what was actually said. [...]

I always feel safer if I set at the beginning of my shift – if I have such an unwell patient that I say to the parents, ‘I am very worried about your baby, and I don’t know if it’s making it through the night.’ Because I don’t want to be in the situation where I might have to call them at 2:00 in the morning, and they’ll be like, ‘But you didn’t tell us that my baby is that unwell.’ So I think it’s yes, part of our role to kind of remind them that their baby is very, very unwell, and that it might not survive. [Senior Nurse #2]

I must make a clarification in concluding this subsection. I said that the two potential distortions I have identified are symmetrical in the sense that they each arise from giving excessive weight to one of the premises of the constitutive dilemma of GTWP. However, this does not mean that distortions are distributed evenly and that they manifest themselves equally in the functioning of the NICU.

Conclusion

In section 1, I have shown how GTWP is premised on a dilemma between respecting the parents' agency and the perception that they do not have the requisite capacity to exercise this agency in such a way that would achieve an outcome in line with HCPs' view of best interests.

As the pragmatic answer to this dilemma, GTWP calls HCPs to tread a fine line in their dealings with parents to achieve their purpose while respecting their normative commitments. In section 2 I show how HCPs attempt to construct and manage a common frame of reference with parents. The construction of the frame of reference involves transmitting the building blocks of the treating team's conclusion to parents so that parents may find themselves equipped to reach the conclusion favoured by HCPs and make it their own. In this process, the transmission of facts and emotional, psychological and spiritual support are intertwined.

When it succeeds, GTWP manages to reconcile respect for the agency of parents in relation to their child with a commitment to further the best interests of the child. The consent process is therefore deployed to empower the parents and to assist them in becoming agents in both their lives and their child's

However, although HCPs are deeply committed to it, the process does not always succeed. As I explain in section 3, a significant challenge for HCPs lies in knowing when it is time to shift gears and move the issue to a different forum. The clinical ethics committee is not seen as particularly helpful, although it might occasionally rekindle GTWP. Similarly, HCPs trust the court to uphold the child's best interests but they are even more reluctant to engage with that process than with the clinical ethics committee. The legal process is experienced by HCPs as shattering the investment they have made in their relationship with parents, and being alien to their work ethic, and inefficient. HCPs are therefore rarely eager to turn to it.

This sometimes leads HCPs to rely on GTWP even when its chances of success

have drastically diminished. In tense and tragic circumstances, it can be difficult to know exactly how much to push and yet preserve a relationship or when one has crossed a line that will irremediably damage the relationship. This generates two symmetrical potential distortions: putting parents first and pushing parents to get there.

Having completed the presentation of the two main processes constituting the GNM – ‘Justifying intensive care’ and ‘Getting there with parents’ – I now turn to its critical assessment in the next two chapters.

Chapter VI - The chronotope of best interests in the NICU

Introduction

In the preceding chapters, I constructed a rich and detailed account of the way HCPs in the London NICU approach decision-making about the withholding and WLST. My challenge now is to push forward the interpretation of the data I generated and question the grounded normative model ('GNM') to make recommendations on how to improve the practice of the unit.

So far, I sought to model the processes underlying the functioning of the NICU. I inquired into participants' normative perspectives, but I refrained as much as possible from evaluating these perspectives and the processes I have inferred from our interactions in the GNM. In this chapter and the next, I hope to illustrate the potential of the GNM as a grounded point of departure for thinking about decision-making for critically ill neonates and infants.

These two discussion chapters track the GNM's two main processes. In this chapter, I will mostly discuss *Justifying intensive care* ('JIC'), the process I described in Chapters III and IV. Drawing on the notion of legal chronotope developed by Mariana Valverde, I demonstrate how the WLST's recommendations flow from intertwined understandings of space and time contributing to the constitution of the NICU's distinct normativity.

In this chapter, I discuss the way in which HCPs in the London NICU elaborate their view of their young patients' best interests in JIC. As I argued, 'HCPs get *there* first' then attempt to take parents along with them to an already determined destination. The initial construction of this destination by HCPs is therefore crucial. It determines the subsequent orientation of the interactional process with parents by establishing the hypothesis upon which it will be predicated.

Broadly stated, my argument is that the emphasis put by HCPs on justifying intensive care and how it is equated with the appreciation of best interests leads to a too narrowly determined conclusion. Parents are not afforded a sufficient opportunity to participate in shaping it. The sequence in which HCPs conduct the analysis has normative implications because every subsequent step depends on the conclusion reached in the previous one.

The GNM does not make sufficient room for competing perspectives at the initial stages of the analysis. When the options HCPs present to parents already result from an internal consensus-building process aimed at identifying a reasonable and practicable solution, the interactions with parents I described as GTWP are impoverished. The potential input of parents is significantly limited. Notwithstanding their broad access to the NICU as a physical space, parents are excluded from the precise moments when the determination of a child's medical best interest occurs.

Building on the framework proposed by socio-legal scholar Mariana Valverde to analyse the spatiotemporal particularities of normative orderings and governance, I argue that the medical emphasis of the process limits the understanding of the child and their best interests to a unilaterally medical and physiological perspective, which then makes the introduction of competing perspectives more difficult and limited.

Valverde repurposes key notions from the work of the 20th century Russian literary theorist, Mikhail Bakhtin to analyse how a given perspective comes to prevail in a social issue's governance. JIC can fruitfully be analysed as revealing a particular 'chronotope', that is as resting on the interaction between conceptions of time and space. This distinct spatiotemporal make-up determines how the NICU and the child – their illness and their relationships with others – are understood. It anchors the debate by defining the considerations that are acceptable and those that are not, which in turn influences whose perspective prevails.

I will highlight three observations about JIC which Valverde's spatiotemporal analysis illuminates. First, HCPs understand the NICU as a transitional space. They therefore expect reliance on life-sustaining treatments to be temporary. HCPs negatively evaluate time spent in the NICU, characterising it as painful and burdensome. This judgement frames their appreciation of best interests and casts intensive care as needing to be justified.

Secondly, the emphasis on the transitional, temporary and burdensome nature of NICU care influences the way in which HCPs envision the possibility their patients might become chronically dependent on life-sustaining treatments or that they might have to live with the long-term consequence of their conditions. The child who becomes dependent on life-sustaining treatments is thus at odds with the ideal trajectory of a NICU patient.

Thirdly, the child is mainly defined in terms of their body, its physiological functioning and its dependency on life-sustaining technology. Again, such characterisation rests on a medically informed temporality focusing on the child's medical history and comparing them with past patients with similar pathologies.

I will then build on these observations to elaborate on Valverde's analysis of legal chronotopes and relate it to the study of best interests of severely ill children, both in the NICU and in the case law dealing with WLST from children.

Finally, I conclude this chapter showing the transition from medical best interests to wider best interests in JIC comes too late. It does not afford sufficient room for allowing the parents' perspectives to be integrated in the determining their child's best interests.

1. The NICU as a transitional space

1.1 WLST as the destination of a passage through the NICU

The NICU is more than just a hospital ward. It embodies understandings of time and

space and of the relationship between those two fundamental conditions of human experience. This entanglement orients and shapes how HCPs approach the possibility of withdrawing life-sustaining treatment from a child. The ethical implications of time spent by children in the NICU are intertwined with how HCPs view the NICU spatiotemporally and vice versa. As noted by Laura E. Navne and Mette N. Svendsen, who studied a Danish NICU:

[t]here are so many moves, spaces, temporalities, and actors involved in life-and-death decisions in the NICU that the concept of a standard process of decision-making fails to do justice to the complex efforts of moving infants in or out of life.¹⁸⁸

It influences how the quality of life of a severely disabled child is apprehended and projected into the future. It also contributes to defining the critically ill child primarily as an ensemble of physiological systems the integrity of which requires protection.

HCPs view the NICU as a temporary and transitional space. The temporality of intensive care is one where HCPs expect progress: it aims at improving a situation understood as unjustified and unbearable. The GNM converges with the observations of Katie Gollop and Sarah Pope, two barristers involved in recent treatment withdrawal cases, that HCPs need clear reasons to provide the treatments they are providing, especially when they perceive it to be at odds with their commitment to avoid harming the child and furthering their best interests.¹⁸⁹

The purpose of the NICU is to remove the very need for staying in it. HCPs consider intensive care as punctual, acute and short as opposed to chronic care which can go on indefinitely. A swift movement toward discharge characterises intensive care: patients are admitted to the NICU on their way to somewhere else. More than the pressure to admit new patients to the unit, which I found HCPs feel but do not act upon, the urge to discharge patients quickly is the main reason explaining why the

¹⁸⁸ Laura Emdal Navne and Mette Nordhal Svendsen, 'A Clinical Careography: Steering Life-and-Death Decisions Through Care' (2018) 142 *Pediatrics* S558, S560.

¹⁸⁹ Katie Gollop and Sarah Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help' (*The Transparency Project*, 22 May 2018) <<http://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/>> accessed 8 November 2019.

status quo is untenable in the NICU.

Thus, time spent in the NICU has an ethical valence. HCPs conceive it as painful, uncomfortable, and burdensome.¹⁹⁰ As Bakhtin would say, it is ‘thick’.¹⁹¹ HCPs view the exposure to invasive treatments for any longer than strictly necessary as inimical to children’s best interests. As an illustration, consider the following list of ‘routinely applied painful procedure’ compiled in a recent study:

Heel lancing; Venepuncture; Adhesive removal; catheter insertion; Gastric tube insertion; Nasal suctioning; Oral suctioning; [Retinopathy of prematurity] exams; Chest physiotherapy; Bladder puncture; Lumbar puncture; NCPAP cannula insertion; Endotracheal intubation; Tracheal suctioning; Nasal cannula insertion; Rectal stimulation; Chest tube insertion; Needle aspiration; Umbilical catheter insertion; Arterial catheter insertion; Aggressive stimulation; Arterial puncture; Intramuscular injection; Urinary catheter insertion; Central catheter insertion; Subcutaneous injection and Wound treatment.¹⁹²

Discharge from the unit and WLST are thus two faces of the same coin: they aim at stopping the continuous assault on the child’s body. A child leaving the NICU is what gives meaning to their time on the unit. It turns ‘*chronos* [...] the mere passing of time’ into ‘*kairos* [...] moments in which time is experienced as charged with significance’.¹⁹³ Children who don’t follow the short time cycle of the NICU are cast as outliers and their prolonged stays requires justification. Without a horizon for weaning off, providing intensive care is distorting the unit’s purpose. If discharge home or to a less intensive ward cannot be achieved, the implication will often be that the child would be better off without life-sustaining treatments.

1.2 A gloomy outlook on the future of children with severe disability

The presumption against prolonged life-sustaining treatment relates to certain HCPs’ gloomy outlook on severe disability, as discussed in chapter IV. The negative perception of severely disabled children’s lives rests on the comparison with able-

¹⁹⁰ Wilkinson (n 4) 24.

¹⁹¹ Mariana Valverde, *Chronotopes of Law: Jurisdiction, Scale and Governance* (Routledge 2015) 9.

¹⁹² Manal Kassab and others, ‘Number and Frequency of Routinely Applied Painful Procedures in University Neonatal Intensive Care Unit’ (2019) 28 *Clin Nurs Res* 488, 494.

¹⁹³ Mette Nordhal Svendsen and others, ‘A Life Worth Living: Temporality, Care, and Personhood in the Danish Welfare State’ (2018) 45 *American Ethnologist* 20, 23. See also Christine S Davis and others, ‘A Time to Live and a Time to Die: Heterotopian Spatialities and Temporalities in a Pediatric Palliative Care Team’ (2019) 34 *Health Communication* 931.

bodied children exemplifying the romantic notion of the carefree child doing the ‘normal things’ a child does while progressing toward autonomous adulthood.¹⁹⁴ The temporality of a life with disability flows much more slowly than hospitalisation in the NICU, but remains filled with burdens. Yet it lacks the clear sense of direction associated with critical care. Prolonged exposure to the pain and stress of critical care thus appears more difficult to justify. While HCPs conceive time spent in the NICU as thick with the pain and discomfort of treatments, they justify it by its curative aims and its short duration. Conversely, some HCPs envision with distaste the possibility that the said treatments might chronically support a life with severe disability.

The mediocre quality of life associated with severe disability is also seen as somewhat contagious. HCPs worry it might spread to those close to the child and charged with answering their constant need for care.¹⁹⁵ The burdens of the child’s condition eventually turn into the burdens of their caregivers. The disabled child thus appears both isolated and isolating. The demands involved by their care are such that HCPs fear their social network of support will dissolve or be damaged: their parents’ marriage and their relationships with their other children, who run the risk of being neglected if too much energy is devoted to the care of a disabled child. The worry is that the burden of the care will accumulate over time, such that the family risks collapsing under the weight—both actual and symbolic—of the child as they grow up.¹⁹⁶

1.3 The body of the child as the focal point of best interests in the NICU

Discussing teamwork in a British NICU, Steven D. Brown and David Middleton suggest that ‘the neonate may be variously treated either as a baby, with needs and rights, or as set of interrelated biological mechanisms at differing stages of development’. They associate ‘ [t]his oscillation’ to ‘a more general tension in

¹⁹⁴ Tillie Curran, ‘Disabled Children’s Childhood Studies: Alternative Relations and Forms of Authority?’ in Tillie Curran and K Runswick-Cole (eds), *Disabled Children’s Childhood Studies: Critical Approaches in a Global Context* (Palgrave Macmillan 2013) 125.

¹⁹⁵ *ibid* 129.

¹⁹⁶ For a review of the impact of disability on families, see Wilkinson (n 4) 113–119.

neonatal care in that these children are, formally speaking, neither fully 'social' nor completely 'natural' as they owe their existence to technology and medical expertise'.¹⁹⁷

At the medical best interests stage, the physiological dimension of the child dominates the analysis to the point of constraining the interpretation of their identity and rights. This in turn leads to giving significant weight to a conception of the child's right to bodily integrity that – paradoxically – can be criticised as disembodied.

The focus on the child's body and the correlative neglect of other aspects of the child's emerging and yet undetermined identity is entrenched in the spatialised temporality of the NICU. It operates a synecdoche, whereby a part (the body) becomes the whole (the child). The insistence from nurses that they are always with the child, spending 12-hour shifts at the bedside illustrates this. During this time, they mount guard, so to speak, over the body of the child and purport to acquire a deep and intimate understanding of the child's needs and interests.¹⁹⁸

Related to the urgency of critical care is a focus on the present. Here and now is the body of the child, afflicted with a critical condition requiring intensive care to survive and give HCPs enough time to implement effective treatments. A physiological focus on the body of the child foregrounds certain relationships to the detriment of others, and emphasising certain elements of the child's past and future. What would be integral to the child's identity in a different context is deemed to be of limited relevance in the urgency of the moment. This pushes what sets children apart to the fringes of the analysis, highlighting instead what can be generalised and predicted about their condition and response to treatment.

The primary relationship considered is that between the child and the life-sustaining treatments provided to them. The purpose of these treatments is to make themselves useless by restoring the independent physiological functioning of the

¹⁹⁷ Steven D Brown and David Middleton, 'The Baby as Virtual Object: Agency and Difference in a Neonatal Intensive Care Unit' (2005) 23 *Environ Plan D* 695, 697.

¹⁹⁸ See also Foteini JD Vouzavali and others, "'The Patient Is My Space": Hermeneutic Investigation of the Nurse-Patient Relationship in Critical Care' (2011) 16 *Nurs Crit Care* 140.

child's body. The interest of the child lies in severing this relationship of dependence with the treatments. The child's body is also inscribed in a temporality where its physiological characteristics are related to those of similar bodies. HCPs look at the child as of part of a long chain of patients who have gone through both the NICU and the NICUs of the world, as their passage is documented and reported in the global medical literature.

Patients admitted to the NICU have only been born for a short time and often have never lived outside hospitals. As such, their most relevant history is their *medical* history. This places them in a wholly different position from older children whose personality and preferences are emerging and therefore easier to ascertain. As Svendsen *et al.*, put it: '[t]here is a space for decision-making as biography has not yet begun'.¹⁹⁹

Each person is unique, but bodies are quantifiable and interchangeable when apprehended medically. A child's physiological functioning is but one component of a thriving human being.²⁰⁰ Limiting the subject of the determination of best interests to the body of the child establishes the medical discourse as the main source of authority and legitimacy in the NICU. HCPs claim that in doing so, they adopt a narrow focus on the child, however, it can also narrow their understanding of the child.

2. The chronotope of best interests in the NICU

I now return to these observations considering Valverde's framework of analysis built upon Bakhtin's chronotope. For Bakhtin, each literary genre results from the encounter of particular understandings of space and time, each particular spatiotemporal mode constitutes the "essence" of each genre, each major mode of cultural expression²⁰¹. It is therefore the specificity of each literary genre that Bakhtin sought to capture through the notion of the 'chronotope', a neologism formed from the Greek 'chronos' – time and 'topos' – place.

¹⁹⁹ Nordhal Svendsen and others (n 193) 26.

²⁰⁰ J Malek, 'What Really Is in a Child's Best Interest? Toward a More Precise Picture of the Interests of Children.' (2009) 20 J Clin Ethics 175, 176.

²⁰¹ Valverde (n 191) 10.

2.1 A projection of human experience

Valverde's overarching argument is that legal and ethical principles, especially open-ended ones such as best interests, are 'collectively produced and culturally established way of telling stories and capturing human relations'.²⁰² Bridging literary theory and legal analysis, she states: 'like literary genres, different legal processes, are shaped and given meaning by particular spacetimes'. Bakhtin's understanding of a literary genre can therefore also describe legal processes: '[a] genre is the set of means for a collective orientation in reality, aiming for completion'.²⁰³

Valverde further develops Bakhtin's analysis through the notion of a chronotope's scale. As it results from the convergence and interdependence of representations of space and time, a specific scale across each dimension defines each chronotope. As a projection of human experience, a chronotope highlights certain features of the circumstances and interactions it encompasses, while also obscuring others.²⁰⁴ The scale at which a phenomenon is apprehended implicitly influences who has authority to intervene or decide and, consequently how issues will be decided.²⁰⁵

The chronotope of best interests in the NICU arises from the conjunction of the spatial scale adopted by HCPs, which is largely limited to the physiological features of the child's body, and of the temporal scale of urgent critical care. By fixing the scale at which to consider the child, the chronotope firmly established the jurisdiction of HCPs and foremost that of NICU consultants. As already noted, a chronotope aims at completion in the way it encompasses a human situation. Focusing on the aspect of a child's situation that can be apprehended through a medical lens makes the situation of the child intelligible for HCPs, it organises information in a coherent form for discussing it and eventually reaching a practical consensus as to what ought to be done. It also allocates decision-making authority to those who produce and master the knowledge that is central to the chronotope.

²⁰² *ibid* 9.

²⁰³ *ibid* 11.

²⁰⁴ *ibid* 62.

²⁰⁵ *ibid* 84.

These spatiotemporal parameters frame and constrain the way HCPs interpret and apply best interests. It reflects the sense in which the NICU appears as a transitional space, which a child cannot occupy over the long term. The urgency and exceptionalism characterising it, along with the focus on the body of the child, delineate what is possible and impossible, what is permissible and what is not. The notion of chronotope highlights the conditions of possibility of the narrative deployed by HCPs to make sense of the situation of the child and their duties toward them. The spatiotemporality of the NICU mediates the inflection of the concepts of bodily integrity and quality of life.

Long-term dependence upon critical care is difficult to apprehend at the scale of the NICU. However, the gloomy outlook on life with disability adopted by some HCPs in the NICU does not result exclusively from the scale of the chronotope. Besides their scale, a certain mood can colour a chronotope. Through the notion of mood, Valverde introduces the 'affective and aesthetic dimensions of different governance rationalities'.²⁰⁶ She notes that 'governance responses' will vary 'depending on whether the prevailing mood is that of can-do, reformist, evidence-based optimism, or whether the mood is apocalyptic and fatalistic'.²⁰⁷ Valverde insists further that 'the kind of rational, number-driven, proactive policy process favoured by academics and experts is not properly characterized as lacking in passion, affect and aesthetics: the passion for technocracy and rational risk management is a passion too, and has its own (modernist) aesthetic'.²⁰⁸ As such, although the predominant mood of the NICU is scientific and rational, a negative disposition toward disability also imbue it, although the latter appears to contradict the former.

2.2 Fencing off the body of the child

The body of the child and its physiological functioning anchors the spatiotemporal scale where best interests are determined. On one hand, the focus is on the child's

²⁰⁶ *ibid* 77.

²⁰⁷ *ibid* 78.

²⁰⁸ *ibid*.

body and the physiological dysfunction that brings them to the NICU. On the other, the body of the child is isolated from other bodies, notably those of their parents. In both cases, the child's body continues to be understood mainly in the temporality of intensive care that I have described above.

The chronotope of best interest the NICU integrates the principle of bodily integrity as one of its most important values and thus inflects the interpretation of best interests. As stated by John Harrington, analysing law in terms of chronotopes is particularly illuminating when the analysis is at the level of a doctrine within a legal discipline. He writes: 'while there is not one underlying spatiotemporal logic to medical law, it is marked out by a distinctive ensemble of chronotopes'.²⁰⁹ I would further suggest that a particular medical sub-speciality like neonatology, and the specific site where it is practised are susceptible of being analysed in terms of their own chronotopes. The particular spatiotemporal understanding of a doctrine of medical law such as the best interests of the child therefore shapes how it will be interpreted and applied in that context.

In conformity with the basic tenets of medical law, HCPs define the child's body as inviolable and her right to bodily integrity as fundamental.²¹⁰ The provision of invasive life-sustaining treatments thus appears as a potential violation of the right to bodily integrity in virtue of which '[t]ouching a person without their consent – however benevolently – is prima facie unlawful'.²¹¹ In this regard, the body of the child appears 'as bounded territory or property to be policed and defended against the encroachment of others'.²¹²

Yet, in cases where HCPs recommend WLST, they turn the principle on its head. While the integrity of the child is usually invoked to justify providing necessary care

²⁰⁹ John Harrington, 'Time and Space in Medical Law: Building on Valverde's Chronotopes of Law' (2015) 23 *Fem Leg Stud* 361, 362.

²¹⁰ Jonathan Herring, *Medical Law and Ethics* (United Kingdom : Oxford University Press 2016) 22.; Emily Jackson, *Medical Law : Text, Cases, and Materials* (Oxford University Press 2010) 165–166; Marie Fox and Michael Thomson, 'Bodily Integrity, Embodiment, and the Regulation of Parental Choice' (2017) 44 *J Law Soc* 501, 512–13.

²¹¹ Emily Jackson, *Medical Law : Text, Cases, and Materials* (Third edition, Oxford University Press 2013) 165–166.

²¹² Fox and Thomson (n 210) 503.

to children in the NICU, it is also invoked to justify WLST. Instead of justifying the care, the suffering of the child's body justifies WLST. Again, this converges with the conclusions of the Svendsen *et al.*'s ethnography of a Danish NICU:

Moreover, what counts as legitimate responses to suffering depends on caregivers' agency and authority. Paradoxically, maybe, the NICU – aiming at facilitating good beginnings of life – becomes the site in which ambivalent experiences of care as violence facilitate a space for including death in life.²¹³

Foregrounding the violence of intensive care reinforces the norm that life-sustaining treatments must be justified as they are painful and burdensome. Nowhere has the idea that bodily integrity is sometimes better promoted through taking steps leading to the death of a child than in *Re A (conjoined twins)*, where each of the three justices relied on bodily integrity in deciding that it would be lawful to separate conjoined twins despite their parents' refusal to consent to the proposed intervention.²¹⁴ Lord Justice Walker puts it most directly: '[t]he operation would give [Mary], even in death, bodily integrity as a human being'.²¹⁵

Conceiving the body of the child as a space to be fenced off and defended cuts it off from the relationships that could give it a different meaning.²¹⁶ Adopting this scale has a direct impact on what Valverde describes as 'the game of jurisdiction' played between parents and HCPs. The scale at which a phenomenon is apprehended implicitly influences who has authority to intervene or decide and, consequently how to decide issues.²¹⁷ Valverde uses the notion to point to 'disputes over authority that are not legally classified as jurisdictional disputes, but that have the same form'.²¹⁸ Debates about the events or conditions that will either confer or withdraw jurisdiction are closely linked to substantive outcomes. For instance, in debating a child's best interests, who gets to ascertain it, whether it is HCPs, parents or the Court will have

²¹³ Iben Mundbjerg Gjødsbøl, Laura Emdal Navne and Mette Nordhal Svendsen, 'Suffering, Agency, and the Value of Early and Late Life' (*Somatosphere*, 27 June 2019) <<http://somatosphere.net/2019/suffering-agency-and-the-value-of-early-and-late-life.html/>> accessed 18 October 2019.

²¹⁴ Fox and Thomson (n 210) 513.

²¹⁵ *Re A (Children)* [2000] EWCA Civ 254, [259].

²¹⁶ Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (OUP 2011) ch

3.

²¹⁷ Valverde (n 191) 84.

²¹⁸ *ibid* 83.

a direct impact on which values are given more weight and what outcomes are more likely to ensue. At play is also the modern rejection of the notion that parents could be seen to own the body of the child.²¹⁹ Displacing the authority of parents creates a void HCPs wielding medical knowledge then fill. As experts of the functioning of the child's body, HCPs gain authority over how to govern that body at the expense of parents. As I will sketch out in the next subsection, the courts only rarely contest this allocation of decision-making power.

Although centred on the child's body, such an understanding is largely disembodied, for they do not have agency nor are they afforded the means to acquire it. Marie Fox and Michael Thomson argue for reframing bodily integrity as embodied integrity, which they suggest, 'would go beyond respecting the physical boundaries of children protected by conventional conceptions, to encompass corporeal change and development, and would acknowledge the importance of psychological integrity. It would also recognize the child as relational, rather than existing in isolation from her family'.²²⁰ Fox and Thompson's conception of embodied integrity also seeks to protect the emergence of the child subjectivity, and the right to an open future.²²¹

Since their point of departure is the differential legal treatment of male and female genital cutting, Fox and Thompson pay attention to the potentially 'excessive power that law has accorded parents to make irreversible non-therapeutic interventions on their children's bodies'.²²² However, a symmetrical argument is possible to renegotiate the boundary of the child's body to recognise that, notwithstanding their burdensome characteristics, life-sustaining treatment make possible an alternative vision of integrity whereby the child's relationship with their family and extended support networks prop up their individuality, alongside life-sustaining treatments.

Applying Valverde's reinterpretation of Bakhtin's chronotope allows us to see how the

²¹⁹ Jonathan Montgomery, 'Children as Property?' (1988) 51 MLR 323, 342.

²²⁰ Fox and Thomson (n 210) 523.

²²¹ *ibid* 521–530.

²²² *ibid* 530.

entanglement of time and space I observed in the NICU constitutes it as normatively distinct and firmly establishes the authority of HCPs on the determination of best interests. For this reason, it could be concluded that this chronotopes' influence is limited to the NICU. However, the courts also accept the chronotope of best interests in the NICU when called upon to weigh in on disagreements between HCPs and parents.

2.3 Competing chronotopes in the case law

The case law echoes this chronotope. I will briefly review the opening paragraphs of the first decision rendered by Justice Hayden in the *Evans*²²³ case where I argue the adoption of the chronotope of intensive care over that of parenthood is manifest. For contrast, I will also discuss a more recent court case, that of *Barts NHS Foundation Trust v Raqeeb & Ors*,²²⁴ which I read as recognising competing chronotopes and the consequence of choosing one over the other.

2.3.1 The chronotope of intensive care at work

In normal, everyday, circumstances, the authority of parents on their newborn child is not questioned. However, when tragedy erupts, a different narrative ensnares child and family. Rupture in the traditional trajectory of parenthood requires a different type of governance. The jurisdiction of HCPs eclipses that of parents. As experts, they are in a much better position to apprehend what would be in the best interests of the child from there on.²²⁵

This is apparent from the very first paragraphs of Justice Hayden's reasons in the Alfie Evans case. When Justice Hayden lays out the background to the case, the chronotope of new parenthood is presented in an intimate and sentimental key. The unfolding of the child's illness is set against the background of a blissful picture in which delighted parents welcome the arrival of a perfect child, while their familial networks unite behind the new family.

²²³ *Alder Hey Children's NHS Foundation Trust v Evans & Anor* [2018] EWHC 308 (Fam).

²²⁴ *Barts NHS Foundation Trust v Raqeeb & Ors* [2019] EWHC 2530 (Fam).

²²⁵ Herring, 'Medical Decisions about Children' (n 46) 144.

Alfie was born at the Liverpool Women's Hospital. He was delivered at full term with a healthy weight and discharged home three days after the birth. Alfie's mother was then 18 years old and this was her first pregnancy. Alfie's father Tom was 19 years of age. Though self-evidently very young and though Alfie had not been planned his parents were delighted by him. They were both determined to be good parents and, from what I have seen and read, were instinctive and natural. The couple were well supported by their respective extended families. Alfie was a happy smiling baby who seemed to be perfectly well.²²⁶

The arrival of a child is a powerful chronotope. It can transform a student flat into a home, it opens up the timeline of a new generation, making parents of those who, until then, were youth, grandparents of their own parents and so on. The infant represents the future in its most promising and open guise. Alfie's parents are described as stepping up to their new status as parents and its responsibilities and therefore growing up from late adolescence into adulthood. The young parents have a lot to learn, but their natural instinct along with the benevolent attention of their delighted families will ensure the child will thrive. They obviously have their son's best interests at heart. Although Alfie's parents could otherwise be described as young and inexperienced, the decisions they made for him are protected.

The child's illness disrupts this rosy picture and gives way to the chronotope of best interests in intensive care. In Justice Hayden's recital of facts, the medical severity of the situation progressively displaces the perspective of parents and replaces it with that of the medical team and the broad range of experts upon whose opinions they rely. In relating how and when suspicions arose as to Alfie's development, the judge mentions the observations and worries of his parents, and the steps they took to ensure care for their son. However, when the lead consultant for Alfie's care and main witness for the hospital is introduced in the recital of facts, Justice Hayden writes that the summary of events he provided 'requires to be stated in full' and he proceeds to quote it for the best part of a page.²²⁷ From that point on, the chronotope of intensive care has taken over the judgement, and the judge grants the declarations sought by Alder Hey Hospital.

The chronotope of best interests in intensive care provides the judge with a template

²²⁶ *Evans* (n 223) [3].

²²⁷ *ibid* [9].

to weigh the medical opinions of HCPs against the emotional response of the child's parents and their personal preferences. It organises the facts of the case and their normative evaluation so that it appears inevitably clear that the father's hope for a cure is insufficient to counter the systematic analysis of the medical evidence presented in support of the hospital's position. Faced with a child who probably does not experience pain, Justice Hayden evokes his dignity, echoing the analysis of bodily integrity I developed above:

Alongside all this it must be remembered that Alfie cannot sustain life on his own. It is the ventilator that has been keeping him alive for many months, he is unable to sustain his own respiratory effort.

All this drives me reluctantly and sadly to one clear conclusion. Properly analysed, Alfie's need now is for good quality palliative care. By this I mean care which will keep him as comfortable as possible at the last stage of his life. He requires peace, quiet and privacy in order that he may conclude his life, as he has lived it, with dignity.²²⁸

My point is not to argue the case was wrongly decided. I simply want to show that the HCPs' approach to such cases is often adopted almost integrally by the courts, so that the chronotope finds itself reinforced by this endorsement.

2.3.2 A rejection of the chronotope of best interests in intensive care

Justice MacDonald's decision in *Raqeeb* provides a useful contrast. The case concerns a 5-year-old girl who suffered a 'ruptured arteriovenous malformation' in her brain that caused bleeding which led to 'extensive and irreversible damage'.²²⁹ MacDonald J's reasons appear predicated upon a recognition of the competing chronotopes that can govern the situation of a critically ill child. The opening paragraph reads as follows:

The dilemma presented by cases concerning, as this case does, the withdrawal of life-sustaining treatment from a child rests on the fact that they address what many see as an appalling present, but a present that for many also remains sanctified morally or as an article of religious faith because life subsists. For the treating doctors involved in such cases, seen through the prism of medical best interests life is at best a barely wakeful shadow burdened by futile medical treatment or, at worst, mere oblivion. For parents, seen through the prism of abiding love and fierce devotion and the amplifying effect on those emotions of the flattering voice of hope, life is still a faded jewel that has not yet been robbed away from the body and one that may yet regain its lustre. Within this context, the decision for this court in these

²²⁸ *ibid* [61]-[62].

²²⁹ *Raqeeb* (n 224) para 8.

concurrent proceedings is a grave, multifaceted and complex one.²³⁰

Justice MacDonald acknowledges that the dilemma at the centre of the case is largely concerned with choosing between competing interpretations of the meaning of time, referring respectively to ‘the prism of medical best interests’ and ‘the prism of abiding love’. On one hand, the NHS Foundation Trust’s position provides another illustration of the chronotope of best interests in the NICU, insisting on the burden of ‘an appalling present’ for a child submitted to futile treatments. On the other, the judge links the position of the parents both to the hope of a better future and to the metaphysical and religious timeframe of sanctity of life.

I read *Raqeeb* as a rejection of the chronotope of best interests in intensive care. It is one of the rare decisions where the High Court has dismissed the application made by a healthcare institution on the basis that WLST would be in the best interests of a child. The chronotope of best interests in intensive care largely requires giving the perspective of HCPs a preeminent place in assessing best interests, while departing from it demands that its importance be significantly relativised. MacDonald J signals his adoption of a broader scale when he specifies that the position of the NHS Foundation Trust, which he considers to be too narrow, reflects ‘medical best interests’ and opposes it to ‘the overall approach to best interests’.²³¹

Although it is not mentioned at the outset of the case, *Raqeeb* also involved an important tension at the spatial level. Central to the debate was the refusal of the NHS Foundation Trust to allow the transfer of the child to an Italian hospital willing to pursue life-sustaining treatments indefinitely.²³² In conjunction with the choice of temporality mentioned above, this raised the question of the appropriate scale at which to situate the determination of best interests. Justice MacDonald appears to find support for his decision to refuse the Trust’s application in the fact that,

²³⁰ *ibid* 1.

²³¹ See *ibid* 75 and 122; See also Emma Cave, Joe Brierley and David Archard, ‘Making Decisions for Children—Accommodating Parental Choice in Best Interests Determinations: Barts Health NHS Trust v Raqeeb [2019] EWHC 2530 (Fam); Raqeeb and Barts Health NHS Trust [2019] EWHC 2531 (Admin)’ (2020) 28 *Medical LR* 183, 192–193.

²³² *Raqeeb* (n 224) para 16.

notwithstanding the position of the treating doctors and their colleague who provided second opinions, Italian doctors considered the care advocated for by the parents to be in her best interests. Justice MacDonald goes as far as to state that England ‘does not hold the monopoly on legal and ethical matters’.²³³

Again, it is beyond the scope of this discussion to conclude whether *Raqeeb* was rightly decided or not. However, by giving weight to the emerging agency of the young Tafida and her appreciation of the tenets of the Islamic faith her parents brought her up in, the judge adopted the chronotope defended by the parents and effectively handed them victory in the ‘game of jurisdiction’ at the centre of the case. As Cave *et al.* argued, ‘the application of the [best interests] test in *Raqeeb* protects parental choice in an unprecedented manner’.²³⁴

It remains to be seen whether *Raqeeb* will initiate a movement in the case law or will be confined to its specific facts.²³⁵ As nascent as they were, the preferences that were attributed to the child herself rather than to her parents appear to be a necessary component of the judge’s reasoning.²³⁶ The background the judge presents about ‘a joyful little girl’ who speaks two languages and whose interests include ballet and the film ‘Frozen’ is not available for patients in the NICU.²³⁷ As such, this decision does not appear to be readily applicable to cases concerning the care of newborns and young infants whose personal preferences and inclinations remain impossible to ascertain.

3. The initial determination of best interests is not sufficiently ideal

In their commentary on *Raqeeb*, Cave *et al.* judiciously argue that if HCPs indeed limited their assessment of best interests to the *medical* best interests of the child, they did not apply best interests properly according to both law and medical

²³³ *ibid* 178.

²³⁴ Cave, Brierley and Archard (n 231) 186.

²³⁵ But see Cressida Auckland and Imogen Goold, ‘Re-Evaluating “Best Interests” in the Wake of *Raqeeb v Barts NHS Foundation Trust & Anors*’ (2020) 83 *The Modern Law Review* 1328.

²³⁶ *Raqeeb* (n 224) [para 165-168].

²³⁷ *ibid* 8.

guidance.²³⁸ The GNM shows that HCPs in the London Unit are aware of that distinction. This is why, in the GNM, HCPs add an assessment of wider best interests to their assessment of medical best interests.

Despite that, the GNM is not immune from criticisms. I have shown that the GNM displays a clear hierarchy between medical and wider best interests. In the latter process, the conclusions of the former process are taken as established *prima facie*. The considerations associated with wider best interests are therefore seen as secondary factors. Postponing the participation of parents to that later stage in the overall process is detrimental to the quality of the determination of best interests in the NICU. It marginalises and sets aside considerations, which if not considered initially, will be much more difficult to reintroduce and consider thoroughly at a later stage.

The process moves quickly toward identifying treatment options HCPs accept as reasonable, although parents have not yet been meaningfully involved. The move from ideal to reasonable leads to discounting considerations such as the projected quality of life of the child to account for non-ideal circumstances when they are presented to parents. Other considerations, such as religiously inspired deference to the principle of sanctity of life, are set aside because they are only marginally represented in the ethos of the unit. The interactions I theorised as GTWP are impoverished by the emphasis on a consensus-building process aimed at identifying a reasonable and practical option. The potential input of parents is therefore significantly limited. This loss, I would suggest, is a major unintended consequence of the strong norms of collegiality governing the interactions of HCPs at that stage.

Building on the work of Loretta Kopelman who identifies three conceptually distinct but related meanings of best interests, I argue the determination of best interests HCPs conduct before putting it to parents would benefit from being more 'ideal'. HCPs should give relevant considerations their full force before modulating them.

²³⁸ Cave, Brierley and Archard (n 231) 192.

Only once both parties have elaborated an ideal solution can it be adapted to real-world constraints through a standard of reasonableness, again with parents.

However, in keeping with the contextualised methodology guiding my study, I would like to start by using the morning rounds at the beginning of the day to give a concrete illustration of the exclusion of parents from the initial determination of best interests at the stage of JIC.

3.1 Morning rounds: best interests behind closed doors

Morning rounds provide a telling illustration of the exclusion of the perspectives of parents from the operation of the chronotope of best interests in the NICU. I already introduced the functioning of morning rounds as part of presenting the deliberative processes through which best interests is determined by HCPs.²³⁹ In summary, parents are afforded considerable and largely unrestricted access to the NICU. They are always allowed in the bed space, except for morning rounds.

Yet, the exclusion of parents from morning rounds is symptomatic of their relegation to the outskirts of the NICU's decision-making timespace. It evidences the tight separation between the two processes constituting the GNM. In JIC, HCPs elaborate a hypothesis as to the child's best interests, while in GTWP, they endeavour to take parents as closely as possible to this conclusion. Asking parents to leave the bedside excludes them from a crucial moment. Just like 'courtrooms are [...] temporally specific because the space only becomes a court of law at a highly particular time'²⁴⁰, in the NICU, the determination of medical best interests only takes place at times and places in which parents are not invited.

Similarly, parents are not privy to the informal discussions between consultants or to psychosocial rounds. Of course, parents are sometimes invited to take part in multidisciplinary team meetings ('MDTs'). However, parents are not systematically invited to these meetings. They are organised at the initiative of HCPs and parents

²³⁹ See Chapter III, section 1.4

²⁴⁰ Valverde (n 191) 16.

are only invited if it is deemed to be relevant. For this reason, the participation of parents in MDTs would seem more closely aligned to the goals of GTWP than to that of determining best interests.

Raising that fact might suggest that I am arguing for including parents into morning rounds. However, while such a change might indeed be advisable, it is not an end in itself. The morning rounds are an archetypical instance of the interactions between HCPs. They embody the collegiality of the decision, with its input from several specialists, the leading roles of the NICU consultant and surgeons, and the emphasis on medical considerations.

Without addressing the underlying conditions supporting the chronotope of best interests in the NICU, the concrete impact of a change in the practice of the unit would likely be limited. Morning rounds would possibly be divested of their normative potential and the chronotope of best interests would be instantiated in a different guise. A more fundamental change in the attitude of HCPs toward the implication of parents in the determination of best interests would appear necessary.

3.2 An ideal determination of best interests as a point of departure

'Prioritising the child' is the most fundamental value underlying the approach of HCPs in the NICU. However, the way this priority is interpreted as requiring the exclusion of parental preferences and is implemented through the prism of a medically laden chronotope, involves a serious risk of reducing the child to her physiological dimension. Prioritising the child might therefore turn into narrowing the child. For this reason, HCPs ought to initially consider a more ideal understanding of best interests to prioritise the child truly.

The GNM already comprises a two-step process through which HCPs formulate a hypothesis as to the child's best interests as 'medical best interests' then specified as 'wider best interests'. However, neither step is sufficiently ideal and relevant considerations are significantly weakened by the timing in which they are

considered. The idea of a more 'ideal' process I would like to bring forward comes from the functional typology of best interests proposed by Kopelman in a seminal article. According to her, best interests can play the role of an ideal, a threshold for intervention or a standard of reasonableness in choosing between available options.²⁴¹ The meaning of best interests can change slightly as it is adjusted to the task at hand. By distinguishing these tasks, it is possible to gain a better understanding of what is expected of the standard in specific circumstances. Here I am particularly interested in the interplay between the best interests as ideal and best interests as a standard of reasonableness.

Best interests as ideal is the most literal and most exacting of the three meanings.²⁴² In the medical context, it requires focusing the inquiry on the child and 'instructs us to evaluate all options and act on that option providing the absolute best outcome for the individual in question, without regard to anyone or anything else'.²⁴³ This echoes the idea of prioritising the child by excluding other considerations, be it the preferences of parents or the competing interests of other children in accessing healthcare resources. However, it is only part of the requirements of an ideal process.

Best interests as ideal crucially requires '[s]tating and evaluating different conceptions about what is best'.²⁴⁴ To take advantage of the open-ended nature of best interests as ideal, it is necessary to conduct a broad review of the range, not only of possible outcomes, but also of different ways of conceptualising and understanding the issues raised by the medical condition of the child.

On the contrary, JIC adopts a determined perspective on best interests which I have cast as the chronotope of best interests in the NICU. Whether we call them conceptions of the good, grand narratives or chronotopes, HCPs consider the

²⁴¹ Loretta M Kopelman, 'The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness' (1997) 22 J Med Philos 271, 282.

²⁴² *ibid* 277.

²⁴³ *ibid* 278.

²⁴⁴ *ibid* 284.

fundamental values that give meaning to the lives of the child's parents with suspicion. Beliefs such as hoping for a miracle or longing for the rewards of eternal life associated with religious belief are mostly seen as irrational. Yet, they situate human life in different chronotopes than that of the NICU which excludes or minimises considerations incompatible with its predominantly scientific, objective and predictive – yet slightly pessimistic – mood.

The fact that HCPs also derive normative conclusions from their medical and clinical observations and hypotheses compounds the effects of narrowing the understanding of the child to her physiological functioning within the spatiotemporality of the NICU. They add a broader range of considerations at the wider best interests stage, but this addition comes late in the process.

These considerations are set against a default position already strongly oriented by the chronotope of best interests in the NICU. The constituting elements of an alternative narrative are to a significant extent, either absorbed or backgrounded by the dominant chronotope. For instance, HCPs consider the child's relationships with her parents and family at the wider best interests stage, but even then, HCPs assimilate them to the body of the child and evaluate them as a further physiological system. The traditional – and rightly critiqued – idea to the effect that children are an extension of their parents²⁴⁵ is thus reversed. The goal is to assess whether and how parents will contribute to the child's functioning. Yet, if we think of children in terms of their relationships with their parents, we can inflect this understanding. These relationships do not only concern parents, they are of utmost importance to the life and identity of the child.

My plea for a more ideal exploration of the ways to interpret the situation of the child is not a call for HCPs to leave their scientific rigour aside. A precise and sophisticated understanding of the child's condition and its possible physiological outcomes must remain a cornerstone of the assessment of best interests. However,

²⁴⁵ David Archard and Colin M Macleod, *The Moral and Political Status of Children* (OUP 2002) 1.

an equally sophisticated approach must be deployed to place the expert information which only clinicians can master and wield it into its broader ethical context.

It is not only the moral and legal duties of HCPs that must be thoroughly explored, but also those of the child's parents. Best interests as ideal therefore tolerates contradictions and uncertainty because its purpose is to explore the implications of the principle to their fullest and for all. The duties identified at this stage are thus *prima facie* only, for they potentially contradict other duties, neglect important considerations or are impossible to materialise in practice.²⁴⁶ The best interests standard understood as an ideal therefore serves as a guide for identifying what ought to be done for a child, but it does not purport to identify a single, mandatory solution.²⁴⁷

3.3 From the ideal to the reasonable

According to Kopelman, the task of specifying concrete requirements among the considerations identified at the stage of best interests as ideal is accomplished through a standard of reasonableness. This second stage conceptually follows the first one. The duties to the child, and her rights and interests, identified at the best interests as ideal stage are to be balanced against other considerations to specify the requirement of the concrete situation. As it aims at generating a practical solution, best interests as reasonableness entails a departure from the ideal and a broadening of the range of relevant considerations, notably through inclusion of elements, which do not strictly relate to the best interests of the child.

... it requires us to focus on the child and select wisely from among alternatives, while taking into account how our lives are woven together. It instructs us to try and pick the option that most informed, rational people of good will would regard as maximizing the child's net benefits and minimizing the net harms to the child without ignoring the rights, needs, and interests of others.²⁴⁸

Although it is more attuned to real-world constraints than best interests as ideal and therefore does not purport to reach an absolutely ideal conclusion, best interests as

²⁴⁶ Kopelman (n 241) 277–278.

²⁴⁷ *ibid* 284.

²⁴⁸ *ibid* 280.

a standard of reasonableness is nonetheless concerned with identifying a solution that is 'better than absolutely minimally acceptable'.²⁴⁹ Accordingly, it must be distinguished from harm as a threshold of best interests.²⁵⁰

Again, the GNM partially reflects this. The way I portrayed it might suggest that the wider best interests stage shares some characteristics of best interests as a standard of reasonableness for it aims at modulating the conclusion of the previous stage of the determination. However, similarly to the medical best interest stage, it entails only limited involvement from the child's parents. Furthermore, an implicit hierarchy of reasons is generated by the sequence in which they are introduced and evaluated. By being considered at a later stage, parental claims run the risk of having less weight than those initially associated with the narrowly defined medical perspective on the child.

The desire to present a unanimous recommendation to parents, especially in cases where such recommendation is to withdraw life-sustaining treatments, also appears to rest on a confusion between ideal and reasonableness. The process for determining the medical best interest of the child purports to aim at identifying the best medical outcome possible for the child; yet I showed in Chapter III that it also bears several features of a negotiation aimed at reaching a mutually acceptable consensus for all or most of the consultants involved.

Achieving unanimity implies prematurely closing off certain options to present a united front. Rightly, the ethical guidance issued by the Royal College of Paediatrics and Child Health warns that unanimity should not be a condition in deciding whether to recommend WLST.²⁵¹ In the GNM, I have highlighted that HCPs incorporate beliefs and values which go beyond the scope of medical science by conferring normative meaning to their factual observations. Such interpretations appear

²⁴⁹ *ibid* 282.

²⁵⁰ *ibid* 275–6; See also Auckland and Goold, 'Parental Rights, Best Interests and Significant Harms' (n 64).

²⁵¹ Larcher and others (n 46) s18.

inevitable. For instance, the notion that it might be in the interest of a child to die earlier rather than later when it cannot be avoided is more controversial than it might appear to HCPs.²⁵² Birchley observes: 'it is not self-evident if treatment or non-treatment serves best interests, since personal values dictate the relative desirability of death and life.'²⁵³ Similarly, characterising life-sustaining treatments as inherently burdensome supposes treating the pain associated with treatment as a form of suffering to be avoided. These value judgements flow from the professional position of the actors adopting them. The primary duties of HCPs are to restore and sustain the health of their patients and to minimise and manage pain. However, the duties of parents toward their children are also worthy of consideration in determining what is in a child's best interests.

That is not to say the normative principles guiding HCPs in formulating their recommendations are not reasonable, plausible or even likely of adherence by many parents. However, the concerns of HCPs are afforded a disproportionate influence if they are used to elaborate a default position then endowed with the weight of a collegial determination, promoted to parents and defended against objections without being thoroughly confronted with potentially contradictory arguments and duties. If it is already presumed that the child has or will have a mediocre quality of life, and therefore, has little interest in surviving, the concerns and values raised by parents are more likely to be seen as extraneous to the child's best interests for they were purposively excluded from the initial picture.

In concluding this section, I would like to add a further argument in support of paying more attention to the ideal stage of the determination of best interests. At the end of chapter IV, I discussed those considerations which HCPs purports to be aware of but nonetheless exclude, notably those relating to resource allocation. I would argue that rather than excluding such considerations, HCPs should acknowledge and discuss them with parents. With its focus on critical care and the swift move toward

²⁵² See e.g. Paul Baines, 'Death and Best Interests' (2008) 3 *Clinical Ethics* 171.

²⁵³ Birchley, 'Deciding Together?' (n 42) 211.

attempting to identify a reasonable conclusion, the chronotope of best interests in the NICU obscures those interests of children over which neither HCPs nor NICU nor parents have much control. A prime example would be the strong interest of disabled children and their families in receiving quality home care and follow-up once they are discharged from the NICU. Again, it is sensible to be as realistic as possible as to the level of resources that are available and on the impact that a lack of resources might have on the quality of life of a child and her family. However, if no one systematically articulates the ideal in terms of post-discharge support, the *status quo* is implicitly reaffirmed and the children who would benefit the most from increased support run the risk of having life-sustaining treatment withheld from them because of bleak projections as to their future quality of life. As Kopelman rightly states:

The use of the best interests standard as an ideal separates how things are from how we think they ought to be. Ideals give us direction to help correct current problems in the system.²⁵⁴

Neither parents nor HCPs should be confined to their respective roles, especially at the best interests as ideal stage. Both are also citizens finding themselves – the former due to unfortunate circumstances and the latter professionally – in a strong political position to articulate and demand more support for disabled children, not just in the NICU but throughout their lives. HCPs are sometimes confronted with parents who think that they seek to withdraw treatments from patients to save money for the hospital. HCPs are troubled by these allegations and they reject them. However, they should acknowledge that resource allocation decisions that are out of their control do influence the way they approach best interests. More transparency as to these resources allocations arbitrage might contribute to dissipate the suspicions of parents and to restore trust in strained relationships.

Conclusion

In this chapter, I mobilised Valverde's notion of the legal chronotope to critique JIC, the first process I theorised in the GNM. I showed that the particularised conception of time and space underlying the self-understanding of HCPs practising in the

²⁵⁴ Kopelman (n 241) 277.

London NICU has significant normative influence on crucial elements of the decision-making process for critically ill children. The chronotope of best interests in the NICU gives meaning to the situation of the child and orients the decisions to be made by delineating what is permissible and what is not.

In section 1, I began with three observations about how time and space are intertwined in the NICU. HCPs judge time spent in the NICU's space sternly. They expect babies to go through the unit quickly and move on elsewhere. They understand an extended stay as detrimental for children. Prolonged recourse to life-sustaining treatments thus appears as exceptional and requiring justification. The speed at which the unit operates generates a narrow focus on medical and physiological considerations about the body of the child, leaving parents in the background. The pain and suffering associated with intensive care imply that one of the unit's fundamental objectives is to ensure that patients do not require staying in it for too long. The chronotope of the NICU inflects how normative concepts related to best interests, such as quality of life and bodily integrity, are interpreted. In both these cases, independence from life-sustaining treatments is preferred. Discharge to another ward, but also WLST are considered more favourably than an open-ended stay in the unit, notwithstanding the tragic nature of the latter.

Valverde's conceptual apparatus allows to underline how the NICU constitutes itself as distinct from other fora for ascertaining best interests. In section 2, I explore how the singular spatiotemporality of the NICU, with its specific scale and mood, delineates the contour of the identity of the child who is the subject of the determination of best interests. It also defines the respective roles and authority of those interacting with the child thus defined. The chronotope of best interests in the NICU purports to be focused narrowly on the interests of the child, but achieves this by narrowing the range of admissible considerations. Prioritising a narrow view of the child thus sustains the precedence of the jurisdiction of HCPs, especially consultants, on the determination at hand.

The chronotope of best interests in the NICU does not only govern the decision process within the unit. Its influence is also pervasive in the rhetoric of legal decisions concerned with application from healthcare institutions to withdraw life-sustaining treatments from critically ill children. To demonstrate this, I compared the opening paragraphs of two recent decisions High Court decision, *Evans* and *Raqueeb*. In the former, the chronotope of best interests in the NICU is dominant, while in the latter it seems displaced in favour of a broader understanding of the relationship between a severely disabled child and her family.

In section 3, I built on my observation of the exclusion of parents from the morning rounds to show that, despite being physically allowed in the NICU, the chronotope of best interests largely leaves parents out. The morning rounds are one of those times where the collegial conversation of HCPs unfolds around the patient, in her bed space. The majority of those involved in the care of the child are present, yet parents are asked to leave.

Finally, I argued that the distinction introduced by Kopelman between best interests as an ideal and best interests as a reasonableness standard allowed to articulate a critique of the priority of medical best interests in JIC and the correlative exclusion of the parental perspective. The hierarchy of reasons found in the GNM risks marginalising and discounting the considerations relating to wider best interests. Without setting aside the indispensable medical perspective, a more thoroughly ideal approach to the determination of best interests can yield a richer and more complete account of the situation of the child and its ethical implications. Notably, the parents' ethical duties toward their child, and their relational role in propping up the identity of the child ought to be given more weight. This, in turn, would enrich the second stage of the process, where a reasonable choice has to be made among the options identified at the ideal stage .

In the next chapter, I turn to GTWP, the GNM's second main process. I concentrate on the HCPs' claim that parents lack capacity to make decisions in their child's best

interests, one of the main justifications offered by HCPs for GTWP as a steering process. I show that while no reasonable argument holds to claim that parents should be seen as lacking legal capacity in the traditional legal sense the reports of HCPs suggests that the peculiar and exacting circumstances of the NICU make parents particularly vulnerable to cognitive biases in how they reason about the best interests of their child.

Chapter VII - Can you take any road to get there? Best interests, influence and manipulation

Introduction

In Chapter V, I presented GTWP, the process unfolding when the conclusion resulting from JIC is that the child's best interests requires WLST. A key aspect of GTWP is that HCPs deploy significant efforts to steer the child's parents toward endorsing such a WLST conclusion, while also recognising the inherent difficulty for parents of actually 'getting there'. Influencing strategies such as those I identified as forming part of GTWP have been observed in other similar settings. Studying English paediatric intensive care units, Birchley *et al.* observed

a process of advocacy to advance the clinical view of best interests. Initially they conveyed technical information to allow parents to understand the medical perspective. If a child's prognosis was poor and parents did not share the clinicians' view of the child's 'best interests,' clinicians reframed their description of the medical plan in terms they thought would be more acceptable to the parents. If not effective, starker explanations were offered to parents.²⁵⁵

Similarly, the tendency for HCPs to attempt to steer parents toward WLST based on a professional consensus is also documented in the study of conversational interactions between consultant neonatologists and parents Shaw *et al.* conducted in an English NICU.²⁵⁶ They found that such conversation followed two main patterns, which they described as 'recommendations' and 'options'. They describe the conversation unfolding according to the 'recommendations' model as follows:

[i]n recommendation sequences, doctors made reference to a robust, corroborated team decision, and one which should be made in the best interest of the baby. These recommendations were designed to strongly favour a particular course of action.²⁵⁷

In this last discussion chapter, I want to problematise the practice of attempting to steer parents to accept the team's WLST recommendation as I theorised it in GTWP. I explore the influence HCPs use toward parents in their attempts to 'get there' with

²⁵⁵ Birchley and others (n 46) 932.

²⁵⁶ Shaw and others (n 58).

²⁵⁷ *ibid* 1237.

them and assess some strategies forming part of GTWP. I briefly state why both rational deliberation and persuasion are the two modes of influence that ought to be considered as ethically optimal and ideal.

However, my focus will be on strategies going beyond the ideal of rational shared decision-making, to answer the question whether some strategies HCPs report using amount to unjustified influence. I show that some strategies used by HCPs to influence parents are indeed manipulative. To do so, I rely on the account of manipulation developed by philosopher Moti Gorin.

I then turn to questioning the justification for resorting to such strategies at the heart of GTWP, namely that some parents lack the capacity to grasp best interests. I relate those suspicions to the conception of bounded rationality emerging from research on the influence of cognitive heuristics and biases on decision-making. I show that several examples of the limited capacity of parents invoked by HCPs map onto documented cognitive heuristics and biases.

Finally, I conclude by arguing that, to the extent that HCPs are right in identifying cognitive biases in the reasoning of parents, they are justified in deploying strategies aimed at promoting the best interests of their patients, although I characterise these as manipulative.

1. The ideal of rationality in paediatric shared decision-making

GTWP helps understand how HCPs reconcile the imperatives of shared decision-making and their commitment to the best interests of the child in practice. GTWP shows HCPs strongly adhere to a duty to consult and cooperate with parents, in the hope of obtaining their consent. At the same time, in the GNM, this duty is subordinated to that of reaching a decision that is as close as possible with their determination of the child's best interests.

Ideally, clinical decision-making would result from a perfectly rational deliberation.

Following a meticulous conceptual analysis of shared decision-making models, Lars Sandman and Christian Munthe propose such a model, which they designate as ‘Shared rational Deliberative Joint Decision’.²⁵⁸ Based on Habermasian communicative action, their ideal model is ‘about working together to find a consensus on what is the most rational or well-founded decision’.²⁵⁹ In this model, there is no predetermined goal or objective and both HCPs and patients partake in the process on an equal footing, not so much as either professionals or patients, but as rational agents.²⁶⁰ In that sense, even ‘the evaluative basis on which to reach a decision’ is open for discussion.²⁶¹

Although fully rational deliberation represents an ideal to which both HCPs and parents ought to strive for, it cannot be the standard against which to evaluate decision-making and influence in the NICU. As noted by Laura Loftis and Laurence McCullough, the best interests of the child principle and shared decision-making are two distinct frameworks whose respective demands can come to clash.²⁶² In paediatrics, the professional duties of HCPs toward the child entail they ought to prioritise the best interests of the child in their discussions with parents. The best interests of the child thus constitutes a fundamental constraint on the decision-making process, which prevents the shared aspect of decision-making to be taken to its fullest extension. The priority of the child principle endorsed by HCPs in the GNM aligns with a model that gives precedence to the best interests of the child over parental discretion, while nonetheless affording it some weight.

As the best interests of the child constitutes the predetermined goal of the process, it can also justify resorting to other types of influence. Next to fully rational deliberation, we find rational persuasion, which involves one party laying out arguments to make a

²⁵⁸ Lars Sandman and Christian Munthe, ‘Shared Decision Making, Paternalism and Patient Choice’ (2010) 18 *Health Care Anal* 60, 78.

²⁵⁹ *ibid.*

²⁶⁰ *ibid.*

²⁶¹ *ibid.*

²⁶² Jennifer S Blumenthal-Barby and others, ‘Should Neonatologists Give Opinions Withdrawing Life-Sustaining Treatment?’ (2016) 138 *Pediatrics* e20162585, 4. See also Birchley, ‘Deciding Together?’ (n 42) 205.

rational case in favour of a course of action that they consider to be the most rationally justified. According to Sandman and Munthe, the main difference between the ideal rational model and a model prioritising the patients' best interests is that the latter allows for open strategic action on behalf of HCPs.²⁶³ They define 'strategic action' in decision-making as follows:

Strategic action aims to reproduce meaning (in the sense of a certain way to understand things) or to achieve a predetermined goal or interest of a person or system/structure.²⁶⁴

Sandman and Munthe further distinguish strategic action that is either 'open', in which case its goal will be transparent and known by the target of the action, or 'latent' where its goals need to be concealed from the target of the action to be achieved.²⁶⁵ They add that 'latent strategic action either works through one of the parties manipulating the other, or through self-deceit by what is called systematically distorted communication'. In their view, only 'open strategic action' is therefore acceptable, as it is a necessary condition to ensure that the patient and her autonomy are respected.²⁶⁶

HCPs making recommendations in the context of the NICU is difficult to criticise.²⁶⁷ The knowledge imbalance between HCPs and parents justifies one side assisting the other in making connections and drawing inferences between numerous elements of complex information. Shared decision-making in the NICU can hardly be achieved without HCPs taking the lead in the discussion.²⁶⁸ Helping parents to understand complex clinical information and assess the weight of different elements is at the core of the role of HCPs. Furthermore, changing one's mind in response to rational arguments is a hallmark of reflexivity and rationality. As such, it appears as a mark of respect for the rational capacities of parents to challenge their position when

²⁶³ Sandman and Munthe (n 258) 79–80. Sandman and Munthe discuss shared decision-making in the context of a relationship between HCPs and a capable adult patient, however, their discussion can be transposed to the paediatric context, see Birchley, 'Deciding Together?' (n 42) 212.

²⁶⁴ Sandman and Munthe (n 258) 80.

²⁶⁵ *ibid.*

²⁶⁶ *ibid.*

²⁶⁷ See e.g. Blumenthal-Barby and others (n 262).

²⁶⁸ Sandman and Munthe (n 258) 78–81; Blumenthal-Barby and others (n 262) 6.

it does not align with HCPs' view of the child's best interests.

However, HCPs report that even rational persuasion is often insufficient to secure parental consent. For them, this leads to the need to manage the frame of reference more actively. Some strategies deployed by HCPs seem to go beyond 'open strategies' as defined by Sandman and Munthe. Indeed, '[t]he line between permissible persuasion and unethical manipulation is not always clear, and slippage occurs easily'.²⁶⁹ Relying on the account of manipulation proposed by Gorin, I will now clarify that distinction and show why I characterise some of these strategies as manipulative. I then turn to the question as to whether they can, nonetheless, be justified.

2. Manipulative strategies in GTWP

In this section, I discuss four strategies that HCPs report using as part of GTWP: 1) not mentioning the possibility of WLST initially in their interaction with parents; 2) highlighting clinical facts converging with the recommendation of the team; 3) repeating recommendations and 4) triggering social norms supporting the team's recommendation. Before I do, I will first introduce Gorin's account of manipulation, which will then allow me to show in which way these four strategies are manipulative.

2.1 Manipulation as failure to track reasons

For Gorin, manipulation amounts to an agent (the manipulator) causing (or attempting to cause) behaviour in another (the manipulee) through a deliberate and non-coercive failure to track the normative reasons that are applicable to the manipulee's behaviour.²⁷⁰ As a way to influence behaviour, manipulation can be contrasted, Gorin argues, with 'rational persuasion with the right intentions', which constitute 'an ideal type of interpersonal influence'.²⁷¹ In rational persuasion,

²⁶⁹ Robert D Truog and others, 'Microethics: The Ethics of Everyday Clinical Practice' (2015) 45 *Hastings Cent Rep* 11, 14.

²⁷⁰ Moti Gorin, 'Paternalistic Manipulation' in Kalle Grill and Jason Hanna (eds), *The Routledge Handbook of the Philosophy of Paternalism* (Routledge 2018) 245–6.

²⁷¹ Moti Gorin, 'Towards a Theory of Interpersonal Manipulation' in Christian Coons and Michael Weber (eds), *Manipulation: Theory and Practice* (Oxford University Press 2014) 96.

everything links up nicely: the motivations of the influencer are grounded in the reasons she believes really do support the behavior she seeks to bring about, the means of influence (e.g. sound argument) reliably “aim at” or “link up with” these reasons, and the mental states of the person being influenced also refer to the reasons that support the behavior.²⁷²

In Gorin’s account, the distinctive sign of manipulation is to influence an agent who is responsive to reasons, ‘to engage in behaviour that is defective insofar as it is detached from [...] the reasons that ought to govern that agent’s behavior’.²⁷³ Independently of an attempt at influencing the behaviour of an agent, the question whether it amounts to manipulation will be answered first by asking whether the behaviour can be seen to have ‘normative worth’.²⁷⁴ Behaviour can be considered as having normative worth, ‘if and only if the motivating reasons that explain the behavior coincide with the reasons that justify the behavior’.²⁷⁵

If an agent’s behaviour lacks normative worth, the question then becomes whether an attempt to influence the agent has caused the defect resulting from the mismatch between normative and motivating reasons.

2.1.1 Reasonable and paternalistic manipulation

Influence failing to track reasons and inducing behaviour lacking normative worth can operate at different junctures of interpersonal interactions and ‘the location of breakdowns will determine whether the manipulation is reasonable or unreasonable, paternalistic or non-paternalistic’.²⁷⁶ Here, the only relevant types of manipulation are reasonable and paternalistic manipulation. The GNM does not indicate that HCPs attempt to influence parents to behave in a way that is unsupported by reasons (unreasonable) nor in a way that would go against their interest in acting in the best interests of their child (non-paternalistic).

The process I conceptualised as JIC, whereby HCPs determine best interests is collegial and rational. HCPs see it as guaranteeing the accuracy of the result it

²⁷² *ibid.*

²⁷³ Gorin, ‘Paternalistic Manipulation’ (n 270) 246.

²⁷⁴ *ibid.* 244.

²⁷⁵ *ibid.* 245.

²⁷⁶ Gorin, ‘Interpersonal Manipulation’ (n 271) 96.

yields. From the point of view of HCPs, the conclusion arising from JIC and the recommendation derived from it are supported by a strong set of reasons they consider to be the right reasons. Here, I will assume the reasons HCPs adopted are, by and large, the right reasons, meaning they do justify the recommended course of action. One can challenge this assumption, as I did in the previous chapter. However, as parents routinely adopt the reasons put forward by HCPs and the courts uphold them, my assumption appears justified in the present case.

Since HCPs' intentions are never to mislead parents such that they would behave in a way that does not correspond to the normative reasons they identified in JIC, the strategies used by HCPs are also paternalistic in seeking to promote the good of both child and parents.²⁷⁷ Paternalistic manipulation is a revealing lens through which to consider the interaction between HCPs and parents. Gorin's account of manipulation as failure to track reasons captures instances of influence that are ethically questionable and yet do not involve wrongs often associated with manipulation such as deception or harm.²⁷⁸ As it is aligned with the interests of the manipulee and with the reasons applicable to the manipulee's predicament, successful paternalistic manipulation does not leave him or her worse off in these regards. Yet,

[w]hen a manipulator intends a manipulee to behave in ways the manipulator believes to be supported by reasons and yet deliberately fails to make these reasons apparent as action-guides to the manipulee, the manipulator displays an indifference to [...] the *normative worth* of the manipulee's behavior'.²⁷⁹

In instances of paternalistic manipulation, the manipulator focuses on the desired outcome at the expense of the reasons justifying it for the manipulee. In the terms of GTWP, some strategies deployed by HCPs suggest they might be more concerned about getting parents *there* than about how parents *get* there.

However, before concluding that paternalistic manipulation is ethically reprehensible,

²⁷⁷ Gorin, 'Paternalistic Manipulation' (n 270) 241.

²⁷⁸ Gorin, 'Interpersonal Manipulation' (n 271).

²⁷⁹ Gorin, 'Paternalistic Manipulation' (n 270) 244.

it is also important to ask if the target of the manipulation is indeed responsive to the reasons that are relevant to the decision contemplated. As observed by Gorin,

[i]f an agent is incapable of non-defective action there can be no obligation on the part of those wishing to influence her to avoid causing her to behave defectively. In such a case, it is sufficient from a moral point of view that the influencer aims to bring about behavior she believes to be endorsed by good reasons and that she believes *would* guide the behavior of the manipulee were the manipulee capable of recognizing and appropriately responding to these reasons.²⁸⁰

2.2.2 The strength of Gorin's account

Moti Gorin's analysis of manipulation as failure to track reasons allows to articulate a precise normative critique of some aspects of GTWP. The philosophy of manipulation and its controversies are beyond the scope of this chapter.²⁸¹ However, I hope to illustrate the strength of Gorin's analysis by showing how well adapted it is to the question of the appropriate type of influence to use in interacting with parents as it arises in GTWP.

Gorin's account provides a more neutral understanding of manipulation than competing accounts building on the negative connotation associated with the common understanding of the term to argue that manipulation is inherently wrong. Importantly for my purpose, it also allows to pinpoint exactly what is problematic with paternalistic manipulation, that is well-intentioned influence aimed at furthering the good of the manipulee, which does not reliably track reasons.²⁸² Finally, it makes room for the ethical appreciation of manipulative influence to change whether the agent influenced responds to reasons or not.²⁸³

Gorin's conception is more abstract than most other conceptions of interpersonal

²⁸⁰ *ibid* 245.

²⁸¹ See Robert Noggle, 'The Ethics of Manipulation' in Edward N Zalta (ed), *The Stanford Encyclopedia of Philosophy* (Summer 2020, Metaphysics Research Lab, Stanford University 2020) <<https://plato.stanford.edu/archives/sum2020/entries/ethics-manipulation/>> accessed 22 July 2020; See also Gorin, 'Interpersonal Manipulation' (n 271).

²⁸² Gorin, 'Paternalistic Manipulation' (n 270) 241; Marcia Baron, 'The Mens Rea and Moral Status of Manipulation' in Christian Coons and Michael Weber (eds), *Manipulation: Theory and Practice* (Oxford University Press 2014) 106.

²⁸³ Moti Gorin and others, 'Justifying Clinical Nudges' (2017) 47 *Hastings Cent Rep* 32, 37; Gorin, 'Paternalistic Manipulation' (n 270) 245.

manipulation put forward in the philosophical literature thus far. In identifying failure to track reasons as the essential feature of manipulation, it is analytically more precise than the continuum approach to persuasion, manipulation and coercion Tom L. Beauchamp and Ruth R. Faden initially articulated.²⁸⁴ Beauchamp and Faden use manipulation as a label for the broad range of influence that is neither coercive nor persuasive. They define manipulation negatively as ‘any intentional and successful influence of a person by noncoercively altering the actual choices available to the person or by nonpersuasively altering the other’s perception of those choices.’²⁸⁵

Yet, Gorin also seeks to answer criticisms against other conceptions, which have sought to identify necessary features of manipulation. He rejects deception, harm, the undermining of autonomy and the bypass or subversion of rational capacities, as necessary elements of manipulation.²⁸⁶ It does not mean that these shortcomings cannot be present in instances of manipulation. Another strength of Gorin’s account is that it incorporates competing accounts. For example, If HCPs lie to parents to get them to consent to withdraw life-sustaining treatments from their child, they would be manipulating them through deception. However, such obviously unethical behaviour does not form part of GTWP. I therefore need a more precise tool to show what is ethically questionable about GTWP.

Having introduced Gorin’s account of manipulation, I can now turn to applying it to GTWP. I first demonstrate that some strategies constituting GTWP are *pro tanto* manipulative. I then address the HCPs’ suspicions regarding the capacity of parents to make decisions in their child’s best interests. I will show that, in certain circumstances, these suspicions can contribute to justifying the manipulative strategies deployed by HCPs.

²⁸⁴ Ruth R Faden and Tom L Beauchamp, *A History and Theory of Informed Consent* (OUP 1986) 354; See also JS Blumenthal-Barby, ‘Between Reason and Coercion: Ethically Permissible Influence in Health Care and Health Policy Contexts’ (2012) 22 *Kennedy Inst Ethics J* 345.

²⁸⁵ Faden and Beauchamp (n 284) 354.

²⁸⁶ Gorin, ‘Interpersonal Manipulation’ (n 271); See also Moti Gorin, ‘Do Manipulators Always Threaten Rationality?’ (2014) 51 *Am Philos Q* 51.

2.2 Four manipulative strategies

To secure their patients' best interests, HCPs prioritise rational deliberation and persuasion. HCPs expose the situation of the child to her parents as transparently as possible and expect parents to reach the same practical conclusion as them, largely based on the same reasons. However, when this fails, HCPs report using strategies 'to get there with parents' that are manipulative according to Gorin's account. As I noted in GTWP, they aim for 'that sort of swing in [parents'] view' [Physician #3]. In this subsection, I present four such strategies and show, using Gorin's account of manipulation, why they do not track reasons and, thus, are manipulative.

2.2.1 Omitting withdrawal of treatment as a likely outcome

The first manipulative strategy HCPs report using is initially refraining from telling parents that WLST is a possible outcome of the determination of their child's best interests. In so 'managing the frame of reference', they are deliberately limiting the range of information parents have access to in forming their appreciation of their child's situation. Paradoxically, plausible information is withheld to avoid parents immediately rejecting it or attempting to refute it. The main stated purpose for initially omitting this central element of the clinical picture is to enable and protect the development of a trusting relationship in the context of which such difficult situations can be discussed with parents.

Of course, HCPs use this strategy for a short amount of time and difficult conversation cannot be avoided for very long. One might explain it by the necessity to protect the integrity of the JIC process, including the need to gather information about the preferences and values of parents, rather than as an attempt to influence parents. It would be too harsh therefore to characterise it as deceptive. Yet, when HCPs proceed in this way to lay the ground for difficult conversations, they are nonetheless omitting reasons that are relevant to a full assessment of the child's situation by her parents.

2.2.2 Emphasising data supporting the teams' recommendation

In GTWP, HCPs use clinical evidence differently than when they are seeking to form

clinical judgement. Similarly, nurses also indicate that they will often seek to highlight clinical details supporting the overall direction of the team's recommendation when they are interacting with parents.

Such strategies might appear more difficult to assess than the omission of WLST as a likely outcome. The informational content of the interaction points toward the reasons that justify the recommendation of the team. As such, it is not misleading as to the conclusion. Yet again, such interactions display both paternalism and a degree of manipulation. HCPs aim at steering the behaviour of parents in a predetermined direction, rather than ensuring that the normative reasons they have identified as relevant support the parents' behaviour.

When HCPs privilege a certain type of evidence because they consider it more convincing than other types of information, they massage what behavioural scientists call the 'choice architecture' to increase the likelihood that parents will acquiesce to their recommendation.²⁸⁷ HCPs select these elements for their potential to influence the perspective and decision of parents, rather than strictly because of their objective value. Such strategic emphasis might therefore lead parents to give some information more weight than it deserves in their reasoning. Consequently, although they might reach the right conclusion in terms of their child's best interests, it would not be for the right reasons. Highlighting clinical details converging with the recommendation of the team by nurses at the bedside is to the same effect, as it makes these details more salient for parents.

These strategies involve a degree of manipulation proportional to the distance between the arguments used by HCPs and the clinical case agreed upon following collegial interactions in JIC. I readily concede that the breadth of the gap between the two will sometimes be small, but would nonetheless argue that acknowledging it provides insight into the nature of certain interactions between parents and HCPs.

²⁸⁷ Jennifer Blumenthal-Barby and Douglas J Opel, 'Nudge or Grudge? Choice Architecture and Parental Decision-Making' (2018) 48 *Hastings Cent Rep* 33, 34.

2.2.3 Frequently repeating the recommendation

Repeating the recommendation of the team needs to be distinguished from the other practices, I am discussing here because it might not be best described as a strategy in itself, but rather as the combined effect of the repetition of an otherwise unobjectionable strategy. I would describe this combined effect as ‘wearing parents down by repetition’. For instance, in section 2.2.3 of Chapter V, I discuss how frequently reiterating the negative aspects of a child’s situation to ensure that parents are aware of them can be seen as ‘pushing parents to get there’.

Even attempts at rational persuasion can be manipulative.²⁸⁸ The sheer repetition of reasons—even valid and true reasons—rather than their rational content can influence someone to act. Such act would thus lack normative worth. Marcia Baron describes such influence:

Another form of manipulation—again, of the type that does not involve wilful misrepresentation of fact or intention—involves browbeating or otherwise wearing the person down. This may consist in making him want nothing so much as to get out of the immediate situation, thereby greatly weakening his resistance to the manipulator’s proposal. Such manipulation can sometimes be pulled off more or less civilly.²⁸⁹

If parents consent to WLST because they feel worn down, they still resist the recommendation, even if their outward actions suggest otherwise. I draw a distinction between a decision made reluctantly because it is unpalatable and a decision made because one has been worn down. The former is perhaps inevitable regarding WLST, but the latter is not.

2.2.4 Triggering social or religious norms converging with the recommendation of the team

The gap between the normative reasons adopted by HCPs and the strategies they adopt to motivate parents to agree to their proposed course of action is wider in the case of the last set of strategies I want to consider. HCPs report often encouraging parents to turn either to family or to religious leaders in the hope that they will be

²⁸⁸ Gorin, ‘Paternalistic Manipulation’ (n 270) 240.

²⁸⁹ Marcia Baron, ‘Manipulativeness’ (2003) 77 Proc Am Philos Ass 37, 41; See also George Tsai, ‘Rational Persuasion as Paternalism’ (2014) 42 Philos Pub Aff 78.

help them overcome the parents' reluctance toward the recommendation of the medical team.

Some interventions aimed at parents, notably some of those I discussed in Chapter V, are reason countering influences, that is as 'influence that operates by countering a person's reasoning capacities, with examples including social norms / pressures, inducing affective states, playing on desires'.²⁹⁰ For instance, discussing and normalising feelings perceived as compatible with accepting the team's recommendation, and facilitating their expression is susceptible to accentuate their influence on the appreciation of such a recommendation.

HCPs can trigger social norms, affective states and desires directly or indirectly. They encourage parents to expose themselves to a broader range of influence than HCPs consider they can exercise directly. The same thing can be said of religious norms if one of the hospital's chaplains gets involved with the parents and discusses religious requirements with them or if HCPs encourage parents to seek the guidance of their spiritual leaders. Underlying these recommendations is often the hope that friends, parents or spiritual advisors might be able to trigger social or religious norms that will undermine the parent's resolve to oppose WLST.²⁹¹

In both cases, the means of influence deployed by HCPs in their effort to 'get there with parents' correspond to the definition of manipulation I adopt here. These strategies provide parents with reasons for accepting the recommendation of the team. Yet, these reasons do not form part of the previously agreed upon case for recommending WLST. The reasons foregrounded by these strategies, be they the opinions of close family members or that of spiritual advisors and religious leaders, are not those that justify the recommendation. Thus, such attempts at influencing parents amount to manipulation because the strategies used do not track the reasons justifying the behaviour encouraged.

²⁹⁰ Blumenthal-Barby (n 284) 349.

²⁹¹ *ibid* 351.

In this section, I sought to relate some strategies constituting GTWP to the account of manipulation developed by Moti Gorin. I have shown that, according to this account in which manipulation means an attempt to influence behaviour in a way that does not track normative reasons, several of the strategies that HCPs report using in their efforts to 'get there with parents' are manipulative. Before turning to the question whether such manipulative strategies can be justified, I want to offer a small point of clarification.

I do not want to imply that manipulation can only be avoided if parents either integrally adopt or reject the reasons HCPs present to them. It is the attempt to steer someone's behaviour by relying on some other reasons than those that would justify that behaviour that constitutes manipulation. Parents can arrive at a decision to consent or not to the team's recommendation using their own set of reasons. If their decision coincides with their reasons, it has normative worth and is, therefore, free from manipulation. Of course, it does not exclude the possibility that parents might be wrong. The question whether their conclusion should be upheld and implemented is to be determined in light of the child's best interests.

Many of the practices forming part of GTWP can therefore be seen as manipulative. However, Gorin's account also allows us to identify situations where such manipulation can be justified. Furthermore, lack of responsiveness to reasons – the criteria identified by Gorin to justify resorting to manipulative strategies – also resonates with the suspicions formulated by HCPs concerning the capacity of parents to make decision for the children in the NICU. In the next sections, I turn to discussing those suspicions and the extent to which they can justify manipulative strategies on the part of HCPs.

3. Deciding with 'upset traumatized people' : do parents lack capacity?

In the previous section, I argued that some strategies deployed by HCPs to get parents to consent to a WLST recommendation are manipulative. However, another important contribution that GNM makes is to provide a hypothesis as to the

underlying justification for adopting an interactional process of influence aimed at steering parents to accept a WLST recommendation. As I detailed in Chapter V, according to HCPs, parents are often incapable of adequately ascertaining what is in their child's best interests, and therefore require assistance.

In this section, I first clarify the meaning to give to these suspicions. Two related but distinct challenges can be made to the decision-making capacity of parents. I label the first challenge the 'robust challenge'. The central claim of the robust challenge is that the capacity of parents to make decisions for their child is so impaired that they do not meet the usually accepted legal threshold for making decisions for themselves. I label the second line of arguments the 'weak challenge'. The central claim of the weak challenge is that while the legal threshold for capacity is met, the predicament of parents with a child in the NICU impairs or weakens the quality of their reasoning.

HCPs in the London NICU do not argue that parents are legally incapable of making decisions for their child. However, because of the ambiguity between the technical understanding of capacity embodied in the robust challenge and the broader meaning used in the weak challenge, it is worth establishing first that the robust challenge fails.

Having set the robust challenge to parental capacity aside, I substantiate the weak challenge. To do so, I will mainly relate the observations of HCPs to the literature on heuristics and biases in decision-making. This will then allow me to argue that in situations where they suspect that parents are not responding to the reasons that are relevant to the determination of their child's best interests, HCPs are indeed justified to resort to manipulative strategies to supplement rational deliberation and persuasion.

3.1 The robust challenge fails

In the GNM, I described the doubts that HCPs entertain about the decision-making

aptitude of parents as suspicions about their capacity. This requires clarification because the term capacity has a defined meaning in English law. Hence, before turning to this section's main argument, I need to set aside the possibility that HCPs might contest the capacity of parents in the strict legal understanding of the term.

English law does not provide any way to challenge the decision-making capacity of parents *per se*. In the medical context, HCPs are bound to further their patients' best interests and it is that issue which is subject to the authority of the courts. Similarly, a local authority would not investigate or challenge the decision-making capacity of parents *per se*, but rather the potential harm on a child, which may result from the underlying causes of that incapacity.²⁹² Even for adults who lack capacity to make decisions for themselves, English law does not rely on surrogate decision makers. Rather, it enables HCPs to provide treatment in the best interest of the person concerned.²⁹³ For this reason, the issue of the capacity of surrogate decision makers is much less salient in England than in other jurisdictions relying on next of kin as surrogate decision makers.²⁹⁴

Nonetheless, since the question of the capacity of parents is central in the GNM, it remains important to consider it. The legal capacity of parents with a child in the NICU appears unassailable, unless exceptional circumstances, such as the presence of a cognitive impairment would lead to challenging it. English Law adopts a strictly cognitive and procedural view on the matter of capacity based on the mainstream understanding of capacity.²⁹⁵ Under the Mental Capacity Act 2005, for a person to lack legal capacity to make a decision, it is required that their inability result from 'an impairment of, or a disturbance in the functioning of, the mind or

²⁹² Children Act 1989 s 31.

²⁹³ Mental Capacity Act 2005 sub-s 1(5) and 4.

²⁹⁴ But see Katrina A Bramstedt and others, 'When Families Complicate Patient Care: A Case Study with Guidelines for Approaching Ethical Dilemmas' (2005) 14 MEDSURG Nursing 122; Rosamond Rhodes and Ian Holzman, 'The Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions' (2004) 25 Theor Med Bioeth 367.

²⁹⁵ Scott YH Kim, *Evaluation of Capacity to Consent to Treatment and Research* (OUP 2010) 18–19; Helena Hermann and others, 'Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments' (2016) 7 Front Psychol 2.

brain'²⁹⁶ and that they be unable:

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate his decision (whether by talking, using sign language or any other means).²⁹⁷

The Mental Capacity Act also seeks to exclude any substantive evaluation of the decisions produced by the person or of the grounds on which they were made in determining whether the person has legal capacity²⁹⁸. Section 1 states that making unwise decisions is not sufficient to conclude that a person is not legally capable.²⁹⁹ Capacity is presumed such that the burden of proving that it is lacking generally lies with whoever wants to challenge it.³⁰⁰ The English legal approach to capacity insists on the importance of fostering and preserving decisional autonomy, even in the face of limitations. The Mental Capacity Act states that '[a] person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success'.³⁰¹

Indeed, I was unable to identify any convincing empirical or theoretical argument in the vast literature I surveyed supporting the proposition that parental decision-making capacity understood in the narrow technical and legal sense could or ought to be systematically questioned or challenged. At the most, some views of HCPs working in the London NICU on the capacity of parents echo critiques levelled against the mainstream view of decision-making capacity. For instance, in a narrative review of arguments contesting the mainstream criteria of decision-making capacity,

²⁹⁶ Mental Capacity Act 2005 s 2(1).

²⁹⁷ *ibid* s 3(1).

²⁹⁸ Hermann and others (n 295) 2; Kim (n 295) 24.

²⁹⁹ Mental Capacity Act 2005 s 1(4).

³⁰⁰ Jackson (n 211) 220; Mental Capacity Act 2005 s 1(2).

³⁰¹ Mental Capacity Act 2005 s 1(3).

Hermann *et al.* identify a cluster of studies claiming that individuals can be so overwhelmed by emotions that the cognitive functions associated with decision-making will be interfered with, therefore compromising their decision-making capacity.³⁰² Yet, none of these studies were concerned with medical decisions made for another person.

Having excluded the possibility that the suspicions voiced by HCPs about the capacity of parents could translate into a legal finding of incapacity, I can now address the more plausible hypothesis to the effect that the decision-making capacity of parents might nonetheless be less than optimal. Although there would be no formal legal implications, if this hypothesis is valid, the ethical landscape would be significantly altered.

3.2 The weak challenge is more plausible

In paediatric care, the notion of capacity is different from that which applies to adults making decision for themselves. While adults can make unwise decision as long as they meet the minimal procedural threshold of legal capacity, parents are bound to make decisions that are in the best interests of their children. As discussed in the previous section, the test for legal capacity establishes the minimal conditions under which an adult's decision ought to be respected. However, HCPs interpret the best interests standard as requiring an appreciation of the *substantive quality* of the decision reached by parents. Hence, the doubts expressed by HCPs concern the capacity of parents to meet that substantive threshold.

I will address two approaches to the capacity of parents to make decisions in a critically ill child's best interests. First, I highlight the normative arguments put forth by Sara Goering in support of the proposition that the autonomy of parents with a child in the NICU is inherently limited. Goering's position converges with that which I have attributed to HCPs in GTWP, yet like many other normative studies dealing with the matter, it does not go far enough in offering supporting empirical evidence.

³⁰² Hermann and others (n 295) 4.

Rather, my main concern will be to argue that I can provide a better justification for the HCPs' doubts by linking their observations with the findings of behavioural sciences on heuristics and biases in decision-making. I show the doubts expressed by HCPs echo many documented biases and heuristics which are susceptible of impairing the quality of parents' decisions. Having thus established the doubts of HCPs appear to be justified, I will be in a position to discuss their ethical implications.

3.2.1 An inherently autonomy-limiting position

One way of approaching the weak challenge is to ask whether the predicament of parents is such that their decision-making capacity is impaired. Many discussions of the ethics of decision-making in the NICU take for granted that the decision-making capacity of parents might be diminished or impaired, yet such affirmations are rarely substantiated.³⁰³ There is a significant gap between the attention given by researchers to the psychological wellbeing of parents with children hospitalised in the NICU versus their capacity to provide an adequate consent to WLST.³⁰⁴ An important body of work dealing with parental stressors in the NICU and the support available to them exists.³⁰⁵ However, I was unable to find any empirical study directly addressing the question as to whether such stressors could impact the capacity of parents in the NICU.

Goering offers one of the most comprehensive normative accounts of that argument, going beyond invoking the incapacitating effect of stress on parents. She identifies a dilemma for NICU teams, which almost exactly maps onto the dilemma I placed at

³⁰³ John D Lantos, 'Ethical Problems in Decision Making in the Neonatal ICU' (2018) 379 NEJM 1851, 1855. Denis Devictor, 'Parents' Autonomy versus Doctors' Paternalism: A Rearguard Battle' (2007) 8 Pediatric Critical Care Medicine 400, 400.

³⁰⁴ See e.g. Ariane Thaise Frello Roque and others, 'Scoping Review of the Mental Health of Parents of Infants in the NICU' (2017) 46 J Obstet Gynecol 576.

³⁰⁵ See e.g. Morgan Busse and others, 'Parents' Responses to Stress in the Neonatal Intensive Care Unit' (2013) 33 Crit Care Nurse 52; Roque and others (n 304); Dua'a Fayiz Al Maghaireh and others, 'Systematic Review of Qualitative Studies Exploring Parental Experiences in the Neonatal Intensive Care Unit' (2016) 25 J Clin Nurs 2745; MR Sanders and SL Hall, 'Trauma-Informed Care in the Newborn Intensive Care Unit: Promoting Safety, Security and Connectedness' (2018) 38 J Perinatol 3; Animesh Sabnis and others, 'Reducing Parental Trauma and Stress in Neonatal Intensive Care: Systematic Review and Meta-Analysis of Hospital Interventions' (2019) 39 J Perinatol 375.

the heart of the GNM:

[...] between calling new parents fully autonomous despite their obvious limitations, and treating them as incompetent because of those limitations and so appropriate targets for paternalism³⁰⁶ [...]

Goering argues that:

[n]ew parenthood – and especially new parenthood that involves a NICU infant – thus seems to be the kind of situation that might aptly be called ‘inherently autonomy limiting.’³⁰⁷

Such limitations on parental autonomy result from the:

intersection of stressful personal circumstances (lack of sleep, physical and mental exhaustion, bodily changes, constant demands from a needy other, inexperience) and strong stereotypes about what constitutes good parenting and the limitations of new parents.³⁰⁸

Specifically, Goering focuses on the relationship between the circumstances of new parenthood and self-trust, which she argues is a necessary condition of genuine autonomy.³⁰⁹

Yet, notwithstanding the intuitive appeal of Goering’s interpretation of the situation of parents in the NICU and its congruence with some views expressed by HCPs working in the NICU, it provides limited support for the claim that the decision-making capacity of parents is inherently limited by their position as parents of a newborn child. Goering’s argument is primarily theoretical, although she also relies on her experience³¹⁰ as a new mother and on previously published case studies³¹¹ to make her case. For this reason, I do not think she convincingly establishes that the autonomy of parents in the NICU is *inherently* limited, although she provides plausible arguments in support of that conclusion.

In my efforts to assess the position adopted by HCPs toward the decision-making

³⁰⁶ Sara Goering, ‘Postnatal Reproductive Autonomy: Promoting Relational Autonomy and Self-Trust in New Parents’ (2009) 23 *Bioethics* 9, 19.

³⁰⁷ *ibid* 15.

³⁰⁸ *ibid* 16.

³⁰⁹ *ibid* 13–15.

³¹⁰ *ibid* 10.

³¹¹ *ibid* 13.

capacity of parents in the NICU, I take the view that the strongest arguments to question the decision-making capacity of parents in the NICU come from the application of the heuristics and biases research programme, to which I turn now.

4. Heuristics and biases in parental decision making

In this section, I explore the possibility that an impaired capacity of parents to appreciate and act upon the reasons presented to them might indeed justify the manipulative strategies used as complements to rational deliberation and persuasion to secure their consent. I demonstrate that the expanding literature on applying the notions of cognitive biases and heuristics developed in behavioural sciences to decision-making relating to clinical decisions is susceptible of providing support to the hypothesis that parents are disadvantaged when it comes to reflecting on the best interests of their child in the NICU. While it is possible such a disadvantage will be compounded by the predicament of new parents whose child is receiving critical care in the NICU,³¹² the 'heuristics and bias' research programme has more general implications than in the sole critical care context. First, I give a brief overview of this line of research. Then, I build on a discussion of biases and heuristics and autonomy by Jennifer S. Blumenthal-Barby to substantiate the plausibility of the doubts expressed by HCPs.

4.1 A brief overview of the heuristics and biases research program

Although the fundamental research on the cognitive dimensions of decision-making that launched this line of inquiry goes back to the work by Amos Tversky and Daniel Kahneman published in 1974,³¹³ it has only relatively recently started to be applied and discussed in a clinical context and, even more so, in paediatrics.³¹⁴

³¹² Joanna L Hart and Scott D Halpern, 'Cognitive Barriers to Effective Surrogate Decision-Making' in Giora Netzer (ed), *Families in the Intensive Care Unit: A Guide to Understanding, Engaging, and Supporting at the Bedside* (Springer 2018) 18.

³¹³ Amos Tversky and Daniel Kahneman, 'Judgment under Uncertainty: Heuristics and Biases' (1974) 185 *Science* 1124.

³¹⁴ See Scott D Halpern, Peter A Ubel and David A Asch, 'Harnessing the Power of Default Options to Improve Health Care' (2007) 357 *NEJM* 1340; Blumenthal-Barby and others (n 262); Blumenthal-Barby and Opel (n 287); Marlyse F Haward, Ryan O Murphy and John M Lorenz, 'Message Framing and Perinatal Decisions' (2008) 122 *Pediatrics* 109.

The underlying assumption of this line of research is that human beings making decisions in real-life circumstances are prone to deviate from norms of decision-making, and, therefore, to making certain predictable errors.³¹⁵ For the present discussion, a cognitive bias is ‘the systematic deviation away from making choices that promote one’s own goals or interests’.³¹⁶ In the lecture he gave upon receiving the 2002 Nobel Prize of Economics, Kahneman described the research programme he developed with Tversky:

Our research attempted to obtain a map of bounded rationality, by exploring the systematic biases that separate the beliefs that people have and the choices they make from the optimal beliefs and choices assumed in rational agent models.³¹⁷

As Kahneman indicates, this contradicts the ideal of rational calculation underlying traditional rational choice theory.³¹⁸ Rubin offers a typical formulation of this ideal:

Rational choice theory is defined as a theory of instrumental rationality; that is, the actor has a set of pre-established ends and then decides how these ends are to be achieved. If the actor chooses the optimal means to achieve her pre-established ends, she is rational; if she chooses suboptimal means, she is irrational. The particular claim of rational choice theory is that people are rational in this sense; that is they choose the optimal means to achieve their ends.³¹⁹

While the rational choice model evokes an idealized actor, with exceptional capacities and stable preferences, taken to the extreme, the numerous biases and heuristics that have been documented throughout the years amounts to a ‘dismal portrayal of people’s decision-making competence’ according to which ‘real and boundedly rational people [...] are fallible, inconsistent, ill-informed, unrealistically optimistic, and myopic, and they suffer from inertia and self-control problems’.³²⁰ Nonetheless, it is also important to remember that ‘the use of heuristics should “confer no shame,” since we all use them’.³²¹ It is beyond the scope of this chapter to

³¹⁵ JS Blumenthal-Barby, ‘Biases and Heuristics in Decision Making and Their Impact on Autonomy’ (2016) 16 *AJOB* 5, 5; Tversky and Kahneman (n 313) 1130.

³¹⁶ Hart and Halpern (n 312) 19.

³¹⁷ Daniel Kahneman, ‘Maps of Bounded Rationality: Psychology for Behavioral Economics’ (2003) 93 *Am Econ Rev* 1449, 1449.

³¹⁸ Ralph Hertwig and Till Grüne-Yanoff, ‘Nudging and Boosting: Steering or Empowering Good Decisions’ (2017) 12 *Perspect Psychol Sci* 973, 974.

³¹⁹ Edward L Rubin, ‘Rational Choice and Rat Choice: Some Thoughts on the Relationship among Rationality, Markets, and Human Beings’ (2005) 80 *Chi-Kent LR* 1091, 1092.

³²⁰ Hertwig and Grüne-Yanoff (n 318) 974–975.

³²¹ Hart and Halpern (n 312) 29.

delve into the matter, but HCPs are certainly not immune from the influence of heuristics and biases.³²²

4.2 Heuristics and biases in the GNM

Few studies of the biases and heuristics on the quality of decision-making by parents in the NICU exist.³²³ However, in an article entitled 'Biases and Heuristics in Decision-Making and Their Impact on Autonomy', Blumenthal-Barby convincingly demonstrates that many of the biases and heuristics identified by cognitive and behavioural sciences represent a challenge for autonomous decision-making in the clinical context. Blumenthal-Barby is concerned with the biases and heuristics that impact the decisions of capable adults concerning themselves. There are important differences between the position of capable adults toward themselves and that of capable parents toward a young child. The main difference is, obviously, that parents asked to make a decision concerning their child are held to the more demanding standard of best interests.³²⁴

Yet, I propose to build on Blumenthal-Barby's analysis to make the point that HCPs appear justified to question the capacity of parents to respond to the reasons that they present to them as part of GTWP. Although Blumenthal-Barby seeks to answer the question whether biases and heuristics impair autonomous decision-making, I will transpose her analysis to the worries of HCPs about the capacity of parents.

Blumenthal-Barby distinguishes formal autonomy and effective autonomy but, for my present purposes, I will focus only on the three components of formal autonomy she identifies: understanding, intentionality and absence of alienating influence.³²⁵ I address each of these components and show how they can be applied to the concerns about the capacity of parents to conform to the best interests principle in

³²² Lantos (n 303) 1857; Rosamond Rhodes, 'How to Respond to Knowledge About Biases' (2016) 16 *AJOB* 29, 30.

³²³ But see Elliott Mark Weiss and David A Munson, 'Action and Uncertainty in Neonatal Intensive Care' (2016) 16 *AJOB* 31; Michal Stanak, 'Nudging in Neonatology: Practical Wisdom and Accountability for Reasonableness' (2019) 35 *Int J Technol Assess Health Care* 5; Blumenthal-Barby and Opel (n 287).

³²⁴ Blumenthal-Barby and Opel (n 287) 35.

³²⁵ Blumenthal-Barby (n 315) 8.

their decisions. Besides the examples given by Blumenthal-Barby, I also elaborate on some of the over 180 biases that have been documented.³²⁶

4.2.1 Impact on understanding

The component of understanding is crucial for evaluating the responsiveness of parents to the reasons HCPs present to them. Adequate decision-making involves acquiring a certain level of understanding of complex clinical information. Of course, it is one of the primary duties of HCPs to share and explain information so that parents can understand it. However, heuristics and biases can threaten such understanding. As Blumenthal-Barby notes, ‘if a person incorrectly apprehends, or fails to apprehend, a key description of the action that the person is about to perform, or a key description of its consequences, then that person lacks the understanding required for autonomy with respect to that action’.³²⁷ In this regard, I will address the optimism bias, the impact bias, the availability bias, the gambler’s fallacy, and the fundamental attribution error.

Blumenthal-Barby first reviews studies demonstrating the presence of an ‘optimism bias’ in decision-making, meaning that individuals have a ‘tendency to overestimate the likelihood of desirable outcomes’ or, on the contrary, to underestimate the likelihood of undesirable outcomes.³²⁸ The presence of an optimism bias in how surrogate decision makers understand prognostic information has been demonstrated in the adult intensive care context.³²⁹ Relatedly, in a study of parents of children with terminal cancer, researchers found that parents whose expectations of a cure remained high, despite a grim prognosis, were slower to accept a shift toward palliative care.³³⁰

³²⁶ Jonathan Howard, *Cognitive Errors and Diagnostic Mistakes: A Case-Based Guide to Critical Thinking in Medicine* (Springer 2019) 4.

³²⁷ Blumenthal-Barby (n 315) 7.

³²⁸ Hart and Halpern (n 312) 20. See also the outcome bias Pat Croskerry, ‘Achieving Quality in Clinical Decision Making: Cognitive Strategies and Detection of Bias’ (2002) 9 *Academic Emergency Medicine* 1184, 1193.

³²⁹ Douglas B White and others, ‘Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients’ (2016) 315 *JAMA* 2086.

³³⁰ Joanne Wolfe and others, ‘Understanding of Prognosis Among Parents of Children Who Died of Cancer: Impact on Treatment Goals and Integration of Palliative Care’ (2000) 284 *JAMA* 2469.

Parents with a child in the NICU appear susceptible to the optimism bias in how they receive prognostic information.³³¹ Indeed, something akin to a misunderstanding caused by an optimism bias could be at play in the following description of parents' reactions to explanations:

Nurse #2: [...] Sometimes we do inform them, when we have already given everything and then there is nothing left for us to give. But in my experience, there are parents that would start asking if their child is going to make it through. So there are times where they would ask, "do you think, in your experience, when you look after this kind of patient, will they make it through, will they survive, will they get better?" And that's when we are sometimes alarmed [...]

Blumenthal-Barby also draws a connection between understanding and the 'impact bias', whereby individuals are unable to assess the consequences of a change in their condition. She illustrates that point by referencing studies showing that healthy individuals exaggerate the negative impact of dialysis on happiness, while kidney transplant candidates exaggerate the positive consequences that receiving a transplant would have on their quality of life and functioning.³³² Commenting on the impact of both optimism and impact biases on surrogate decision-making in the adult context, Hart and Halpern conclude: "these biases lead directly to care decisions that have been informed by inaccurate perceptions of future outcomes and are unlikely to maximize the benefit to patients".³³³

The doubt that HCPs entertain about parents' understanding of the burden of long-term treatment suggests that they suspect an error compatible with the impact bias leading them to underestimate the negative consequences, both for them and for the child, of rejecting a WLST recommendation. Physician #1's interrogations about the understanding of parents provide an illustration:

I wonder if people really know what it means to be in tracheotomy through the night, or having a ventilator, or some of these more intensive interventions, until they do it. I'm not sure I do, you know, and I've done this for 20 years. I have a rough idea that it must be incredibly hard work ... but it would be all the time!

³³¹ Weiss and Munson (n 323) 32.

³³² Blumenthal-Barby (n 315) 9–10.

³³³ Hart and Halpern (n 312) 22.

And you sometimes feel when people make requests, or seem to diminish or downplay that part of the experience, assessing the quality of life thing [...] [Physician #1]

Going beyond the biases Blumenthal-Barby identified, the reports of HCPs allow to expand the list of biases susceptible of compromising the understanding of parents. For instance, another attitude of parents reported by HCPs that can be seen as evidencing a cognitive bias is the tendency to interpret information according to their experience of the previous evolution of their child's illness or of the outcomes of previous episodes in the child's care, rather than as an independent decision about the likelihood of a future event. Allied Professional #1 offers the following description:

But I think the thing that is the hardest—and this is nothing that any human beings do, is when you have a child who is rallied, and then slips back and then rallies again, and slips back, and the third time the doctors are saying, “they're not going to be able to rally,” and the parents say, “but they did it twice already!” [Allied Professional #1]

This observation can be related to several documented biases, but identifying precisely which one would require further research. Indeed, many biases might be at play in any instance. For example, the availability bias suggests that ‘decision makers rely on memory and experience to inform current decisions often selecting the most available, or easily recalled option’³³⁴, such that parents would tend to interpret the likelihood that their child would overcome a grim prognosis because they have personal recent experience of them doing so. The ‘gambler’s fallacy’, which denotes the tendency to ‘believe that independent events are related’ is also a plausible candidate.³³⁵ Again, the fact that a child was ‘able to rally’ following past difficulties in no way determines whether he or she will beat the odds in the future.

Alternative interpretations also include the fundamental attribution error, which ‘reflects the tendency to explain behavior in terms of internal characteristics while neglecting the causal influence of situational factors’³³⁶. It could contribute to explaining a situation whereby the attribution of a character trait to the child, such as

³³⁴ *ibid* 124.

³³⁵ Alessandra Gorini and Gabriella Pravettoni, ‘An Overview on Cognitive Aspects Implicated in Medical Decisions’ (2011) 22 *Euro J Intern Med* 547, 549.

³³⁶ Klaus Fiedler and Tobias Krüger, ‘Language and Attribution: Implicit Causal and Dispositional Information Contained in Words’ in Thomas M Holtgraves (ed), *The Oxford Handbook of Language and Social Psychology* (OUP 2014) 253.

that of a 'warrior' or a 'fighter', could result in downplaying medical considerations likely to impact the child's outcome.

Biases and heuristics affecting understanding concern the understanding of the objective facts underlying the child's condition and the team's recommendation. Gaining a precise appreciation of the situation upon which one is called to form an opinion and make a decision necessitates being responsive to the relevant clinical and physiological facts. If such understanding is biased, it will be difficult for parents make a decision that conforms to their child's best interests. However, factual elements are not the whole story. GTWP also includes reports from HCPs that illustrate their concerns about the alignment between the preferences and commitments of parents – which I theorised as normative expectations – and some of the decisions they make.

4.2.2 Impact on intentionality

The next component in Blumenthal-Barby's framework is intentionality. She links the notion of intentionality to the capacity to plan an action so that, looking back, the actor is able to say, 'I did X as planned'.³³⁷ The quality of parents' decision-making is threatened by a defect in intentionality if they resolve to do something and yet end up not doing it. A bias affecting intentionality can therefore drive a wedge between the preferences of parents or their high-level intentions, such as a commitment to avoiding unnecessary suffering, and the actions they take. Here, I consider the 'commission', 'status quo' and 'ambiguity aversion' biases, as well as the sunk-cost fallacy.

Regarding intentionality, the most relevant bias identified by Blumenthal-Barby is the commission bias, which drives people to be inclined to do something rather than do nothing, even if doing nothing is less risky or more in line with their stated goals.³³⁸ Blumenthal-Barby highlights a study showing that participants presented with a hypothetical diagnosis of cancer chose surgery over watchful waiting, even when the

³³⁷ Blumenthal-Barby (n 315) 7–10.

³³⁸ *ibid* 6.

surgery carried a higher risk of death. According to the authors of the study: ‘motivation for action is so strong that people showed a strong preference for action even when the treatment is more harmful than doing nothing (i.e., watchful waiting)’.³³⁹

Such bias seems congruent with instances of the injunction to ‘do everything’ for a child, for example requests to go ahead with a tracheostomy to support long-term ventilation despite HCPs taking the view that it would not be in the best interests of the child.³⁴⁰

The status quo bias involves ‘[t]he tendency to maintain the current or previous choice rather than making a different choice’. As noted by Baron and Halpern, ‘decision-makers who maintain the status quo are also making a decision’.³⁴¹ Yet, the status quo bias might blur this point for parents who are reluctant to admit that changing the care’s orientation would benefit their child. Indeed, WLST is a paradigmatic example of Baron and Halpern’s suggestion that surrogate decision-makers may thus be managing their perception of their responsibility in the outcome of the patient for whom they are acting as surrogates.³⁴² The tendency to favour the status quo rather than actively choosing a different option may impair intentionality component of autonomy by attenuating the connection that parents can see between their (non-) decision and their child’s outcome.³⁴³

Related to the status quo bias is also the ambiguity aversion bias, the tendency to ‘display [...] preferences for known or certain probabilities over uncertain probabilities regardless of actual benefits’³⁴⁴. It may paralyse the intentionality of individuals who find themselves incapable of forming a decision when faced with two

³³⁹ Angela Fagerlin, Brian J Zikmund-Fisher and Peter A Ubel, ‘Cure Me Even If It Kills Me: Preferences for Invasive Cancer Treatment’ (2005) 25 *Med Decis Making* 614, 617.

³⁴⁰ Weiss and Munson (n 323) 32.

³⁴¹ Blumenthal-Barby (n 315) 9–10.

³⁴² *ibid* 23–24.

³⁴³ *ibid* 11.

³⁴⁴ *ibid* 6.

or more options that are equally uncertain.³⁴⁵ Blumenthal-Barby offers an example to illustrate that possibility which resonates with the tragic choice faced by parents when presented with a WLST recommendation:

A man finds himself in the hospital on a ventilator and paralyzed from the neck down after a head-on motor vehicle accident. Both options (death and life on a ventilator) involved so much uncertainty (uncertainty about an afterlife, uncertainty about whether he could ever regain functioning and if not, what life paralyzed would be like) that he was paralyzingly ambivalent about what to do in the situation. He literally could not make a plan or form an intention about what to do.³⁴⁶

This interpretation of the ambiguity aversion bias sheds a slightly different light on the view of HCPs that some parents are not capable of consenting to WLST: the uncertainty and the complexity of the decision can hinder the process of actually *making a decision*.³⁴⁷

Similarly, even when parents have reached a point where they understand and accept that continuing with life-sustaining treatments will not result in a substantial improvement in their child's situation, the sunk-cost fallacy might thwart their resolve to consent to the course of action that would avoid unnecessary physical suffering. The sunk-cost fallacy involves the 'tendency to increase risk taking in the belief it will yield better returns, even when the demonstrable probability of this is low.'³⁴⁸ This bias might prompt parents to think that so many efforts have been invested to save their child that it would make sense to keep on going a little longer, just in case the result they hope for materialises.

Biases threatening intentionality relate to reason-responsiveness in that they compromise the response of parents to reasons that they themselves take as relevant and important. They may cause a breakdown between the preferences of parents and their reasoning. Such biases can lead to decisions that either do not reflect the preferences of parents or hinder the process of making or revising a

³⁴⁵ *ibid.*

³⁴⁶ *ibid* 11.

³⁴⁷ Weiss and Munson (n 323) 31.

³⁴⁸ Anne Preisz, 'Fast and Slow Thinking; and the Problem of Conflating Clinical Reasoning and Ethical Deliberation in Acute Decision-Making' (2019) 55 *J Paediatr Child Health* 621, 622.

decision. Furthermore, their effects appear likely to be compounded by the tragic and critical nature of decisions contemplated in the NICU context.

4.2.3 Impact on absence of alienating influence

The absence of ‘alienating influence’ is the last component in Blumenthal-Barby’s framework I address. An influence will be alienating if the person who made the decision does not retrospectively perceive the process leading up to a decision as their own.³⁴⁹ No decision can be free of influence; therefore, the question here is one of degree.³⁵⁰ Hence, what is at stake in determining whether an influence impairs autonomy ‘is the person’s attitude toward the influence that is leading that person toward one decision or action or another’.³⁵¹ Under this heading, I consider the bandwagon effect (also known as the conformity bias) and the hot-cold empathy gap.

Absence of alienating influence refers to the subjective appreciation of parents. Several influences might be at play during the decision-making process, but I will limit myself here to those that evidence a cognitive bias. At this point, Blumenthal-Barby suggests that the biases discussed in the previous subsections can alternatively be interpreted as plausible sources of alienating influence. For instance, some parents might reflect on their decision-making process and wonder if their preferences have been influenced by a conformity bias or bandwagon effect that would have led them to endorse a preference without much reflection. The bandwagon effect can be defined as ‘the tendency to be influenced by what others are doing or saying’.³⁵² In this case, such a feeling of alienation would align with the doubts expressed by Physician #1 about the genuineness of some reasons given by parents:

And you sometimes feel when people make requests, or seem to diminish or downplay that part of the experience, assessing the quality of life thing ... whether they are just using a coping mechanism, denial or ... to believe it, or whether they see themselves as slightly

³⁴⁹ Blumenthal-Barby (n 315) 12.

³⁵⁰ *ibid* 8.

³⁵¹ *ibid*.

³⁵² Stanak (n 323) 6.

heroic, or whether... You sometimes hear phrases you know you've heard in movies or on television, and you feel people are saying what they feel they ought to say; and I just worry sometimes that people don't really know [Physician #1]

The 'hot-cold empathy gap' or the 'projection bias' described by George Loewenstein is another potential source of alienating influence for parents in the highly stressful and emotional context of the NICU.³⁵³ Decision-making in the NICU appears a paradigmatic case for an 'interpersonal "hot-cold empathy gap"',³⁵⁴ where decisions have to be made in a 'hot' state of emotional arousal, while many of the consequences of that choice will reveal themselves in a relatively 'cooled down' context—where those involved will have a chance to reflect on their decision. The intrapersonal gap between 'hot' and 'cold' affective states combined with the passage of time has the potential of leading to a situation where parents would not recognise themselves in the decision they took and might therefore feel alienated from it. In a series of experiments, Loewenstein demonstrated that 'affective states have a large influence on people's preferences and, furthermore, that when in one affective state, people have trouble appreciating how they would feel, or predicting what their preferences would be, in a different affective state'.³⁵⁵ Loewenstein highlights two consequences for '[p]eople who are in "hot" states'. On one hand 'they typically believe that they are behaving more dispassionately than they actually are'. On the other, they are prone to 'overestimate the stability of their own current preferences'.³⁵⁶

Once again, some views expressed by HCPs seem to rest on a similar intuition. Of course, parents would have to say whether a cognitive bias has created such a gap and influenced their decision to the point of alienating them from it. Nonetheless, the following excerpt from a discussion group with nurses foreshadows such a realisation on the part of parents:

³⁵³ George Loewenstein, 'Hot-Cold Empathy Gaps and Medical Decision Making' (2005) 24 Health Psychology s49; Monica E Lemmon and Peter A Ubel, 'In Defense of Nudging When the Stakes Are High' (2019) 19 AJOB 62.

³⁵⁴ Loewenstein (n 353) s49.

³⁵⁵ George Loewenstein, 'Projection Bias in Medical Decision Making' (2005) 25 Med Decis Making 96, 97.

³⁵⁶ Loewenstein (n 353) s49.

Nurse #3: [...]. And I've had parents say to me, 'I don't care how [Inaudible] they are, as long as they are here.' And that's probably a big thing for withdrawals.

Nurse #2: But parents don't understand what the consequences are later. They only see their little baby that is absolutely lovely and beautiful, and they can cuddle it and pick it up; they don't see what it's going to be like in 12 months, 2 years, 6 years, 10 years' time. [Nurses discussion groups #4]

As the wording of Nurse #2's comments makes clear ('parents don't understand'), the hot-cold empathy gap could also be interpreted as impacting on understanding as it would seem to be blocking relevant reasons that parents will later see as relevant to their decision-making.

The situations I have described under the headings of intentionality and alienating influence may be understood as conflicts between competing desires or preferences attributed to the parents. It is difficult to treat one set of preferences as autonomous and the other one as autonomy impairing.³⁵⁷ It is therefore difficult to say that in responding to one reason over the other, parents are not being sufficiently responsive to reasons. It is ultimately the individuals concerned with the choice who would be able to say 'which desire or intention is more "true," more closely related to autonomy'.³⁵⁸ That being said, in the case where the decision to refuse WLST has indeed been impaired, we can suppose a time will arise when the projected negative outcome will materialise or that a significant portion of the uncertainty will dissipate. Parents will then come to realise the level and duration of additional suffering that their child has endured. Knowing the outcome, parents will be able to evaluate it. If someone were to present them with evidence that a bias influenced their decision to refuse WLST and asked them to endorse one desire over the other, they would likely opt for the desire that was not biased.

In this section, I demonstrated that the concerns voiced by HCPs regarding the decision-making capacity of parents resonate with the growing number of studies seeking to apply the insight of the heuristics and biases research programme to

³⁵⁷ Blumenthal-Barby (n 315) 13.

³⁵⁸ *ibid.*

decision-making in the clinical context. Building on Blumenthal-Barby's analysis of the impact of heuristics and biases on autonomous decision-making, I sought to demonstrate that the suspicions of HCPs can be reframed as a concern that the decision-making capacity of parents might be impaired by heuristics and bias beyond their control.

More empirical research is necessary to establish firmly whether cognitive biases have an impact on the reasoning of parents in the NICU and on their appreciation of their child's best interests and, if so, which ones and to what extent. Nonetheless, considering researchers have identified such biases in many different medical contexts and that the reports of HCPs in the London Unit converge with such a hypothesis, it is likely that cognitive biases can impair the capacity of parents to make the decisions in their child's best interests. These biases can help explain the limitations of an approach to obtaining consent which relies exclusively on rational deliberation and persuasion.

5. Justifying manipulative strategies

At first glance, manipulating parents appears ethically impermissible, even if the outcome sought is in the child's best interests. *London NICU's HCPs manipulate parents to withdraw life-sustaining treatments* would make a devastating media headline. As already noted, the RCPCH's framework on limiting treatments is clear on the matter. It states that '[p]rofessionals should not manipulate, coerce or deceive patients into doing what they (the professionals) believe would be in the patients' best interests'.³⁵⁹ Indeed, as I also mentioned in the GNM, some HCPs were even reluctant to use the word 'persuasion' in describing their interactions with parents.

Obviously, much turns on the definition given to these terms.³⁶⁰ The RCPCH's framework, for instance, does not define manipulation, coercion, deception nor persuasion. Considering it formulates a general prohibition on manipulation, the RCPCH's framework seems to imply that manipulation is always wrongful. I opted for

³⁵⁹ Larcher and others (n 46) s10.

³⁶⁰ Baron (n 282) 107.

a different approach. In this chapter, I adopted Gorin's conception of manipulation because it is broadly encompassing and that it allows for the possibility that manipulation might, in certain circumstances, be either permissible or justified.³⁶¹ To the extent I conclude that, in certain circumstances, these manipulative strategies are either permissible or justified, the upshot is the same as concluding that they do not amount to manipulation. Yet, distinguishing the identification of manipulation from its evaluation allows for a more precise analysis of the strategies that I have identified as potentially problematic.³⁶²

In this section, I discuss the ethical evaluation of the strategies I have described. I also discuss some relevant considerations when resorting to these strategies. In doing so, I draw some inspiration from the literature on the ethical permissibility of employing 'nudges' to influence behaviour. Cass Sunstein and Richard Thaler have introduced the concept of the 'nudge', largely as a policy response building on the heuristics and biases research programme initiated by Kahneman and Tversky.³⁶³ Bart Engelen and Thomas Nys provide the following definition of a nudge, summarising the refinements of the definition since Sunstein and Thaler formulated it in 2008:

we take nudges to be deliberate changes in people's choice architectures with the intention of predictably influencing their behavior by tapping into a-rational psychological mechanisms – often labelled 'heuristics and biases' – and thus without merely informing, rationally persuading, incentivizing or coercing them³⁶⁴.

While heuristics and biases impair the quality of the decisions individuals make, they are also paradoxically used to devise interventions aimed at improving the outcomes of decisions.³⁶⁵ Paradigmatic examples of nudges include, for instance, placing healthy products at eye level in a cafeteria to catch the attention of consumers and

³⁶¹ Gorin, 'Paternalistic Manipulation' (n 270) 246; Noggle (n 281) s. 3.1.

³⁶² Noggle (n 281).

³⁶³ Richard H Thaler and Cass R Sunstein, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (Yale University Press 2008) 6.

³⁶⁴ Bart Engelen and Thomas Nys, 'Nudging and Autonomy: Analyzing and Alleviating the Worries' (2020) 11 *Rev Phil Psych* 137, 139.

³⁶⁵ Blumenthal-Barby (n 315) 14.

influence them to choose these products instead of less healthy snacks.³⁶⁶

Two main reasons lead me to distinguish the strategies I am discussing here from nudges strictly defined. First, although I would argue that HCPs are intentionally and purposefully using these strategies to obtain parental consent to WLST, these strategies are not explicitly *designed* with that purpose in mind. In that sense, they differ from paradigmatic nudges, which are carefully planned and tested.³⁶⁷ The strategies used by HCPs are perhaps better understood as ‘tricks of the trade’ identified, developed and transmitted informally and intuitively through experience.

Secondly, Yashar Saghai has convincingly demonstrated that for the concept of nudge to be analytically useful, it has to be limited to ‘easily resistible’³⁶⁸ influence. According to Saghai, easy resistibility is a necessary condition if an intervention is to preserve ‘freedom of choice’ as argued by nudges proponents.³⁶⁹ The strategies I am discussing here go over the low threshold of easy resistibility that would qualify them as nudges. The high-stress, worrying and exhausting circumstances in which parents find themselves in the NICU are likely to make resisting manipulative interventions more difficult.³⁷⁰ Similarly, the expertise and authority of HCPs can also affect the capacity of parents to resist their influence.³⁷¹ Furthermore, some social norms triggered by referring parents to their extended families and spiritual advisors can be powerful and hardly ‘easily resistible’.³⁷²

The strategies that HCPs reported using in their interactions with parents nonetheless appear to be structured to harness predictable psychological

³⁶⁶ Anneliese Arno and Steve Thomas, ‘The Efficacy of Nudge Theory Strategies in Influencing Adult Dietary Behaviour: A Systematic Review and Meta-Analysis’ (2016) 16 BMC Public Health 676, 5; Thaler and Sunstein (n 363) 1–3.

³⁶⁷ Bart Engelen, ‘Ethical Criteria for Health-Promoting Nudges: A Case-by-Case Analysis’ (2019) 19 AJOB 48, 49; See also Halpern, Ubel and Asch (n 314) 1341; JS Blumenthal-Barby and Hadley Burroughs, ‘Seeking Better Health Care Outcomes: The Ethics of Using the “Nudge”’ (2012) 12 AJOB 1.

³⁶⁸ Yashar Saghai, ‘Salvaging the Concept of Nudge’ (2013) 39 JME 487, 489–491.

³⁶⁹ *ibid* 489.

³⁷⁰ *ibid* 490.

³⁷¹ *ibid*.

³⁷² *ibid* 492.

mechanisms to counter the effects of other psychological mechanisms. This is what warrants drawing on the literature on nudges.

5.1 When are manipulative strategies justified?

In this section, I argue that HCPs are, to a certain extent, justified in using manipulative strategies in their interactions with parents. First, I briefly return to Gorin's point about the fact that lack of responsiveness to reasons justifies manipulative strategies when objective reasons support the behaviour promoted. I discuss the predicament of parents with a child in the NICU and elaborate on the reasons justifying resort to strategies I characterised as manipulative in the previous section. I then delineate the limited nature of that justification, insisting on the importance of transparency and proportionality in the use of these strategies. I sketch out the circumstances where those strategies will be most justified and those where they will not be. Finally, in the conclusion to this chapter, I will argue in favour of HCPs filing an application to the High Court when GTWP does not yield the expected results, instead of prolonging it beyond what is justified or applying manipulative strategies to reason-responsive parents.

In exploring whether strategies deployed by HCPs are permissible or wrongful, I must first return to Gorin's account of manipulation. His account makes room for certain instances of manipulation to be ethically permissible based on a lack of responsiveness to reasons on the part of the manipulee. For this reason, in his view:

manipulation is not always even *pro tanto* wrongful, for an influencer cannot be obligated to limit her means of influence to reason-tracking forms of influence when the agents she intends to influence is not responsive to the relevant reasons. [...] When an agent is unable to recognise or respond directly to the reasons that, were she to recognise and respond to them, would promote her good, it is permissible to manipulate her into acting in accordance with these reasons.³⁷³

Clearly, it would be absurd to insist on providing reasons to someone who cannot understand and react to these reasons. Partial or limited responsiveness to relevant reasons might also contribute to making manipulative influence permissible to the extent that it aims at generating behaviour justified by the reasons to which the agent

³⁷³ Gorin, 'Paternalistic Manipulation' (n 270) 246.

is not responsive.³⁷⁴ This points to the main reason why I take the strategies I am discussing here to be permissible if a lack of responsiveness to reasons is present. The relationship between child, parents and HCPs is structured around and gives priority to the child's best interests. Their interactions are inherently oriented toward a predefined and mutually shared goal. Unlike capable adults making decisions for themselves, parents have the duty to make decisions that are in the objective best interests of their child.³⁷⁵ HCPs also have converging duties to propose treatments furthering the best interests of their patients, and to monitor the decisions of parents considering the same standard. Thus, the focal point of their interactions is not the exercise or realisation of parental autonomy, which would significantly raise the bar of permissible influence.³⁷⁶

5.2 The need for transparency

It is important that HCPs be transparent with parents about the structure of their interactions with them. First, HCPs must explicitly state that their overarching concern is to promote the best interests of their patients. They should also stress that it is their duty to do so, and that they will engage in discussions about fundamental beliefs and values with parents. It should be as clear as possible to any parents entering into discussion with HCPs that, while shared decision-making is highly valued, unlike the best interests of the child, it is not an end in itself.

Secondly, HCPs must prioritise transparency and openness regarding the deficiencies in reasoning that they seek to counter through manipulative strategies.³⁷⁷ To keep with the metaphor of the journey underlying GTWP, HCPs must warn parents of the perils lying ahead. Before resorting to nudges or less easily resistible strategies to influence the decisions of parents, HCPs must also inform and educate parents about the risks of biases and heuristics in decision-making. Initially,

³⁷⁴ *ibid.*

³⁷⁵ Rachel Taylor, 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Hart 2019) 52; Blumenthal-Barby and Opel (n 287) 35.

³⁷⁶ Blumenthal-Barby and Opel (n 287) 35.

³⁷⁷ Sandman and Munthe (n 258) 80.

such transparency may translate into a general warning about the risk of cognitive biases, which are intrinsic to every human being and are also susceptible of being compounded in such highly stressful, exhausting, and emotionally demanding situations as having a child in the NICU. Alongside the affirmation of the best interests of the child as the teams' guiding principle, a frank and open disclosure of the fact that HCPs will attempt to detect and alleviate the impact of these biases in their interactions with parents should therefore be a central element of their early interactions with parents.

5.3 The need for proportionality

Although educating surrogate decision makers about cognitive biases and promoting reflexivity about their effects are ethically appealing strategies because they represent the lightest level of intervention, recent empirical research suggests that education and reflexivity might not be sufficient in the critical care context.³⁷⁸ For this reason, in practice, it appears more effective to counter the effect of cognitive biases by using strategies that harness them, rather than simply denouncing them.³⁷⁹

However, if HCPs aspire to a high ethical standard, they should keep paternalistic manipulation to a minimum. Resorting to alternative means of influence must therefore be proportional to the perceived defect in reason-responsiveness. As I already mentioned, rational deliberation about the best interests of the child and rational persuasion are ethically superior to any other means of influence that HCPs might deploy. Hence, other means of influence are only acceptable when it appears that strictly rational means of influence will not lead to a decision sufficiently in line with best interests for HCPs.³⁸⁰ Furthermore, while it would be beyond the scope of this chapter to rule on this question, the possibility that the use of manipulative strategies, even when justified, 'leaves a moral residue' should not be neglected.³⁸¹

³⁷⁸ Hart and Halpern (n 312) 25.

³⁷⁹ Blumenthal-Barby (n 315) 14.

³⁸⁰ Jo Bridgeman, 'Beyond Best Interests: A Question of Professional Conscience?' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Hart 2019).

³⁸¹ Baron (n 282) 117.

The requirement of proportionality also involves moving as slowly as possible from rational deliberation to persuasion and paternalistic manipulation. Before considering evidence of biases as justifying manipulative strategies, HCPs might also use such evidence in rational deliberation, building on earlier and more general transparent conversations about the risk of biases. They can point parents to parents which of their responses and attitude they are concerned might instantiate the kind of biased thinking against which they had previously warned them. Again, if resort to non-reason tracking strategies as a complement to rational influence is announced and expected and their use is tied to previously introduced reasons, it will be more easily kept to a minimum.³⁸²

5.3.1 Assistance in identifying preferences

For this reason, non-reason tracking strategies will be most appropriate in cases where the complexity of the situation, compounded by the effect of cognitive biases, make it difficult for parents to align their values, beliefs and preference with a particular outcome. Such a situation would arise, for example, when parents are dedicated to acting in the best interests of their child but cannot decide whether that should translate into prolonging or withdrawing life-sustaining treatments. Gorin and others, addressing the justification of nudges in adult care settings, write: ‘when a patient’s values are indeterminate with respect to her options [...] then it is permissible to steer her toward an independently justified option’.³⁸³

In such cases, HCPs may be seen more as helping parents to decide what they want for their child than as forcing their values upon them.³⁸⁴ Furthermore, some strategies – although they do not strictly track reasons – may allow parents to gain a clearer understanding of their child’s situation and therefore be in a better position to make decisions reflecting their preferences. Blumenthal-Barby and Naik observe that paying attention to the way information is shared is likely to assist decision makers in

³⁸² *ibid* 118–119.

³⁸³ Gorin and others (n 283) 36.

³⁸⁴ *ibid*; Engelen (n 367) 54.

understanding the ‘gist’ or the essential elements of the information shared with them.³⁸⁵ For instance, if the information is framed so as to highlight risks of morbidity or disability, as long as this framing objectively reflects the situation, the ‘gist’ understanding of the situation will be easier to relate to their values and preferences than seemingly neutral information. In that case, the parent’s decision would be more informed than if they were simply presented with the ‘bare facts’ without any orienting guidance.

Similarly, steering parents toward what HCPs take to be the child’s best interests might relieve them from ‘the decisional burden regarding what is in the child’s best interests’ and thus be welcomed by parents.³⁸⁶ Indeed, this is what I have described in the GNM as ‘Easing the burden from the parents’ shoulders’ in chapter V. HCPs perceive that some parents find it extremely difficult to make the decision to withdraw life-sustaining treatment themselves, although they understand the reasons underlying the recommendation. Blumenthal-Barby and Opel support this position by relying on studies indicating that over 80% of family members involved in end-of-life decision-making in the intensive care context show symptoms of post-traumatic stress, while a significant portion of adults wish to delegate decision-making either entirely or partially to HCPs.³⁸⁷

5.3.2 Respecting strong preferences

On the other hand, parents with strong preferences against WLST are unlikely to be swayed by the way the information is framed or by any of the strategies described above. Indeed, while they might not be responsive to the rational case HCPs put to them, these parents are responsive to reasons, albeit to a different set of reasons than those wielded by HCPs.

Hence, the justification for resorting to manipulative strategies is much weaker. First,

³⁸⁵ JS Blumenthal-Barby and Aanand D Naik, ‘In Defense of Nudge–Autonomy Compatibility’ (2015) 15 *AJOB* 45, 46.

³⁸⁶ Blumenthal-Barby and Opel (n 287) 37.

³⁸⁷ *ibid.*

such strategies appear to be much less efficient in such cases than in others.³⁸⁸ Again, as noted by Gorin and colleagues: evidence suggests that decision-makers, including patients, can and do override nudges to select alternative options when they see fit to do so. In the context of shared decision-making, it seems even less likely that patients would be so overwhelmed or confused by a nudge that they would fail to select options that align with their values.³⁸⁹

Religious or spiritual beliefs are often (although not necessarily, nor exclusively) at the root of such strong preferences. The literature suggests that some parents who hold strong religious preferences against WLST do resist that recommendation. For instance, Brierley *et al.* identified fervent religious beliefs as roadblocks on the way for parents to accept a recommendation to withdraw life-sustaining treatment in the PICU, notwithstanding the prolonged interactive process described in that study³⁹⁰. Similarly, Haward *et al.* found that parents who indicated a strong preference for preserving life, and those who identified with a strong religious faith, were less likely to be influenced by the framing of information about perinatal resuscitation decisions.³⁹¹

This also suggests that these parents will not derive much benefit from exposure to a prolonged interactional process like GTWP. Indeed, they might suffer from it, especially if they experience it as a lack of respect for their most fundamental beliefs. If we accept that, in the case of neonates, shared decision-making is largely justified by the interests of the child's parents, GTWP loses much of its underlying legitimacy when it does not achieve that purpose.³⁹² HCPs ought therefore to be particularly attentive to identifying parents with strong preferences, for in their case, resorting to manipulative strategies would both be inefficient and unjustified.

This distinction between those parents who seem to be less responsive to reasons,

³⁸⁸ Gorin and others (n 283) 36. Blumenthal-Barby and Opel (n 287) 36.

³⁸⁹ Gorin and others (n 283) 36.

³⁹⁰ Brierley, Linthicum and Petros (n 4) 574.

³⁹¹ Haward, Murphy and Lorenz (n 314) 112.

³⁹² Birchley, 'Deciding Together?' (n 42) 219.

notably because of cognitive biases, and those who are responsive and yet disagree with the recommendation of HCPs is crucial. In the former case, I have argued that it is permissible to gently steer parents toward what HCPs view as the child's best interests. On the contrary, in the latter case, resorting to manipulative strategies is not permissible. However, this does not mean that HCPs must accept the position of parents. If rational deliberation and persuasion fail to yield a result that is acceptable to HCPs, they must turn to other strategies. Similarly, if GTWP does not succeed in securing the consent of parents to an acceptable course of action, increasing the pressure on parents or indefinitely prolonging GTWP is not a viable option.

6. When you can't get there: going to court as the ethically superior option

In this chapter, I used Moti Gorin account of manipulation as influence that fails to track reasons. In the case of reason-responsive agents, the wrong of manipulation is thus to attempt to influence them to behave in a way that does not accord with their reasons for acting, despite a legitimate end-goal. However, I have also shown that HCPs are sometimes justified in applying manipulative strategies in their interactions with parents for the latter's reason responsiveness may be impaired by cognitive biases.

This chapter and indeed this thesis, are mainly concerned with the processes of influence taking place in the NICU between HCPs and parents. However, to conclude, I would like to share a few thoughts on the options for HCPs beyond GTWP. As I explained in section 3 of Chapter V, HCPs perceive the alternative solutions available to them negatively, namely taking the matter to the clinical ethics committee or to the High Court, and only turn to them with reluctance. This reluctance, I suggested then, involves the risk of distorting GTWP.

This reluctance has been documented in other studies conducted in the United Kingdom. Birchley *et al.* indicate that clinicians working in PICUs rely heavily on interactional processes and display distaste for going to court.³⁹³ Similarly, in Brierley

³⁹³ Birchley and others (n 46) 933–34; Birchley and Huxtable (n 40) 122–123.

et al.'s study, the High Court was only approached in one of the 203 cases reviewed. In discussing their results, the authors note that it is only 'after many weeks or months of protracted unsuccessful discussions, with both sides trying to get the other to see their point of view, [that] a request is made to the courts for a declaration on how to proceed'. They add that '[m]any [HCPs] are unused to or unprepared to take this route and leave the child in an unacceptable condition for fear of unfavourable publicity or costs or outcome'.³⁹⁴

However counter-intuitive this might appear to HCPs (and probably to parents as well), I argue that bringing the matter to court is a morally superior option than unduly prolonging GTWP.³⁹⁵ According to HCPs, court applications are unpalatable notably because they are redundant and because of their perceived impact on the welfare of parents. I will briefly address both points.

Redundancy can be interpreted negatively as a synonym of inefficiency, but it can also be a quality of well-designed systems contributing to their efficacy and resilience.³⁹⁶ Hence, I do not want to refute the claim that the court process is redundant; rather I want to suggest that it should be seen in a more favourable light. Importantly, the judicial process aims at ensuring that the final decision tracks the reasons that are applicable to the child's situation as closely as possible. Thus, it is uniquely placed to deliver an outcome conforming to the normative reasons identified by HCPs, although the primary processes which were used to implement them – rational deliberation, persuasion and gentle steering – did not succeed. There is an undeniable element of repetition between the two processes. Taking the matter to court appears redundant from the perspective of HCPs because it is not premised on a fundamentally different intellectual process than the one they carry out to determine best interests. If the process I have described as JIC has been conducted conscientiously and thoroughly, the same reasons identified then by HCPs will be

³⁹⁴ Brierley, Linthicum and Petros (n 4) 576.

³⁹⁵ Austin and Huxtable (n 39) 217.

³⁹⁶ Janice Gross Stein, 'Bad Translation or Double Standard? Productivity and Accountability Across the Private, Public and Voluntary Sectors' (2002) 2 *Rev Econ Perf Soc Prog* 259, 264.

presented to the Court. There is also a high probability that the court will acknowledge these reasons as amounting to a convincing view of the child's best interests. Yet, by introducing a neutral third party along with numerous procedural guarantees, the judicial process offers a chance to reevaluate the respective positions of both parents and HCPs and to bring back the focus on the child.³⁹⁷ By operating at a different, much slower pace than clinical decision-making, the judicial process ensures that if any aspect of the child's situation has been overlooked, the contradictory debate between the parties is likely to bring it to the forefront. Ultimately, it is a safety net, adding to the protection of the interests of the child.

Court proceedings are also perceived as arcane, stressful and costly for all parties involved. There is undoubtedly more than a modicum of truth in this perception and HCPs are often reluctant to bring an application to court, for they see it as going against the welfare of the child's parents. Yet, these negative perceptions should be balanced against the fact that the judicial process (notwithstanding its many shortcomings) entails a recognition of the status of parents as agents who are rational and responsible for their actions. The observations made by Jeremy Waldron about the role played by legal procedure in upholding human dignity can be transposed to the matter at hand:

law is a mode of governing people that treats them as though they had a perspective of their own to present on the application of norms to their conduct and situation. Applying a norm to a human individual is not like deciding what to do about a rabid animal or a dilapidated house. It involves paying attention to a point of view. As such it embodies a crucial dignitarian idea – respecting the dignity of those to whom the norms are applied as beings capable of explaining themselves.³⁹⁸

Just like respect for personal autonomy means HCPs cannot force their preferred treatment on competent adults, they should not impose their assessment of parents' welfare on them.³⁹⁹ Again, as argued by Waldron, the fact that in court proceedings arguments have to be presented and defended by the parties is another way in which the law respects human dignity:

³⁹⁷ Birchley, 'Deciding Together?' (n 42) 215–216.

³⁹⁸ Jeremy Waldron, 'How Law Protects Dignity' (2012) 71 Cambridge LJ 200, 210.

³⁹⁹ Ian Kennedy, *Treat Me Right: Essays in Medical Law and Ethics* (OUP 1991) 56.

In this way too, then, law pays respect to the people who live under it, conceiving them as the bearers of reason and intelligence. The individuals whose lives law governs are treated by it as thinkers who can grasp and grapple with the rationale of that governance and relate it in complex but intelligible ways to their own view of the relation between their actions and purposes and the actions and purposes of the state.⁴⁰⁰

To take only one example, it must have been a terrible ordeal for everyone to be involved in the series of hearings concerning Charlie Gard. Neither HCPs nor parents could have been happy to find themselves in front of a judge and dispute each other's assessment of best interests, while continuing to care for baby Charlie daily. Nobody's welfare was enhanced by going down this route. Not even the child's: if we accept the outcome of the case, WLST would have been in Charlie's interests much earlier than when it happened.⁴⁰¹ Yet, there is value in the fact that the issues could be debated extensively, almost exhaustively. The position of parents challenged the fundamental philosophical underpinnings of this area of law, contesting the distribution of authority to determine the best interests of a child between HCPs, the state and parents. Although the court ultimately rejected the parents' position, it remains that, throughout, the process was premised on 'respect for freedom and dignity of each person as an active intelligence'.⁴⁰² This is, in my view, a strong reason why, if a reasonable amount of time has passed and it is apparent that an acceptable consensus cannot be reached through deliberation and persuasion, it is much more respectful for both the autonomy of parents and the best interests of their child to make an application to court for an authoritative determination of the dispute than to prolong GTWP.

⁴⁰⁰ Waldron (n 398) 211.

⁴⁰¹ Bridgeman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom' (n 3) 301.

⁴⁰² Waldron (n 398) 212.

Concluding overview

In this brief conclusion, I provide an overview of my thesis. I start by briefly restating the questions that prompted and guided my research. I then sketch out grounded normative theory, the research methodology I developed for this project and introduce my research design. I then highlight the main elements of the two constituting parts of this thesis: Getting There With Parents, the grounded normative model I elaborated on the basis of the fieldwork I conducted in the London NICU, and the normative critique of the GNM I articulated in the thesis' last two chapters.

1. Research questions

This thesis' overarching research question is: *how can the way healthcare professionals approach legal and ethical issues relating to WLST in the London NICU be improved?* In every step along the way to answering this question, I sought to stay close to the specific context of the London NICU. This led me to dedicate a significant portion of the thesis to a preliminary descriptive question *how do healthcare professionals in the London NICU approach legal and ethical issues relating to WLST?* Indeed, any attempt at reform needs to be grounded in an understanding of the dynamics and processes at play in the targeted setting.

2. Grounded normative theory: research methodology and design

A central component of this thesis is therefore the GNM that I constructed on the basis of the case study of the London NICU I conducted over a period of 27 months. In addition to observing the NICU and the CEC, I conducted 16 in-depth interviews with HCPs practising in or around the NICU. Physicians, surgeons, nurses, solicitors, allied professionals and a member of the CEC contributed to the data generating process at this stage. I also conducted six discussion groups : four with nurses, one with consultant intensivists and one with the CEC.

To direct the conduct of the empirical component of my thesis, I devised a methodology, which I called 'Grounded normative theory' and presented in Chapter II. This methodology builds on the empirical ethics research programme interpreted through the lens of pragmatism, social constructivism and legal pluralism, which I introduced in Chapter I. Giving a leading role to empirical data to define and seek to resolve normative questions allows to attune the research to the experiences and concerns of those confronted with normative issues in practice, therefore increasing the resonance of normative proposals or critiques elaborated to respond to these issues in the second half of this thesis. Grounded normative theory is also significantly indebted to grounded theory, a qualitative research methodology. From grounded theory, I borrowed the qualitative data analysis methods I applied in constructing the GNM, but also a focus on the interactional construction of social reality. I endeavoured to be reflexive and transparent about my use of grounded theory methods, notably coding and memo writing and gave an account of how I inserted them into my project.

Following Ives,⁴⁰³ I used the notion of reflexive balancing to bridge the gap between the descriptive exercise culminating in the construction of the GNM and the normative exercise through which I criticised certain aspects of the GNM and made suggestions for improvement in the practice of the London NICU. First, as the intertwined data collection and data analysis processes unfolded, I increasingly tried to involve participants in the normative assessment of the model I was constructing on the basis of our interactions. Once the GNM was completed, I then took it as the starting point of my normative inquiry about interactional processes relating to WLST in the London NICU. The GNM thus guided me in choosing which issues to address and in identifying the literature which spoke to these issues instead of imposing issues arising from the literature on the practice of HCPs in the London NICU.

3. Getting There With Parents: a grounded normative model

In itself, the GNM is a significant contribution to knowledge about the details of the

⁴⁰³ Ives, 'Reflexive Balancing' (n 18).

interactional process concerning WLST from neonates and infants in the NICU. Spanning over Chapters III to V, the GNM forms the heart of this thesis. Careful interpretation of the data I generated in collaboration with the participants allowed me to elaborate a theory of decision-making surrounding WLST. It shows how the best interests of the child are understood and operationalised by HCPs in the NICU. The GNM is entitled Getting There With Parents. It involves two main processes: Justifying intensive care (JIC) and Getting there with parents (GTWP).

3.1 Justifying intensive care

In Chapters III and IV, I present JIC, which models how HCPs arrive at a recommendation to WLST following a two-factor process for determining the child's best interests. The first set of factors, 'medical best interests' is the main one, while the second set of factors, 'wider best interests', modulates medical best interests' initial conclusion.

Considering medical best interests, I show how a recommendation to WLST results from a collegial and deliberative process in which medical expertise and clinical data are central and where the best interests of the child is largely equated with deploying the full extent of the treatments available in the NICU. Critical care in the NICU is fast paced and aims at a quick turnaround of patients.

However, when a child spends more time than average in the NICU, an ethical question comes into sharper focus: that of justifying providing aggressive intensive care to that child. The presumption in favour of aggressive treatment aimed at curing or managing the child's conditions appears to be rebuttable as HCPs begin to question both the current experience of the child and project their medical condition into the future. HCPs thus balance the significant burdens they associate with aggressive treatment in the NICU against their projection about the future of the child in terms of functional outcome and survival.

For HCPs, this implies that continuing with painful life-sustaining treatments might

not be justified and therefore that WLST would be in the child's best interests. The plausibility of this conclusion distinguishes HCPs practising in the London NICU from many parents who might never have had to contemplate it, as well as from HCPs practising in a different clinical setting who might either have a less proximate relationship with neonatal death or organise their practice around different values. In the most extreme cases, which I presented in the conclusion to Chapter III as 'nursing a corpse in the bed', the elements considered under the heading of medical best interests will be sufficient for HCPs to recommend WLST.

However, in more nuanced cases, HCPs derive a working hypothesis from their analysis of medical best interests. They then modulate this analysis considering a second set of factors, which I labelled as wider best interests in Chapter IV. At that stage, HCPs expand their perspective to situate the child in a broader context, which includes a projection of the child's future quality of life and the preferences of the child's parents. The status of predictions about the child's future quality of life is ambiguous because not everyone agrees whether it should be assessed primarily by parents or by HCPs. Nonetheless, there is a widespread consensus as to their relevance to best interests.

I also highlighted that quality of life is regularly used by HCPs as a euphemism to discuss the long-term impact of severe disability on children. Indeed, there are pessimistic overtones the way many HCPs consider the life of a child with severe disability. HCPs tend to associate significant burdens with the severe end of the range of outcomes following a prolonged stay in the NICU. Often, these burdens are conceived in opposition with HCPs' perceptions of the normal development of children without disability.

The second component of wider best interests I discussed was the preferences of parents. At that stage, when the purpose for HCPs is still to formulate a recommendation as to the child's best interests, parental preferences are afforded limited weight in the assessment. They are primarily considered in connection with

the feasibility of proposed treatment plans and potential outcomes for the child.

HCPs clearly indicate that, while they consider the preferences of parents at the wider best interests stage, they do not consider them to trump their assessment. Confronted with a broad range of parental preferences, they rely on their medically informed conception of best interests as a guide in deciding which preferences ought to be accommodated and which ones should not.

I concluded Chapter IV and my presentation of JIC with a discussion of two factors HCPs explicitly reject as forming part of their assessment of a child's best interests: optimising resource allocation and protecting the reputation of the hospital. HCPs acknowledge these factors could play a role in a decision relating to WLST, but insist they do not. At the most, some HCPs admit that once a conclusion has been reached as to the child's best interests, its implementation might be influenced by resource allocation considerations but never to the detriment of the child's best interests.

3.2 Getting there with parents

While JIC is concerned with the elaboration of a recommendation as to the child's best interests, GTWP is the process through which HCPs seek to carry out their recommendation. In Chapter V, I present a fundamental dilemma HCPs face between obtaining the consent of parents before WLST and their suspicions about the capacity of parents to adequately assess their child's best interests. These two opposing premises set GTWP into motion.

HCPs recognise that it is easier and quicker for them to accept that WLST might be in a child's best interests. Consequently, HCPs deploy significant efforts to build and manage a common frame of reference in their discussions with parents, so the latter come to accept their recommendation. On one hand, they try to steer the parents' factual expectations by adapting the clinical information they introduce to parents to match their objective. On the other, HCPs also seek to ensure that parents receive

psychosocial support to come to terms with the tragic situation they face. In this context, managing expectations also involves HCPs being attuned to the preferences of parents regarding the role they are willing to play in deciding that WLST is in their child's best interests.

I then discussed GTWP's potential breakdowns and the ensuing alternatives to it. I observed that HCPs are significantly committed to GTWP. Even when they cannot get where they want to go with parents, HCPs are reluctant to shift gears and turn to other forums such as the CEC or the High Court. Abandoning GTWP is perceived as personal failure by many HCPs and going to court is seen as expensive and often redundant.

Finally, I concluded Chapter V and my presentation of the GNM by analysing two symmetrical ways in which HCPs perceive GTWP as susceptible to go astray. When HCPs put parents first, they give too much weight to the latter's preferences to the detriment of the objectively assessed best interests of the child. Conversely, when they push parents to get there, HCPs prioritise the implementation of their recommendation at the expense of the agency of parents.

4. Assessing Getting There With Parents

The GNM provides a detailed and empirically grounded picture of the interactional processes surrounding WLST in the London NICU. In the last two chapters of the thesis, I moved from the descriptive to the normative with a constructive critique of the processes of decision-making captured by the GNM. On the basis of the deep acquaintance with the data I acquired in my fieldwork and in constructing the GNM, I selected one line of critique for each of the two major processes constituting Getting There With Parents.

4.1 The chronotope of best interests in the NICU

In Chapter VI, I explored the spatiotemporal construction of the NICU's normativity in JIC. I argued that the determination of best interests by HCPs is deeply influenced

by what I described — following Valverde⁴⁰⁴ — as the chronotope of best interests in the NICU. Building on illustrations from the GNM, I demonstrated that determined conceptions of time and space coalesce to give meaning to the situation of the child and guide the decisions, by delineating what is permissible and what is not.

The chronotope of best interests in the NICU instantiates a narrowly determined appreciation of the best interests of a child hospitalised in the NICU. This results from conceiving the NICU as a transitional space and the treatments provided therein as burdensome, with a focus on the physiological dimension of the child. It also creates an equivalence between discharge from the NICU and WLST.

Furthermore, the chronotope of best interests in the NICU has an isolating effect on children who find themselves cut off from their relationships with their parents. The chronotope of best interests is also operative in the way judges approach best interests when HCPs apply for permission for WLST. Furthermore, it entails a hierarchy of reasons which results in parents being excluded from the determination of best interests in JIC.

I therefore suggested giving more attention to the ideal dimension of the determination of the child's best interests to avoid marginalising the perspective of parents from inception. In concluding Chapter VI, I also noted that paying more attention to the ideal dimension of best interests would allow both HCPs and parents a better view on the political aspects of the situation they are confronted with, notably in relation to resource allocation.

4.2 Best interests, influence and manipulation

Finally, in Chapter VII, I analysed the practice of steering parents toward accepting the treating teams' recommendation, which I theorised as GTWP. First, applying Morin's philosophical account of manipulation as failure to track reasons, I pinpointed four strategies used by HCPs and showed how they could be characterised as

⁴⁰⁴ Valverde (n 191).

manipulative.

I then turned to exploring the justification offered by HCPs in relation to GTWP, namely the fact that parents lack the capacity to adequately assess their child's best interests. After concluding that the suspicions of HCPs could not be equated with a lack of legal capacity, I found a more plausible characterisation of the suspected incapacity of parents in terms of cognitive biases and heuristics. I reviewed several documented cognitive biases susceptible of impairing understanding or intentionality, as well as biases susceptible of leading to an alienating influence. I related these biases to the reports of HCPs about the attitudes and reactions of parents in the NICU.

I then addressed the question whether manipulative strategies used in response to cognitively impaired reasoning could be justified in the context of the NICU. Returning to Morin's account, I explained that failure to track reason could not be seen as ethically reprehensible if the target of the manipulation is unresponsive to the relevant reasons. Since cognitive biases are susceptible of causing such unresponsiveness to reasons, they can form the basis of a justification of manipulative strategies.

Yet, suspicions of cognitive biases do not justify resorting to manipulative strategies in all instances. I argued that such strategies have to be both transparent and proportional. On one hand, HCPs must warn parents of the risks of cognitive biases and inform them of the strategies they might rely on to counter them. On the other, HCPs also need to tailor these strategies to the extent of the lack of responsiveness to reasons they have identified. This, I suggested, entails that strategies aimed at enabling parents to align their preferences with their actions are more likely to be permissible than strategies aimed at overcoming strong preferences against WLST.

I concluded Chapter VII with a reflection on the reluctance of HCPs to bring disagreements with parents to court. I argued that when GTWP does not work or is

unlikely to work, going to court is the ethically superior option to prolonging GTWP for it tracks reasons and respects the dignity of parents as agents in both their own and their child's lives.

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Appendix A: The legal framework applicable to withdrawal of life-sustaining treatment from infants and young children

Introduction

In this appendix, I wish to summarise the formal legal framework applicable in England to WLST from infants and young children with no capacity to express preferences as to their favoured course of action. In this thesis, I aim to study how HCPs understand and use the principle of the best interests of the child. I am particularly focusing on how the best interests principle is used to justify a recommendation to WLST. In certain cases, the interactions between parents reach a stalemate and one of the parties, usually the NHS Trust running the hospital where the child is cared for, brings the question whether the recommendation corresponds to the best interests of the child to the courts for determination. However, a central assumption underlying this thesis is that these cases, despite their wide public exposure, are rare. Rather, what I seek to bring to light are the processes taking place in the NICU before the issue is brought to another forum, either the courts or the clinical ethics committee. Of course, these processes take place in a social context where formal law, as enacted by Parliament and as understood and applied by judges, plays a central role. HCPs have their own understandings of what formal law allows and forbids them to do and rely on these understandings in their interactions, both among themselves and with the parents of their patients.

Hence, I am synthesizing the formal in this appendix primarily to set out this social context and to allow for an appraisal of such understandings. For this reason, the discussion of the applicable law that I propose here does not have the depth and the breadth that could be expected if a critique of the law were in itself the main focus of this thesis. Here, I will restrict myself to offering a thematic and synthetic exposition of English law. Consequently, I will resist the temptation to provide an historical

presentation of the evolution of the law on WLST.⁴⁰⁵ Likewise, I do not purport to cover all decided cases. My discussion of the case law is therefore more illustrative than exhaustive and more expository than critical.

A few years have passed between the fieldwork that constitutes the core of this study and the time of writing this section. During that period, the issue of WLST for infants and young children has been the focus of intense scrutiny, from the media, the general public, in academia, and from all levels of courts, including the Supreme Court of the United Kingdom and the European Court of Human Rights. Of course, the judicial sagas surrounding Charlie Gard and Alfie Evans immediately spring to mind in this regard.⁴⁰⁶

This time lag led me to wonder whether to present the law as it stood when I was doing fieldwork or as it stands at the time of writing; in the latter case, I would be relying on judicial pronouncements that did not yet exist when I was discussing the subject matter of this thesis with participants. I finally opted for the latter to address the legal issues from the perspective of the present day. The legal framework has evolved during my fieldwork and since then, but I would argue that this evolution was mostly marginal. New facts have been litigated, some aspects of the law have received a different emphasis and some alternative arguments have been rejected, but, in the main, core legal principles remain the same. The differences between the two temporal points from which I could approach the law are not sufficiently important to justify focusing on an arbitrary point in the past and neglecting recent developments.

I begin by discussing the position of parents as primary decision makers for their children when there is no conflict as to the latter's best interests through the prism of the concept of parental responsibility. Next, I discuss the involvement of courts when

⁴⁰⁵ See e.g. Elliston (n 56) ch 4; Morris (n 4).

⁴⁰⁶ See e.g. Cave and Nottingham (n 3). MS Dauber, 'Bioethics and the Law: Should Courts Be Allowed to Make End of Life Decisions? Reflections on the Charlie Gard and Alfie Evans Controversies' (2018) 6 *Ethics, Medicine and Public Health* 94. and Bridgeman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom' (n 3).

HCPs and parents disagree or are uncertain as to the requirements of the best interests principle. First, I present the basis of the jurisdiction of the High Court to make decisions for children in such cases. This leads me to the most substantial part of this summary, where I will rely on a recent judicial restatement of the applicable legal principles as a springboard to discuss how courts assess the best interests of a young child when it is suggested that WLST might be required. Finally, I conclude my presentation of the current state of the law by reviewing certain arguments that have been raised in opposition to the English legal framework, most of them stemming from human rights law, but which were ultimately rejected by the courts.

1. The default legal position: parental responsibility

Before focusing on the way the High Court addresses cases where it is argued that it might be in the best interests of a child for life-sustaining treatment to be withdrawn or withheld, it is important to outline the default legal position of parents with regard to decisions concerning their children. I also highlight that because HCPs, like parents, have duties toward the child, the latter's position changes when a disagreement arises as to best interests requirements.

1.1 Parents as primary decision makers

Parental responsibility is defined by the Children Act 1989 (the 'Children Act') as 'all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property'.⁴⁰⁷ The Children Act does not elaborate any further on the substance of parental responsibility. Authors often rely on a list of prerogatives derived from the common law to substantiate parental responsibility.⁴⁰⁸ In most day-to-day, non-conflictual situations, holders of parental responsibility enjoy a broad discretion to determine how they wish to rear their children and to make the specific decisions necessary to realise their conception of parenthood, as long as they respect the duties that are imposed upon them.⁴⁰⁹ The

⁴⁰⁷ Children Act 1989 s. 2(1).

⁴⁰⁸ An authoritative list is found in Nigel V Lowe and Gillian Douglas, *Bromley's Family Law* (OUP 2007) 377. See also Stephen Gilmore and Andrew Bainham, *Children: The Modern Law* (4th edition, Jordan Publishing 2013) 330–331.

⁴⁰⁹ Andrew Bainham, 'Is Anything Now Left of Parental Rights' in Rebecca Probert, Stephen Gilmore and Jonathan Herring (eds), *Responsible parents and parental responsibility* (Hart 2009).

discretion afforded to parents is often said to be indirectly justified by the fact that they are best placed to appreciate the precise requirements of the situation at hand, and by the close and intimate connection between parents and their children.⁴¹⁰ More controversially, some authors add that parents are not bound by the welfare or best interests principle in their everyday decisions about their child. For instance, according to Bainham and Gilmore, parents—as they must balance their own interests, obligations, and aspirations, along with those of other members of their family, and therefore cannot be seen as being obliged to prioritise the welfare or best interests of one child over those of others.⁴¹¹ In any event, the state does not actively monitor the exercise of parental responsibility, such that even if a duty exists, it is not enforced.⁴¹² However, when a conflict or a potentially harmful situation is brought to the attention of a court of law by one of the holders of parental responsibility, by the child, by a concerned third party such as a healthcare institution, or by a local authority, the welfare principle undoubtedly bounds the court's determination.

Furthering and preserving the health the children in their charge is at the heart of parental duties, and it this responsibility undeniably entails certain duties and powers. With regard to the relationship between parents and children in the medical context, the default position is that those who hold parental responsibility for a child—usually the parents—have both the duty to seek medical treatment for the child in situations where it is needed, and the power to consent to such treatment. As noted by Bridgeman

It is parental responsibility which gives the holder the duty, powers, and authority to provide day-to-day care and to make major decisions concerning a child's health and wellbeing from a visit to the doctor for treatment for a persistent cough, to making decisions about a child's treatment for cancer, to agreeing to the cessation of active treatment and the provision of palliative care to a child with a life-limiting condition.⁴¹³

1.2 The specificity of the medical context

Herring observes that parental responsibility operates differently in the medical context than in everyday circumstances, largely because of the weight of medical

⁴¹⁰ See e.g. Bridgeman, 'The Provision of Healthcare to Young and Dependent Children' (n 56) 377.

⁴¹¹ Gilmore and Bainham (n 408) 70–71.

⁴¹² Jonathan Herring, *Family Law* (8th edn, Pearson 2017) 464.

⁴¹³ Bridgeman, 'The Provision of Healthcare to Young and Dependent Children' (n 56) 379–380.

expertise.⁴¹⁴ In a medical context, the proposed course of action comes from doctors, who have a duty to further the best interests of an incapable patient and cannot be forced to provide a treatment they do not consider to be compatible with that duty.⁴¹⁵ It is clearly established that neither a capable patient nor the parents of an incapable child can force a doctor to provide a treatment that she is not disposed to offer.⁴¹⁶ The breadth of parental discretion is thus significantly diminished, being limited to consenting to or opposing to the course of action proposed by doctors, subject to the important caveat that such consent can come from somewhere else, notably the court, if parental refusal to consent is deemed to go against the best interests of the child.⁴¹⁷ In *Re A (Conjoined Twins)*, Ward LJ summarised the principle succinctly, stating: 'Parental right is, however, subordinate to welfare'. Medical treatment is fundamentally characterised as an invasion of bodily integrity and, as such, requires consent from the person concerned or a legally authorised representative. Again, in the words of Ward LJ in *Re A (Conjoined Twins)*: 'every person's body is inviolate'. As young children do not have the capacity to give consent to medical treatment themselves, parental responsibility entitles its holder to provide such consent. As stated by Lord Goff, this consent makes lawful what would otherwise be a tort or a crime:

It is well established that, as a general rule, the performance of a medical operation upon a person without his or her consent is unlawful, as constituting both the crime of battery and the tort of trespass to the person.⁴¹⁸

HCPs have a duty of care toward their patients that requires them to defend and further their best interests.⁴¹⁹ When HCPs take the view that the holders of parental responsibility are not acting in the child's best interests, or when they disagree with them as to what best interests entail, they ought to call upon the courts to ascertain what the child's specific circumstances require.⁴²⁰ This duty also flows from the

⁴¹⁴ Herring, 'Medical Decisions about Children' (n 46) 144.

⁴¹⁵ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [18]-[20].

⁴¹⁶ *ibid.*

⁴¹⁷ Herring, 'Medical Decisions about Children' (n 46) 145.

⁴¹⁸ *F v West Berkshire HA* [1991] UKHL 1, 20-21.

⁴¹⁹ *ibid.*; See also *R (Burke) v General Medical Council & Ors* [2005] EWCA Civ 1003 (Admin) [32].

⁴²⁰ *Glass* (n 45) [79].

principle of inviolability of the body; any treatment that is not in the best interests of a child is unlawful and cannot be made lawful in any way, not by parental consent nor by authorisation of the Court. Consequently, it will also be lawful to withdraw or to withhold it.⁴²¹ This principle was clearly set out by the Supreme Court in *Aintree*, its first case under the Mental Capacity Act 2005:

22. Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it.⁴²²

The formulation of the Supreme Court has since been adopted by the Court of Appeal in the context of decisions concerning children.⁴²³

2. Interventions by the courts

When presented with an application for declarations on whether or not it is lawful or not to continue to provide life-sustaining treatment to a young child, the High Court must consider the application in light of the best interests principle. In their reasons to refuse permission to appeal to the parents of Alfie Evans, a young boy suffering from a rare and unidentified neurodegenerative disorder, the Supreme Court described best interests assessments as 'the gold standard':

13. A child, unlike most adults, lacks the capacity to make a decision in relation to future arrangements for him. Where there is an issue in relation to them, the court is there to take the decision for him as it is for an adult who lacks that capacity.

14. The gold standard, by which most of these decisions are reached, is an assessment of his best interests. The first provision in the Children Act is that the child's welfare shall be the court's paramount consideration. Parliament's provision reflects international instruments, particularly the UN Convention on the Rights of the Child. And in the Human Rights Convention, the rights of a child under article 8 will, if inconsistent with the rights of his parents, prevail over them.⁴²⁴

⁴²¹ *Airedale NHS Trust v Bland* [1993] AC 789 (HL) 883.

⁴²² *Aintree* (n 415) [22].;

⁴²³ *Re A (A Child)* [2016] EWCA Civ 759, [31].

⁴²⁴ *Supreme Court of the United Kingdom, Reasons for the determination in the matter of Alfie Evans, 20 March 2018*. As per the Supreme Court of the United Kingdom Practice Direction 3, '[t]he reasons given for refusing permission to appeal should not be regarded as having any value as a precedent' (at 3.3.3) however they arguably should be regarded as carrying persuasive authority. Indeed, it is worth noting that the reasons

The implications of the best interests principle in withholding or withdrawal of life-sustaining treatment cases have been explored extensively ever since the first such cases have reached the courts. Yet, the basic criteria remain essentially the same and it has become commonplace in recent years for judges to state that, notwithstanding the tragic circumstances surrounding these applications and the need to pay close attention to the case at hand, these matters are governed by well settled legal principles.⁴²⁵ Indeed, there seems to be an increasing reluctance on the part of judges to engage in a detailed analysis of the precedents underlying the principle. For instance, in the *Evans* case, Justice Hayden wrote that:

47. The legal framework is now relatively easy to state though always difficult to apply in applications as sensitive and fact specific as this. I do not consider that an exegesis of the applicable Law is required here, indeed the risk is that to do so might eclipse the lode star which guides the Court's approach i.e. 'the best interests of the child'.⁴²⁶

Nonetheless, it is important for our purpose to review the main elements of that legal framework. I begin by laying out the basis of the jurisdiction of the High Court to determine the best interests of a child. I then present how this jurisdiction is exercised by the courts.

2.1 The jurisdiction of the High Court

The jurisdiction of the High Court to intervene with regard to the medical treatment of children originates in the doctrine of *parens patriae* and now also, from the Children Act. *Parens patriae* jurisdiction, literally translatable as 'parent of the country', represents the delegation of the responsibility to care for vulnerable or incapable individuals from the sovereign to the courts.⁴²⁷ Although some argue that *parens patriae* jurisdiction should be distinguished from the inherent jurisdiction of the High

provided by the Supreme Court to refuse permission to appeal have been cited in further cases, notably by the Court of Appeal in its decisions in the Alfie Evans case.

⁴²⁵ See e.g. *Re C (An Infant)* [2018] EWHC 2750 (Fam) [27]; *Kings College Hospital NHS Foundation Trust v Haastrup (Withdrawal of Medical Treatment)* [2018] EWHC 127 (Fam) [68]-[69]; *Great Ormond Street Hospital v Yates & Ors* [2017] EWHC 972 (Fam) [12].

⁴²⁶ *Evans* (n 223) [47].

⁴²⁷ Generally on *parens patriae* jurisdiction, see John Seymour, 'Parens Patriae and Wardship Powers: Their Nature and Origins' (1994) 14 *Oxford Journal of Legal Studies* 159; Graeme T Laurie, 'Parens Patriae Jurisdiction in the Medico-Legal Context: The Vagaries of Judicial Activism' (1999) 3 *Edinburgh Law Review* 95; See also Jonathan Herring, *Vulnerable Adults and the Law* (OUP 2016) ch 4.

Court⁴²⁸ because of their different historical origins, it must be acknowledged that *parens patriae* jurisdiction is indeed seen as inherent to the High Court and is often designated either as ‘the inherent *parens patriae* jurisdiction’⁴²⁹ or simply as ‘the inherent jurisdiction’.⁴³⁰ *Parens patriae* jurisdiction evolved over a long period of time. As Seymour explains, it first emerged as feudal wardship proceedings with the finality to fill the void with regard to property in the absence of a child’s parents.⁴³¹ However, nowadays the link with property having disappeared,⁴³² the purpose of *parens patriae* jurisdiction is entirely protective.⁴³³ It is also recognised that wardship does not exhaust the jurisdiction and is merely one procedural vehicle to exercise it.⁴³⁴ *Parens patriae* jurisdiction is broader than that of the child’s parents and therefore allows courts to go beyond what parents are allowed to do in protecting the child.⁴³⁵ This latter point is illustrated by the decision of the Court of Appeal in *Re R*. With regard to the question of whether, unlike the parents of a ‘Gillick competent’ child, the High Court is entitled to override the refusal to consent to care of a ‘Gillick-competent’ 15-year old who is also a ward of the Court, Lord Donaldson wrote:

It is, however, clear that the practical jurisdiction of the court is wider than that of parents. The court can, for example, forbid the publication of information about the ward or the ward’s family circumstances. It is also clear that this jurisdiction is not derivative from the parents’ rights and responsibilities, but derives from, or is, the delegated performance of the duties of the Crown to protect its subjects and particularly children who are the generations of the future [...]⁴³⁶

The *parens patriae* jurisdiction can either be exercised punctually to address a specific issue brought to the attention of the Court, or in the broader context of

⁴²⁸ Margaret Hall, ‘The Vulnerability Jurisdiction: Equity, *Parens Patriae*, and the Inherent Jurisdiction of the Court’ (2016) 2 Can. J. Comp. & Contemp. L. 185, 189.

⁴²⁹ See e.g. James Munby, ‘Protecting the Rights of Vulnerable and Incapacitous Adults - The Role of the Courts: An Example of Judicial Law Making’ (2014) 26 Child & Fam. L. Q. 64, 68.

⁴³⁰ See e.g. Rob George, ‘The Inherent Jurisdiction and Child Protection’ (2015) 37 Journal of Social Welfare and Family Law 250, 250.

⁴³¹ Seymour (n 427) 159.

⁴³² *ibid* 176.

⁴³³ *ibid* 180.

⁴³⁴ Gilmore and Bainham (n 408) 645.; Rob George, ‘The Inherent Jurisdiction and Child Protection’ (2015) 37 Journal of Social Welfare and Family Law 250, 250.

⁴³⁵ Seymour (n 427) 179–180.

⁴³⁶ *Re R (a minor) (wardship: medical treatment)* (1991) 4 All ER 177 (CA Civ); See also Bridgeman, ‘The Provision of Healthcare to Young and Dependent Children’ (n 56) 371.

wardship proceedings.⁴³⁷ The main difference here is that under wardship proceedings, the child is made a ward of the court, which implies an 'all-embracing, automatic, and ongoing control of major issues in the child's life which have to be referred back to the court'.⁴³⁸

A specific order can also be sought under the Children Act.⁴³⁹ Bridgeman notes that, despite the introduction of specific orders in the Act, most applications concerning medical treatments are still made pursuant to the High Court's inherent *parens patriae* jurisdiction.⁴⁴⁰ George, for his part, contends that 'the Children Act provides remedies which can be used in this context perfectly well in the vast majority of cases and, that being so, it is inappropriate for the court to continue to rely on its inherent jurisdiction'.⁴⁴¹ Bridgeman also suggests that favouring the statutory route might influence the methodology of the courts and afford better protection for the rights of children.⁴⁴²

Notwithstanding these arguments, which would reserve the exercise of the inherent jurisdiction for exceptional cases not covered by the Children Act, the current practice is either to make an application under both the inherent jurisdiction and section 8 of the Children Act or to rely solely on the inherent jurisdiction. Furthermore, in the vast majority of cases, the judge then proceeds as if the application had been made under the inherent jurisdiction.⁴⁴³

In principle, the welfare principle found in the Children Act and the common law principle of best interests applicable under the inherent jurisdiction are considered to

⁴³⁷ Gilmore and Bainham (n 408) 647; Jackson (n 211) 258.

⁴³⁸ Gilmore and Bainham (n 408) 645.

⁴³⁹ Children Act 1989 s. 8.

⁴⁴⁰ Bridgeman, 'The Provision of Healthcare to Young and Dependent Children' (n 56) 365.

⁴⁴¹ Rob George, 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard* (Hart 2019) 83.

⁴⁴² Bridgeman, 'The Provision of Healthcare to Young and Dependent Children' (n 56) 371. See also George, 'The Legal Basis of the Court's Jurisdiction' (n 441) 83.

⁴⁴³ But see *Re JM (A Child)* [2015] EWHC 2832 (Fam).

be perfectly equivalent and calling for application of the same legal approach. Lady Hale made that point very clearly in her reasons for denying permission to appeal to the Supreme Court *In the matter of Charlie Gard*:

6. Firstly, applications such as this are provided for by statute: the Children Act of 1989. There was an application for a specific issue order in this case, and under the inherent jurisdiction of the High Court. Both are governed by the same principles. Section 1, sub-section 1 of the Children Act 1989 provides that the welfare of the child shall be the paramount consideration in any question concerning the upbringing of the child in any proceedings.⁴⁴⁴

Next, I can turn to presenting the way in which these principles are interpreted and applied by the courts.

2.2 The interpretation and application of best interests by the courts

The approach adopted by English Courts in applying the best interests principle in cases involving medical treatment of children has been summarised as a series of ‘intellectual milestones’.⁴⁴⁵ Up until the most recent string of highly publicised withdrawal of life-sustaining treatment cases, the most influential iteration of these intellectual milestones was proposed by Justice Holman who systematised them as a series of ten propositions in *An NHS Trust v MB*.⁴⁴⁶ This way of presenting the applicable legal framework has endured in the case law but Holman J.’s list of propositions has recently been updated to reflect more recent judicial pronouncements.

The revised list of propositions elaborated by Justice MacDonald in *Kings College Hospital NHS Foundation Trust v Haastrop (Withdrawal of Medical Treatment)* appears as a strong candidate to play the role that Holman J.’s list had played until then. Although it is fairly lengthy, MacDonald J.’s list of proposition is worth reproducing in its entirety for it provides a good overview of the principles that are applied by the Court in such cases. In what follows, I elaborate on some aspects of the propositions and expand on further principles which are not explicitly found in the list.

⁴⁴⁴ *In the matter of Charlie Gard, Lady Hale’s explanation of the Supreme Court’s decision, as delivered in court on June 8 2017* [6].

⁴⁴⁵ *Wyatt & Anor v Portsmouth Hospital NHS & Anor* [2005] EWCA Civ 1181, [87].

⁴⁴⁶ *An NHS Trust v MB* [2006] EWHC 507 (Fam) [16].

69. The legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not 'Gillick' competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgement.

ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.

iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled: 'This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism.'

iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.

v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption, however, is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.

vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.

vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.

viii) Each case is fact specific and will turn entirely on the facts of the particular case.

ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

'The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.'

x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.⁴⁴⁷

The first three propositions put forward by MacDonald J. are the most general. In what follows, I have therefore organised my discussion around them, introducing the other propositions in relation to one of three main clusters of themes: best interests are paramount and must be assessed objectively, afresh, and independently; best interests are to be assessed from the perspective of the child; and best interests are to be assessed by balancing a broad range of considerations.

2.2.1 Best interests are paramount and must be assessed objectively, afresh, and independently

The first proposition combines the two main legal principles governing judicial decision-making in WLST cases. On the one hand, it affirms the paramountcy of the interests of the child, as commanded both by the Children Act and the common law. Lady Hale observed that, in this regard, the requirements of English Law exceed those of the *Convention on the Rights of the Child*, which merely requires that the interest of the child 'shall be a primary consideration'.⁴⁴⁸ This places the child at the centre of the best interests assessments and gives priority to his or her views (when they can be expressed) as indicated in the tenth proposition. It also has the effect of subordinating the interests and views of anyone else, notably the child's parents and siblings in the assessment of the court, to those of the child being considered. This also relates to MacDonald J's second proposition, which states that the analysis must be undertaken from the point of view of the child, which also implies that other

⁴⁴⁷ *Kings College Hospital NHS Foundation Trust v Haastrop (Withdrawal of Medical Treatment)* (n 425).

⁴⁴⁸ Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 s. 3(1).

points of view should be left in the background.

On the other hand, the first proposition also establishes the scope of the jurisdiction of the court, which is to address the question of the best interests of the child objectively and entirely afresh. As the fourth, sixth, and ninth propositions specify, the High Court is not bound by the views of the child's parents, nor by the views or clinical assessment of HCPs, although paying proper attention to the particulars of the child's situation—as the eighth proposition demands—requires that each be carefully considered.

2.2.1.1 Deference toward medical expertise

The fourth and sixth propositions require the judge to form a view on the medical aspects of the case. In that regard, the clinical assessments of doctors are generally treated with deference but are not conclusive at law. Determining what course of action is in the best interests of a child goes beyond identifying which one would allow doctors to discharge their duty of care toward the patient and therefore be immune from liability in negligence. It is therefore not sufficient that the proposed course of action be consistent with the *Bolam* test, which states that

[a doctor] is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art.⁴⁴⁹

As argued by Foster and Miola, the *Bolam* test logically allows for more than one acceptable answer, while best interests do not.⁴⁵⁰ As they also note, this has been acknowledged by the Court of Appeal in a case concerning the sterilisation of an incapable woman.⁴⁵¹ This interpretation has then been transposed to the paediatric context in *Re K*, a case concerning withdrawal of parenteral nutrition from an infant suffering from severe congenital myotonic dystrophy.⁴⁵² That being said, it must be acknowledged that, in practice, judges very rarely disagree with the view of doctors regarding best interests.

⁴⁴⁹ *Bolam v Friern Hospital Management Committee* [1957] All ER 118, 121.

⁴⁵⁰ Foster and Miola (n 29) 519.

⁴⁵¹ *SL v SL* [2000] EWCA Civ 162. Foster and Miola (n 29) 519–520.

⁴⁵² *Re K (A Minor)* [2006] EWHC 1007 (Fam) [43–[45]].

2.2.1.2 The relevance of medical guidelines

Relatedly, the courts often look into whether the determination of best interests conducted by doctors in forming their view has taken into account relevant ethical guidelines. The leading professional ethical guidelines on WLST from children are found in the document produced by the Law and Ethics Advisory Committee of the Royal College of Paediatrics and Child Health ('RCPCH'). It is entitled *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* (the 'RCPCH Guidance'), now in its third edition.⁴⁵³

Again, while conformity with relevant professional guidelines might suggest that the proposed course of action meets the *Bolam* test, this is not in itself sufficient to establish that the posited action is in the best interests of the child.⁴⁵⁴ Nonetheless, the RCPCH Guidance and its application by the child's doctors are regularly considered by the courts in their assessment of the best interest of a child. On appeal in *Re A (A Child)*, King LJ acknowledged the latest edition of the Guidance and noted that it constitutes a useful tool in assessing best interest while underlining that it has no legal force of its own:

The President of the Royal College of Paediatrics and Child Health has issued from time to time guidance entitled 'Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children; a Framework for Practice' (the Guidance). This guidance was updated in March 2015 and is, as it is described in the foreword, 'A live document and not an end point for discussion and learning'. The Guidance is exactly that. It is not binding on a court and has no legal force. Nevertheless, in reality it forms the backdrop against which multidisciplinary medical teams conduct their assessments when they address what is described in the Guidance as 'the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child'. Each of the experts has used the Guidance in this case.

Indeed, as noted by the President of the Family Division of the High Court, Sir James Munby, 'both the relevant *legal* principles [...] and the Royal College's *medical* guidance point, as one would expect, in the same direction'.⁴⁵⁵ The RCPCH identifies

⁴⁵³ Larcher and others (n 46).

⁴⁵⁴ Ash Samanta and others, 'The Role of Clinical Guidelines in Medical Negligence Litigation: A Shift from the Bolam Standard' [2006] Medical LR 321, 334–336.

⁴⁵⁵ *Re Jake (A Child)* [2015] EWHC 2442 (Fam) [42].

three categories of cases where withholding or withdrawing life-sustaining treatment is considered to be in the best interest of a child. These are identified as 'Limited quantity of life',⁴⁵⁶ 'Limited quality of life: where there is no overall qualitative benefit'⁴⁵⁷ and 'Informed, competent, supported refusal of treatment'.⁴⁵⁸ Of the three categories, only the first two are relevant for our purposes. It worth citing how these two categories are presented in the executive summary to the RCPCH Guidance, which is the formulation courts refer to most often:

I When life is limited in quantity

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- A. Brain stem death, as determined by agreed professional criteria appropriately applied
- B. Imminent death, where physiological deterioration is occurring irrespective of treatment
- C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

II When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life.
- C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.⁴⁵⁹

2.2.1.3 Unease toward the views of parents

For its part, the ninth proposition highlights the unease with which the views of parents are perceived by the courts. As this proposition and the precedents cited in support of it attest, suspicion as to the objective quality and reliability of the views of parents has reached the status of an intellectual milestone. Most decisions will insist on the importance of carefully considering the views of parents, notably when their proximity and intimacy with the child might give them access to relevant information likely to have been missed by HCPs or serving to nuance their views.⁴⁶⁰ However,

⁴⁵⁶ Larcher and others (n 46) at p. s13.

⁴⁵⁷ *ibid* at p. s14.

⁴⁵⁸ *ibid*.

⁴⁵⁹ *ibid* at pp. s4-5.

⁴⁶⁰ *Re C (An Infant)* (n 425) [29].

the relevance of the views of parents is often discounted, along with their observations, on the ground that, as they are likely to be founded upon emotions such as love and hope or upon religious beliefs, they are antithetical to an objective assessment of a child's best interests. For instance, in the words of McFarlane LJ in the Charlie Gard case:

... [I]t is well recognised that parents in the appalling position that these and other parents can find themselves may lose their objectivity and be willing to 'try anything', even if, when viewed objectively, their preferred option is not in a child's best interests.⁴⁶¹

In this regard, the decision of the Court of Appeal in *Re T* could be cited as a counterexample.⁴⁶² In *Re T*, the child's parents took the position that an invasive life-prolonging liver transplant would not be in the best interests of their child. The Court of Appeal sided with the mother (who alone had parental responsibility), overturning the decision of the High Court judge who had deemed her position unreasonable and found the transplant to be in the child's best interests. Yet, it is not the views of the mother *per se* that persuaded the Court of Appeal, but rather their potential impact on the welfare of the child. The Court of Appeal considered that the adherence of the mother (who alone had parental responsibility) to the care plan was an important factor in determining whether imposing the plan was in the best interests of the child.⁴⁶³ Furthermore, this case has been severely criticised ever since it was decided.⁴⁶⁴ As Jackson concludes, 'Re T is, however, probably best regarded as an idiosyncratic and anomalous judgement'.⁴⁶⁵

In section 3, I show that most of the arguments that have been put forward by parents on appeal in recent cases and that have ultimately been rejected aimed at securing recognition of a more decisive weight for the views of parents.

⁴⁶¹ *Yates & Anor v Great Ormond Street Hospital For Children NHS Foundation Trust & Anor* [2017] EWCA Civ 410, [112]; *An NHS Trust v SR* [2012] EWHC 3842 (Fam) [22].

⁴⁶² *Re T (A Minor)* [1996] All ER 906 (CA Civ).

⁴⁶³ *ibid* 914–916.

⁴⁶⁴ See e.g. Marie Fox and Jean McHale, 'In Whose Best Interests?' (1997) 60 MLR 700. Andrew Bainham, 'Do Babies Have Rights?' (1997) 56 Cambridge LJ 48.

⁴⁶⁵ Jackson (n 211) 262; See also AC Elias-Jones and J Samanta, 'The Implications of the David Glass Case for Future Clinical Practice in the UK' (2005) 90 Arch Dis Child 822, 824.

2.2.2 Best interests are to be assessed from the perspective of the child

The second proposition insists on anchoring the assessment of best interests in the perspective of the child. In *Aintree*, Lady Hale made the following statement, which is treated by courts as integrally applicable to the children context⁴⁶⁶ and has directly influenced the formulation of MacDonald J.'s propositions:

39. The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.⁴⁶⁷

2.2.2.1 Appointment of a children's guardian

Very young children have limited ways to express their preferences, and no prior views or attitudes are available to be referenced in assessing what they may want. These inherent difficulties confer added importance to the procedural mechanisms in place to keep the focus of the proceedings on the perspective of the child. The main mechanism in this regard is the appointment of a 'children's guardian' to represent the child. In practice, a children's guardian is always appointed to represent a child who is subject to an application for WLST, although this application does not technically belong the category of cases where such appointment is obligatory unless the court is 'satisfied that it is not necessary to do so to safeguard his interests'.⁴⁶⁸ Unlike in public law cases, 'which involve public intervention in the family'⁴⁶⁹ and are listed as, 'specified proceedings' under subsection 41 (6) of *Children Act*, the appointment of a children's guardian in applications concerning the determination of the best interests of a child undergoing medical treatments is not the default rule. However, pursuant to rule 16.2 (1) of the *Family Procedure Rules 2010* ('FPR'), '[t] he court may make a child a party to proceedings if it considers it is in the best interests of the child to do so'. Making the child a party to the proceedings then triggers the application of rule 16.4 (1) (c) FPR which states

⁴⁶⁶ *Re A (A Child)* (n 423) [31].

⁴⁶⁷ *Aintree* (n 415) [39].;

⁴⁶⁸ Children Act 1989 s 41.

⁴⁶⁹ Gilmore and Bainham (n 408) 743.

that '[t] he court must appoint a children's guardian'. Practice Direction 16A, which supplements Part 16 of the FPR, indicates that although the decision to make a child a party to the proceedings is 'exclusively that of the court, made in the light of the facts and circumstances of the particular case', it may be justified 'where there are complex medical or mental health issues to be determined or there are other unusually complex issues that necessitate separate representation of the child'.⁴⁷⁰

The responsibilities of the children's guardian appointed under rule 16.4 FPR are set out as follows in paragraph 7.6 of Practice Direction 16A:

7.6 It is the duty of a children's guardian fairly and competently to conduct proceedings on behalf of the child. The children's guardian must have no interest in the proceedings adverse to that of the child and all steps and decisions the children's guardian takes in the proceedings must be taken for the benefit of the child.

The children's guardian will generally be an officer of the Children and Family Court Advisory and Support Service ('CAFCASS').⁴⁷¹

2.2.3 Best interests are to be assessed by balancing a broad range of considerations

The third proposition addresses the core of the best interests assessment. As Lady Hale also makes clear in the quotation above, best interests is to be approached broadly.⁴⁷² No consideration or type of considerations 'capable of bearing on the decision' is to be excluded from the assessment.⁴⁷³ In acknowledging the wide range of considerations that can be relevant, the third proposition offers a typology that goes well beyond the illustrative list of considerations found in subsection 1 (3) of the *Children Act* to include 'emotional' and 'instinctive' considerations alongside 'medical' and 'sensory' ones. Indeed, the quotation from Justice Hedley in the *Wyatt* case accompanying the third proposition suggests that the range of relevant considerations extends all the way to the ineffable mysteries of religion,

⁴⁷⁰ Practice Direction 16A — Representation of Children 7.2(e).

⁴⁷¹ *ibid* 7.4(a); Children Act 1989 s 41.

⁴⁷² *Aintree* (n 415) [39].;

⁴⁷³ *Kings College Hospital NHS Foundation Trust v Haastrop (Withdrawal of Medical Treatment)* (n 425) [69].

metaphysics, and human nature. However, notwithstanding the lack of certainty surrounding the determination of best interests that such a wide and open-ended range of considerations entails, the court cannot shy away from taking a decision.

2.2.3.1 Balancing burdens and benefits

The third proposition also encapsulates the balancing methodology used to apply the best interests of the child principle. The relative burdens and benefits of a proposed course of action are set against one another to determine whether the posited initiative will contribute to the welfare of the child. Such a 'balance sheet' approach has been recommended by the Court of Appeal, whereby parties and ultimately judges are asked to juxtapose the benefits and burdens (or advantages and disadvantages) of a proposed course of action.⁴⁷⁴ However, the balance sheet remains a tool in the overall assessment of best interests, not an end in itself. The Court of Appeal has warned against the risk that establishing the balance sheet might detract from the duty of the court to approach the situation comprehensively. In a case where much attention had been devoted in the High Court to determining whether a child experienced pain, Lady Justice King opined as follows:

At the end of the day, as was emphasised by Baroness Hale in the *Aintree* case, the test to be applied by the courts in such cases is simply this: what is in the best interests of the child at the particular time in question, having regard to his welfare in the widest sense, not just medical, but social and psychological? Too heavy a focus on a balance sheet may, as was recognised by McFarlane LJ, lead to a loss of attribution of weight. In the present case almost the entirety of the oral evidence and a substantial part of the judgement related to the issue of 'pain'. Although it is undoubtedly the case that a single factor can be of such overwhelming importance as to be determinative (for example where a child is in significant and unmanageable pain or distress) the emphasis here focussed disproportionately on one item which, although relevant, did not in reality go to the heart of the decision. As a consequence there was a real danger, repeated again before us, of a failure to stand back and consider A's welfare in its widest sense.⁴⁷⁵

In response to the inherent difficulties associated with the identification and balancing of relevant considerations, notably the wide range of possible beliefs about the meaning of life and death, the fifth and seventh proposition can be read as articulating a compromise between conflicting views. In the case of very young

⁴⁷⁴ *Wyatt & Anor v Portsmouth Hospital NHS & Anor* (n 445) [89].

⁴⁷⁵ *Re A (A Child)* (n 423) [57].

children with little or no prior history, such an approach also helps to flesh out what it entails to adopt the point of view of the child as mandated by the second proposition. The point of departure of the analysis is the rebuttable presumption, first formulated by Lord Donaldson in *Re J*, to the effect that receiving treatment aimed at prolonging life will be in the best interests of a child. Foreshadowing the aforementioned pronouncement from Justice Hedley in *Wyatt*, Lord Donaldson offered a double foundation for that presumption, invoking both the religiously inspired principle of sanctity of life and a naturalistic reference to the deeply seated human instinct for survival. The Supreme Court also endorsed that position in its interpretation of the Mental Capacity Act 2005 in *Aintree*.⁴⁷⁶

However fundamental the principle of sanctity of life is made out to be, the fact that it is treated as buttressing a *rebuttable* presumption remains of crucial importance. Through this mechanism, as was already plain in Lord Donaldson's reasons in *Re J*, the court is invited to consider the actual quality of life of the child from the perspective the child:

We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life. As explained, this formulation takes account of this and also underlines the need to avoid looking at the problem from the point of view of the decider, but instead requires him to look at it from the assumed point of view of the patient. This gives effect, as it should, to the fact that even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's, desire to survive⁴⁷⁷.

The elements that have been identified as contributing to the quality of life of a severely disabled child and therefore amounting to benefits when they are present or as burdens when they are absent, include the capacity of the child to derive pleasure from relationships with his or her parents and family and the capacity to derive pleasure from interaction with the world, notably sensory stimulation from music, films and reading.⁴⁷⁸ In *An NHS Trust v MB*, the judge found both aspects to be

⁴⁷⁶ *Aintree* (n 415) [35].;

⁴⁷⁷ *Re J (A Minor) (Wardship: Medical Treatment)* (n 44) 47.

⁴⁷⁸ *An NHS Trust v MB* (n 446).

present in the life of a boy suffering from spinal muscular atrophy. He concluded that despite the numerous burdens that dependence on artificial ventilation imposed on him, these benefits carried more weight in the balance, such that the presumption in favour of offering life-prolonging treatment was not rebutted.⁴⁷⁹ More recently, in *Re C*, Justice Russell also mentioned the child's capacity to give and receive love and affection among potential benefits:

Thus, when considering his best interests, I include C's medical, emotional, sensory perceptions (including his ability to give and, in C's case as a small baby, especially to receive love and affection, his awareness of his surroundings, and his pain and suffering) and the human instinct to survive and prolong life.⁴⁸⁰

Nonetheless, it is widely accepted in the case law that in certain circumstances the balance of benefits and burden will point toward WLST. For instance, in *Re C*, Justice Russell sets out in detail the burdens associated with treatment for this infant suffering from a severe brain anomaly, along with several other serious malformations and concluded that

[...] the evidence is that C has suffered, and continues to suffer, pain, discomfort and distress constantly and frequently every day of his short life.⁴⁸¹

This led the judge to acquiesce to the application of the Trust requesting a declaration to the effect that it would be lawful not to escalate C's treatment by intubating him or providing him with resuscitation measures in case of cardiac or a respiratory arrest and to provide him only with palliative and comfort care. He ruled as follows:

The conclusion that I have reached is that it is in C's best interests for the court to make the declarations sought by the NHS Trust because the intervention and invasive treatments which his parents seek confer no real benefit and subject C to continuous, and ultimately futile, pain, suffering and distress; it follows that it is lawful for the treatments to be withheld.

Indeed, *An NHS Trust v MB* stands as one of only a few cases where the court has rejected the application of an NHS trust seeking a declaration that it would be in the best interest of a child to withdraw or withhold life-sustaining treatment. Carrying on with treatment that can be characterised as futile is afforded significant weight on the

⁴⁷⁹ *ibid.*

⁴⁸⁰ *Re C (An Infant)* (n 425) [27].

⁴⁸¹ *ibid* [35].

burdens side of the balance sheet. However, such a characterisation does not put an end to the best interests balancing exercise.

2.2.3.2 Futility is no different from other considerations

The judgement of the Supreme Court in *Aintree* offers relevant guidance in interpreting the meaning of the notion of futility. In her reasons, Lady Hale reviewed the interpretation of the following sentence found in the Mental Capacity Act Code and which the High Court judge had applied:

There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery.⁴⁸²

Writing for a unanimous bench, Lady Hale, rejected the interpretation adopted in the Court of Appeal to the effect that a futile treatment is a treatment that does not have ‘a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering’. This interpretation, according to Lady Hale, is too restrictive for it only focuses on the therapeutic or medical benefits that can be associated with receiving treatment. Rather, taking the view that ‘[a] treatment may bring some benefit to the patient although it has no effect upon the underlying disease or disability’, she concluded that the High Court judge had been right to situate the notions of futility in the broader context of the best interests assessment, such that treatment that is likely to serve no therapeutic or medical purpose can nonetheless be seen as providing another type of benefit to the patient.

Therefore, futility is no different from any other consideration, it must be addressed within the broader context of the balancing of burdens and benefits to the patient rather than from a purely medical or physiological angle. In *Aintree*, Lady Hale endorsed the High Court judge who approached the issue from the perspective of the patient, asking whether the proposed treatment might allow the patient to resume a quality of life *he* would regard as worthwhile and weighing that against the burdens of treatment. To the same effect, Lady Hale also approved of the weight that had been given by the High Court judge to the quality of the relationships between the

⁴⁸² *Aintree* (n 415) [28].

patient and his family.⁴⁸³

2.2.3.3 Pain and suffering in the balance

When it is established that invasive treatment involves a significant amount of pain and suffering for the child, the courts often look to identify a counterbalancing prospect of improvement of the child's overall situation. Again, as established in *Aintree*, the prospect of recovery, while relevant, has to be evaluated in regard of the child's overall situation. It does not have to be complete, nor does it have to 'avert the looming prospect of death' as the Court of Appeal had suggested. Lady Hale concluded on that point with a reference to the judgement of Lord Donaldson in *Re J*:

Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities. As was emphasised in *Re J* (1991), it is not for others to say that a life which the patient would regard as worthwhile is not worth living.

If no such potential countervailing benefit is identified, the court will likely conclude that continuing on with invasive treatment is not in the child's best interests because it is overly burdensome. For instance, this was the key reason supporting the conclusion reached by Justice Francis that it would not serve Charlie Gard's best interests to continue to be artificially ventilated in order to receive the experimental treatment advocated by his parents, considering the almost non-existent chance that it would lead to a noticeable improvement of his condition.⁴⁸⁴ Similarly, in the *Wyatt* case, Justice Hedley declared on two separate occasions that initiating artificial ventilation in the event of an infection or of respiratory collapse would not be in the best interest of a child suffering from severe cognitive disabilities and chronic respiratory disease arising from prematurity because it would lead to heightened suffering for the child while offering or leading to no tangible benefit to her.⁴⁸⁵ Like that of Francis J in *Gard*, Hedley J's decision was endorsed by the Court of Appeal.⁴⁸⁶

⁴⁸³ *ibid* [40].

⁴⁸⁴ *Great Ormond Street Hospital v Yates & Ors* (n 425) [126].

⁴⁸⁵ *Portsmouth NHS Trust v Wyatt & Ors* [2004] EWHC 2247 (Fam) [38]; *Wyatt v Portsmouth NHS Trust & Anor* [2005] EWHC 693 (Fam) [16].

⁴⁸⁶ *Yates & Anor v Great Ormond Street Hospital For Children NHS Foundation Trust & Anor* (n 461);

The approach to best interests is not fundamentally different in cases where there is serious doubt as to the capacity of the child to experience pain, notably as a result of severe brain injuries. For instance, in the case of Baby X, a child who suffered ‘a severe neurological injury resulting in his being profoundly unconscious’, it was argued that the child’s lack of awareness of pain negated the burdens associated with prolonged artificial ventilation, such that even if the benefits of continuing to live were ‘slight’, on balance they favoured carrying on with life-sustaining treatment.⁴⁸⁷ This argument was rejected by Justice Hedley who, while recognising that Baby X was ‘very probably unaware of any burden in his continued existence’, gave considerable weight to the fact that carrying on with artificial ventilation would not support any chance of improving Baby X’s condition. Hedley J also characterised the life-sustaining treatments that Baby X received as a distinctly ‘persistent, intense and invasive’ burden, regardless of whether Baby X was consciously aware of them or not. This suggests that Hedley J. attributed value to bodily integrity, independently of the conscious experience of a violation thereof. Finally, Hedley J reprised the reasoning he had applied in Charlotte Wyatt’s case to the effect that when death is inevitable, the manner in which it takes place is relevant to the assessment of best interests. In the case of Baby X, as in the case of Charlotte Wyatt, the judge took the view that the best interests of the child were better served by dying while receiving palliative care in the presence of the child’s parents, than in the course of futile treatment.⁴⁸⁸

MacDonald J.’s list of propositions or milestones gives an overview of the kinds of considerations that are relevant to the determination of the best interests of a child receiving life-sustaining treatment. In the preceding pages, I have sought to supplement and contextualise this overview of the applicable law by specifying and illustrating how the law has developed and how it is applied. Next, to more fully highlight the relevant legal principles, I will introduce certain arguments that were

Wyatt & Anor v Portsmouth Hospital NHS & Anor (n 445).

⁴⁸⁷ *NHS Trust v Baby X & Ors* [2012] EWHC 2188 (Fam) [12].

⁴⁸⁸ *ibid* [25].

ultimately rejected by the courts.

3. Recent controversies

As noted above, although several controversial cases have generated a renewed interest in the law pertaining to applications concerning the medical treatment of severely ill children, the core legal principles have remained stable. In the recent series of cases, the most significant developments are perhaps negative. As these cases unfolded, and especially once the parental position had been rejected by the first judge, parents have put forward various legal arguments, many of them relying on human rights law, to establish the priority of their assessment of the best interest of the child over that of the court. Indeed, many novel arguments have been submitted to the courts for consideration but they have been rejected, thereby confirming and strengthening the position of the best interests of the child principle as the one and only relevant legal framework of analysis.

First, the suggestion that the views of parents as to the appropriate course of treatment for their child should only be overturned when they lead to 'significant harm' and the related notion of a 'significant harm threshold' for court intervention were categorically rejected by the Court of Appeal in the *Charlie Gard* and *Alfie Evans* cases. In both instances, the Supreme Court refused to grant permission to appeal but nonetheless published brief reasons explaining its decision, arguments which have been cited in subsequent rulings. Then, also as part of the *Alfie Evans* case, an argument was made by the child's parents and rejected by the courts to the effect that refusal to allow for their son's discharge from the hospital to enable his transfer to an Italian hospital willing to continue to provide him with life-sustaining treatment amounted to illegal detention. I will review each of these arguments in turn.

3.1 The significant harm threshold argument

In the *Charlie Gard* case, it was argued in the Court of Appeal that a new category of cases should be recognised in order to distinguish between those cases where the position argued by the parents is said to represent a viable alternative and those where they simply reject the proposition of the medical team. According to the

argument put forward on behalf of the parents, in the former case, the courts should intervene to overturn the position of parents only when it can be established that the course of action put forward by the parents would lead to significant harm to the child.

3.1.1 The Charlie Gard case: no significant harm threshold applies

The 'significant harm threshold' plays an important role in child protection and family law, with regard to care and supervision under the Children Act. Pursuant to paragraph 31 (2) (a) of the Children Act, '[a] court may only make a care order or supervision order if it is satisfied – (a) that the child concerned is suffering, or is likely to suffer, significant harm'.

According to Lord Justice McFarlane, such a recognition would amount to displacing the applicable standard from an assessment of best interests to a review of the reasonableness of the parents' position. McFarlane LJ also observes that best interests analysis, as it is understood by the courts, does give weight to the preferred views of parents due to the particular nature of the relationship between parents and children.⁴⁸⁹

In her explanation of the Appeal Panel of the Supreme Court's decision to refuse permission to appeal, Lady Hale stated that the Court of Appeal was right to refuse to add a significant harm requirement in the case of an application by a hospital regarding the best interests of a child. Lady Hale also endorsed McFarlane LJ's subsidiary conclusion to the effect that even if a significant harm threshold were applicable it would have been met on the facts of the case, such that the outcome of the case did not turn on that issue.⁴⁹⁰

The ECtHR adopted the same reasoning and characterised as ill-founded the parents' claim to the effect that judicial application of the best interests test rather

⁴⁸⁹ *Yates & Anor v Great Ormond Street Hospital For Children NHS Foundation Trust & Anor* (n 461) [94-96].

⁴⁹⁰ *In the matter of Charlie Gard* (n 444).

than respect for their parents prerogative to determine the appropriate treatment for their child and amounted to unnecessary interference with their parental rights under article 8 of the *European Human Rights Convention*.⁴⁹¹ The ECtHR also clearly distinguished the facts of the *Gard* case from those of the *Glass* case where it had found a violation of article 8:

The Court also recalls that in its judgement in *Glass* (cited above), this Court criticised the treating hospital for failing to approach the courts in similar circumstances. The facts of the present case are wholly different, GOSH quite properly applied to the High Court under the relevant statute and the inherent jurisdiction of that court to obtain a legal decision as to the appropriate way forward.⁴⁹²

3.1.2 The Alfie Evans case: the absence of a significant harm threshold is not discriminatory

The argument was presented in a different guise in the *Alfie Evans* case, only to be also dismissed by the Court of Appeal. The child's parents argued that applying the best interests test to their decision without a preliminary determination of 'significant harm attributable to their care' amounted to discrimination prohibited under article 14 of the European Convention on Human Rights read in conjunction with the article 8 right to family life of the same convention.⁴⁹³

King LJ accepted that Alfie Evans' parents could rely on the 'other status' ground for discrimination found in article 14 to make their case on the basis of their position as the parents of a severely disabled hospitalised child. However, she rejected the argument that the difference in the treatment of parents under care proceedings brought under section 31 of the Children Act, where the harm threshold applies, and under the inherent jurisdiction, where it does not, constitutes unjustified discrimination. First, King LJ found that the parents of a seriously ill child whose best interests are brought before the court for determination under the inherent jurisdiction by an NHS Trust are not in a comparable situation to those parents whose seriously ill child is subjected to care proceedings in the context of which a determination of best interests might also take place. Essentially, according to King LJ, the two situations are not relevantly analogous because care proceedings are

⁴⁹¹ *Charlie Gard and Others v United Kingdom* [2017] ECHR 605, [123-124].

⁴⁹² *ibid* [96].

⁴⁹³ *Re E (A Child)* [2018] EWCA Civ 550, [69].

only appropriate when the harm or risk of harm to the child can be attributed to ‘the consequence of the actions or omissions of one or other or both of the parents’ while no such shortcoming can be identified in the vast majority of cases where HCPs and parents disagree as to the best interests of a severely ill child.⁴⁹⁴ Therefore, care proceedings are not the appropriate jurisdictional route to obtaining a declaration with respect to which treatment is in the best interests of a child. When such a declaration is sought in the rare cases where the child is also subject to care proceedings, it is only fortuitous that the two procedures take place concomitantly. Rather, in the view of the Court of Appeal, the appropriate comparator to an application under the inherent jurisdiction is an application for a specific order under section 8 of the Children Act, both of which are treated alike through the application of the best interests standard.⁴⁹⁵

Notwithstanding that conclusion, which was sufficient to dispose of the argument, King LJ subsidiarily follows through with the rest of the analysis mandated by article 14. First, echoing Lady Hale’s conclusion in the *Charlie Gard* case, she finds that there would be no room to find discrimination because the parents’ refusal to agree to the withdrawal of invasive treatments deemed to be futile under the guidelines applied by HCPs and their corollary refusal to agree to a palliative care regime implicitly amounts to significant harm to the child and would be attributable to them.⁴⁹⁶ Secondly, assuming a contrary conclusion to the effect that there is indeed discrimination in the way the law treats parents in the position of Alfie Evans’ parents, King LJ also concluded that such discrimination would be objectively justified, as she contends here below:

127. In my judgement the need to place the best interests of a seriously ill child (objectively, and independently assessed) ahead of the wishes of even the most devoted and caring of parents provides objective justification for any difference between care proceedings and the inherent jurisdiction.

⁴⁹⁴ *Re E (A Child)* (n 493).

⁴⁹⁵ *Supreme Court of the United Kingdom, Reasons for the determination in the matter of Alfie Evans, 20 March 2018* (n 424) [111].

⁴⁹⁶ *ibid* [118].

The Supreme Court refused to grant Alfie Evans' parents permission to appeal the judgement of the Court of Appeal. In their reasons, the Appeal Panel of the Supreme Court insisted on the importance of the best interests standard with regard to the protection of the rights of children, describing it as the 'gold standard'. The Supreme Court also distinguished care proceedings from applications concerning the treatment of a severely ill child, on the basis that in the former instance 'a powerful extra objective is in play, namely to avoid social engineering'. This additional objective justifies tolerating arrangements that might be regarded as sub-optimal for children are tolerated:

It might be arguable that a child growing up in many households today would be better off elsewhere. But Parliament has provided that that should not be a strong enough reason for removing him. Significant harm must be established.⁴⁹⁷

On the other hand, with regard to applications under the inherent jurisdiction or section 8 of the Children Act, the Appeal Panel states that doctors need to be informed as to what treatment they can lawfully administer and to understand that treatment that is not in the best interest of children is unlawful. The Panel also indicates that the distinction does not discriminate between the parents of severely ill children and those whose children are the subject of care proceedings because 'because their situation is not comparable' thereby implying approval of the reasoning put forward by King LJ in the Court of Appeal.⁴⁹⁸

3.2 The illegal detention argument

In a further ramification of the Alfie Evans case, the Court of Appeal dismissed the possibility of resorting to a writ of habeas corpus to allow for the child's discharge from the English hospital where he was being treated and his subsequent transfer to Italy. In essence, the parents argued that the order of the High Court stating that Alfie Evans treatments 'shall take place at Alder Hey Hospital' amounted to unlawfully detaining him in the hospital because the order violated both his right to self-discharge from the hospital and his parents' rights to make such decisions on his behalf. Consequently, the parents argued that the order of the High Court amounted

⁴⁹⁷ *ibid* [15].

⁴⁹⁸ *ibid* [17].

to a violation of their son's right not to be unlawfully detained, as protected both by the common law writ of habeas corpus and article 5 of the European Convention on Human Rights.

3.2.1 An 'entirely misconceived' application

The Court of Appeal dealt severely with the parents' arguments and reiterated the conclusion of Justice Hayden in the High Court to the effect that their submission was 'entirely misconceived'. The Court of Appeal analysed the parents' submission in two steps. First, it dismissed the argument made on behalf of the parents to the effect that parents had 'unfettered rights' to make decisions for their child, stating that the application of a new label, in this case 'habeas corpus' did not change the applicable legal framework. The Court of Appeal also reiterated that a best interests assessment had been described by the Supreme Court as the 'gold standard' applicable to the determination of the rights of a child. In what appears to be an effort to add to this already powerful image, or at least to stress its foundational aspect, the Court of Appeal then described the protection of the rights and interest of children both as 'a universal consensus [...] reflected in the extent to which the [United Nations Convention on the Rights of the Child] has been ratified' and 'a fundamental aspect of our justice system'. Consequently the Court concluded that the new line of argumentation proposed by the parents did not alter the interpretation of the principle in any way, insisting that the views and preferences of parents must be subordinated to the best interests of the child:

This does not mean, of course, that [the rights and interests of a child] override all other rights and interests but, as has been determined with considerable clarity in this case, Alfie's best interests are determinative when a court has to decide what treatment he should or should not receive. It is wholly wrong, therefore, to suggest that the parents' own views can trump the judicial determination made in this case. It is also precisely because of that judicial determination that Alfie has been lawfully kept in Alder Hey hospital.⁴⁹⁹

3.2.2 Hospitalisation does not amount to detention

The Court of Appeal then dealt more comprehensively with the aspect of the parents' submission that turned on the rights of the child himself, namely the proposition that the order of the High Court amounted to a violation of the child's right not to be

⁴⁹⁹ *Evans & Anor v Alder Hey Children's NHS Foundation Trust & Ors* [2018] EWCA Civ 805, [52].

unlawfully detained. The Court of Appeal treated the common law notion of unlawful detention as equivalent to that of the 'unlawful deprivation of liberty' found in article 5 of the ECHR. Relying on the jurisprudence of the ECtHR and its incorporation in domestic jurisprudence, the Court of Appeal found that the precedents to the effect that hospitalisation does not amount to detention or deprivation of liberty because the restrictions on the person's movement resulted from their medical condition were integrally applicable to Alfie Evans situation.⁵⁰⁰

Allowing for the possibility that it might be wrong as to this first part of the analysis, the Court also concluded that the whole process that led to the issuance of the High Court order and it sbeing upheld on appeal rendered any detention resulting from it lawful:

63. Further, even if there was a deprivation of liberty, it would be clearly be lawful. Indeed, the whole purpose of the substantive proceedings and the previous decisions by the court in this case were to determine whether the provision of the proposed treatment at Alder Hey would or would not be lawful. The court expressly determined that it would be lawful because, to repeat, this was in Alfie's best interests and no other available or proposed course would be.⁵⁰¹

Conclusion

As I have shown, the best interests of the child approach favoured by the courts since the early days of the jurisprudence on WLST from children has emerged unscathed from the most recent wave of assaults against it. All levels of courts have rejected attempts to transpose to the realm of medical treatments those principles of child protection law that might appear to be more deferent to the autonomy and authority of parents. The care and supervision regime found in the Children Act has been distinguished from that of treatment decisions. Both conditions for state intervention found in subsection 31 (2) of the Children Act, namely significant harm to the child or its likelihood and the attribution of that harm or likelihood to the care of the parents have been deemed irrelevant to the determination of the appropriate care to provide to the child. Similarly, all attempts to frame the challenge against the primacy of the court's assessment of the best interests of the child in terms of human

⁵⁰⁰ *ibid* [61]-[62].

⁵⁰¹ *ibid* [63].

rights law have also failed. The best interests methodology has withstood scrutiny under articles 5, 8 and 14 ECHR.

Determination of the best interests of the child is resolutely considered to be a legal matter, as opposed to a matter of professional judgement for the doctors or of moral conscience for parents.⁵⁰² It is also perceived by the courts has a highly contextual determination which is unlikely to be improved by the imposition of more specific guidance such as a threshold of intolerability, significant harm, or the appreciation of the reasonableness of parental wishes. Throughout the development of the law, courts have resisted almost every request to place one criterion above the other. The only principle with a particular status is the sanctity of life. However, considered in light of the evolution of the law on the matter, it is clear that the trajectory of the sanctity of life principles is more that of a demotion than an elevation. Sanctity of life has been placed in a fragile position as a rebuttable presumption. As such, it is only considered as establishing the default position for the assessment.

The succinct description of the legal framework applicable to the withholding or withdrawal of life-sustaining treatment for severely ill infants is premised on the notion that the law in this area is well settled. The recent string of cases has been met by the courts with an unwavering commitment to the firmly established approach to such cases. However, concluding that the law is stable does not preclude from wondering, as some authors have, whether it ought to be revised.⁵⁰³

⁵⁰² See Foster and Miola (n 29) for the distinction between law, professional ethics and morality.

⁵⁰³ Bridgeman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom' (n 3); Dominic Wilkinson and Julian Savulescu, 'Alfie Evans and Charlie Gard—Should the Law Change?' (2018) 361 *BMJ* k1891; Dave Archard, "'My Child, My Choice": Parents, Doctors and the Ethical Standards for Resolving Their Disagreement' (2019) 70 *Northern Ireland Legal Quarterly* 93; Cressida Auckland and Imogen Goold, 'Defining the Limits of Parental Authority: Charlie Gard. Best Interests and the Risk of Significant Harm Threshold' (2018) 134 *Law Quarterly Review* 37.

Appendix B: Information and consent sheet

1. Information and consent sheet



Faculty of Laws
Bentham House
Endsleigh Gardens
London, WCH1 0EG

Exploring and Improving the Normativity of Neonatal Care: perspectives from London and Paris

Participant Information Sheet

You and your colleagues are being invited to participate in this research study. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please read the following information carefully and discuss it with your colleagues. Please contact me if anything is unclear or if you would like more information. Take time to decide whether or not you wish to participate.

Background

My name is Jean Frédéric Ménard. I am a PhD student at the Faculty of Laws, University College London. I am a qualified lawyer in the Canadian province of Quebec and I also have experience as a clinical ethics consultant both in a paediatric hospital and in adult settings. My research is about the way legal and ethical norms are understood and used in relation to the care of neonates.

What is the purpose of the study?

The first aim of the study is to understand the way healthcare professionals approach difficult legal or ethical issues concerning the care of neonates. The second aim is to explore whether some improvement to the way these issues are handled can be proposed. The project is divided in two stages. First, I will observe and interview healthcare professionals from two paediatric hospitals, one in England and one in France. Second, I will invite healthcare practitioners from each hospital to participate in discussion groups where I will present the findings of the first stage and ask for their view on 1) whether the findings appear to reflect current practice in their workplace and 2) whether they think some improvements could be warranted and, if so, which ones.

What is required?

If you decide to participate in this research project, there is several ways in which you can do so. You may accept that I tag along as you perform your professional duties for a few hours per week such that I can get a sense of what you do and the kind of legal and ethical issues that you encounter in your day-to-day practice. If you are a member of the ethics committee, you may accept that I observe the proceedings of the committee. You may also accept to discuss with me the way you approach these issues in an interview lasting approximately one hour. Finally, you may accept to take part in one of the discussion groups that will also last approximately one hour.

It is up to you to decide to join the study. Your level of participation is also up to you. You may take part in as many or as little research activities you like. For example, you may only accept to be interviewed or only accept to be observed or participate in all three phases of the research.

How will the research be conducted?

Observation – Clinical duties

You have to allow me to follow and observe you as you perform your professional duties for a few hours a week over an extended period of time (at least 4 weeks). It can be for one or two half-days or a full day each week. I will be carrying a notepad and will be noting my observations. If at any point you want me to stop taking notes, you only have to ask me and I will stop. Similarly, if you want me to stop observing you, you only have to say so and I will leave.

Observation – Ethics Committee

You have to allow me to observe the meetings and other activities of the ethics committee. I will have a notepad with me and will be noting my observations. If at any point you want me to stop taking notes, you only have to ask me and I will stop. Similarly, if you want me to stop observing, you only have to tell me and I will leave.

Interviews

We will schedule the interview at a time that is convenient for you. It will be held in a private room at your workplace unless you prefer to have it someplace else. The interview will last approximately one hour. It will be recorded and transcribed to ensure that what you say is accurately documented. If you prefer the interview not be recorded, I will only take notes during our discussion. You may ask to stop the recording or discontinue the interview at any time. You will also be given the opportunity to review the transcription of the interview if you wish to do so.

Discussion groups

We will schedule the discussion group at a convenient time for all participants. It will be held in a private meeting room at your workplace. The discussion group will last approximately one hour. It will be recorded and transcribed to ensure that what participants say is accurately documented. You will also be given the opportunity to

review the transcription of the discussion if you wish to do so.

How will confidentiality be protected?

All information collected from you will be treated confidentially. You will be attributed a pseudonym and your name will be removed so that you cannot be recognised from it. Any names that you use in the interview will also be removed. You will also not be identified by name in any subsequent report or publication. I will also avoid using any details that could identify you, such as your age, gender, professional occupation, work schedule, etc. However, although every attempt is made to safeguard confidentiality, this cannot be guaranteed.

What are the potential benefits of taking part in this research project?

There will be no direct benefit to you for taking part in the research. However, you will make a meaningful contribution to a project aimed at understanding and potentially improving the legal and ethical norms applied in relation to neonatal care

What are the potential disadvantages of taking part in this research project?

Some of the issues discussed might be sensitive or you may be reminded of difficult episodes in your personal or professional life. As such, you might be upset by our discussion. If it is the case, you are allowed to withdraw from the research project at any time and I can refer you to support resources.

Who funds the study?

As a PhD student, I receive a stipend from the Centre for Law and Ethics of the Faculty of Laws, University College London and a scholarship from an independent and non-partisan Canadian charity, the Pierre Elliot Trudeau Foundation. The Trudeau Foundation also supports some of my research expenses by paying for research materials (e.g. computer and recording device) and for transcriptions.

How will results of the study be used?

The study will form the core of my PhD thesis. I also hope to disseminate the results in academic presentations and papers. If you are interested in being informed of presentations and in getting copies of papers, please do not hesitate to let me know. I will also offer to give a public presentation of the results the study to the staff of each of the institutions where I will have conducted the research.

What if there is a problem?

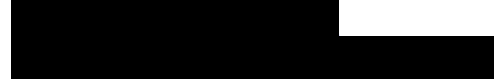
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated, UCL complaints mechanisms are available to you. Please ask me if you would like more information on this. You may also contact Professor Cheryl Thomas, Vice Dean (Research), UCL Faculty of Laws: [REDACTED] or UCL Faculty of Laws, Bentham House, Endsleigh Gardens, London, WCH1 0EG.

Contact details

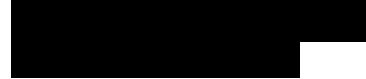
Please do not hesitate to contact me if would like further information or if you want to

take part in the study. You may also contact my supervisor at Great Ormond Street Hospital.

Jean Frederic Menard
PhD Candidate
Faculty of Law
University College London



Dr Joe Brierley
Consultant Paediatric Intensivist
Great Ormond Street Hospital





Faculty of Laws
Bentham House
Endsleigh Gardens
WCH1 0EG

CONSENT FORM

Title of Project: **Exploring and improving the normativity of neonatal care: perspectives from London and Paris**

Name of Researcher: **Jean Frédéric Ménard**

1. I confirm that I have read and understand the information sheet dated 12/12/2016 v6 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I understand that I may be recorded as part of my participation in the study (interview and/or discussion group) and that I can ask for the tape to be erased at any time. I understand that I can ask to see the transcription of any recordings. I also understand that the recordings and transcriptions will be retained in a safe location and destroyed at the end of the research project.

4. I agree to take part in the above study.

Name of Participant _____
Date

Signature

_____/____/____

Name of Person taking consent

Signature

Date

_____ / ____ / _____

When completed: 1 copy for participant; 1 copy for researcher site file.

Appendix C: Topic guides

1. Topic guides for interviews

1.1 Topic guide - Specific case - HCP v1

Exploring and Improving the Normativity of Neonatal Care

Topic guide: Specific case (HCP) November 17, 2014

Introduction

The aim this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form

Confidentiality / Anonymisation

Format:

40-60 minutes.

Can stop anytime

Don't have to answer every question.

Scope of interview:

Specific case

Don't need to limit yourself to the case.

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Training and experience
- Role within the hospital
 - Status
 - Specialism
 - Specific duties
 - Other relevant professional affiliation or responsibilities outside the hospit
- Personal circumstances
 - Children?
 - Any of your children intensive care patient? Any children

- personally close to you?
- Any influence on decision to work in the field, or on any specific interest?

1. The specific case

Aim: To explore the participant experience of a recent difficult case

- The recent case (prompt for details / who was involved / chronology / explain medical terms)
 - Usual or particular?
 - Particular challenges / difficulties

1. Dealing with the case

Aim: Explore how difficult cases are dealt with

- How are these cases dealt with?
 - Who?
 - When?
 - How are the issues raised?
- What kind of considerations?
 - Prompt for:
 - Law
 - Medical Ethics
 - Difference between the two?
 - Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media?
- What kinds of resources are available to deal with such cases?
 - Prompt for:
 - Trust solicitors
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?
 - Adequate? Useful?

1.2 Topic guide - Specific case - HCP v2

Jean Frédéric Ménard
PhD Candidate
Faculty of Laws
University College London

Exploring and Improving the Normativity of Neonatal Care

Topic guide: Specific case (HCP)

v2 26 January 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form
Confidentiality / Anonymization

Format:

40-60 minutes.
Can stop anytime
Don't have to answer every question.

Scope of interview:

Specific case
Don't need to limit yourself to the case.

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any

specific professional interest?

1. The specific case

Aim: To explore the participant's experience of a recent difficult case

Description of the case

- People involved
 - Role of different professionals
 - Role of the parents
- Interactions
 - With parents
 - With other professionals

- Point where situation identified as problematic

Considerations / Standards / Principles

- Best interest
 - Law
 - Medical Ethics
 - Difference between the two

- Obligations towards...
 - Child
 - Parents
 - Team
 - Yourself

- Rights
 - Protected interests
 - Protected autonomy/expertise

- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media

- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

The end of the case

- Immediately after
- Upshot / Aftermath
 - Long term impact
- Relation with other cases
 - Unique features
 - Recurrent features

1. Perception of case

- Level of satisfaction with the process
- Level of satisfaction with the resolution
- Strength and defects of the process
- Suggestions for doing things differently
- Barriers to doing things differently

1. Conclusion

- Anything else they would like to say about this case?
- Reminder re: confidentiality

Thank you!

1.3 Topic guide - HCP v1

Jean Frédéric Ménard
PhD Candidate
Faculty of Laws
University College London

Exploring and Improving the Normativity of Neonatal Care: perspectives from three sites in London, Paris and Montreal

Topic guide – London

v1 25 February 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form

Confidentiality / Anonymization

Format:

40-60 minutes.

Can stop anytime

Don't have to answer every question.

Scope of interview:

Specific case

Don't need to limit yourself to the case.

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- The babies you are caring for

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Most difficult situations arising in neonatology from an ethical perspective

Identifying the issue

- Point where situation identified as problematic
- People involved
 - Role of different professionals
 - Role of the parents
 - Ethics committee
- Interactions/discussions
 - With parents
 - With other professionals

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media
- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

Legal Process

- Decision to go to court
 -
- Suitability of process to solve disagreements
 - Impact on relationship with families
 - Impact on working environment
- Anything you think you are legally entitled to do but would not do?
- Anything you think you should do but you are not legally entitled
- Grey areas

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
- The legal process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
-

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.4 Topic guide - HCP v2

Jean Frédéric Ménard
 PhD Candidate
 Faculty of Laws
 University College London

Exploring and Improving the Normativity of Neonatal Care: perspectives from three sites in London, Paris and Montreal

Topic guide – London v2 6 March 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form

Confidentiality / Anonymization

Format:

60 minutes

Can stop anytime

Don't have to answer every question.

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- The babies you are caring for in the NICU
- Contrast with children in the PICU

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Something that works particularly well in relation to ethics in neonatology

Most difficult situations arising in neonatology from an ethical perspective

Addressing ethical issues

- Identifying problematic situations
- People involved
 - Role of different professionals
 - Role of the parents
 - Ethics committee
- Interactions/discussions
 - Parents
 - Colleagues and other professionals
 - Context/Forum

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media

- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

Legal Process

- Decision to go to court
- Suitability of process to solve disagreements
 - Impact on relationship with families
 - Impact on working environment
- Legal but not ethical
- Ethical but not legal
- Grey areas

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
- The legal process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
-

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.5 Topic guide - HCP v3

Jean Frédéric Ménard
PhD Candidate
Faculty of Laws
University College London

Exploring and Improving the Normativity of Neonatal Care: perspectives from three sites in London, Paris and Montreal

Topic guide – London v3 13 March 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form
Confidentiality / Anonymization

Format:

60 minutes
Can stop anytime
Don't have to answer every question.
Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?

- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- The babies you are caring for in the NICU
- Contrast with children in the PICU

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Something that works particularly well in relation to ethics in neonatology

Most difficult situations arising in neonatology from an ethical perspective

Addressing ethical issues

- Identifying problematic situations
- People involved
 - Role of different professionals
 - Role of the parents
 - Ethics committee
- Interactions/discussions
 - Parents
 - Colleagues and other professionals
 - Context/Forum

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations

- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media
- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

Legal Process

- Decision to go to court
- Suitability of process to solve disagreements
 - Impact on relationship with families
 - Impact on working environment
- Legal but not ethical
- Ethical but not legal
- Grey areas

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
- The legal process

- Level of satisfaction
- Strength and defects of the process
- Suggestions for doing things differently
- Barriers to doing things differently

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.6 Topic guide - Legal Team

Jean Frédéric Ménard
 PhD Candidate
 Faculty of Laws
 University College London

Exploring and Improving the Normativity of Neonatal Care

Topic guide – London (Legal Team)

v1 3 June 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form
 Confidentiality / Anonymization

Format:

60 minutes
 Can stop anytime
 Don't have to answer every question.
 Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Something that works particularly well in relation to ethics in neonatology

Most difficult situations arising in neonatology from an ethical perspective

Addressing ethical and legal issues

- Involvement in assessing situations before going to court. Clinical ethics processes
 - Discussions with HCPs
 - Role with ethics committee
 - Rapid response?
- Role in bringing matters to court
 - When?
 - Criteria
 - Too late?
 - How?

- Administrative authorisation?
- Second opinions?
- Instructing barristers
- Why?

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media
- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process

- Suggestions for doing things differently
- Barriers to doing things differently
- The legal process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
-

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.7 Topic guide - Surgeons v1

Jean Frédéric Ménard
 PhD Candidate
 Faculty of Laws
 University College London

Exploring and Improving the Normativity of Neonatal Care: perspectives from three sites in London, Paris and Montreal

Topic guide – London — Surgeons

v1
 6 March 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form
 Confidentiality / Anonymization

Format:

60 minutes

Can stop anytime

Don't have to answer every question.

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of intensive care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- The babies you are caring for in the NICU
- Contrast with children in the PICU

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Something that works particularly well in relation to ethics in neonatology

Most difficult situations arising in neonatology from an ethical perspective

Addressing ethical issues

- Identifying problematic situations
- People involved
 - Role of different professionals
 - Role of the parents
 - Ethics committee

- Interactions/discussions
 - Parents
 - Colleagues and other professionals
 - Context/Forum

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media
- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines
 - Medical ethics literature
 - Other?

Legal Process

- Decision to go to court
- Suitability of process to solve disagreements
 - Impact on relationship with families

- Impact on working environment
- Legal but not ethical
- Ethical but not legal
- Grey areas

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
- The legal process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
-

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.8 Topic guide - Surgeons v2

Jean Frédéric Ménard
 PhD Candidate
 Faculty of Laws
 University College London

Exploring and Improving the Normativity of Neonatal Care
Topic guide – London — Surgeons
 v2 Surgeons 16 March 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form

Confidentiality / Anonymization

Format:

60 minutes

Can stop anytime

Don't have to answer every question.

Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Training and professional experience (length, context, etc.)
 - Previous experience
- Current role
 - Status
 - Specialism
 - Specific duties
 - Other professional affiliation or responsibilities outside main occupation
- The babies you are caring for in the NICU

1. Decision-making in neonatology

Aim: To explore the participant's experience of decision-making

Something that works particularly well in relation to ethics in neonatology

Most difficult situations arising in neonatology from an ethical perspective

Addressing ethical issues

- Identifying problematic situations
- People involved
 - Role of different professionals
 - Role of the parents

- Ethics committee
- Interactions/discussions
 - Parents
 - Colleagues and other professionals
 - Context/Forum

The reasoning process

Exploring the factors considered in assessing a situation

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
 - Coherence over time
- Other relevant factors
- Any other source of influence or pressure on the reasoning?
 - How the decision may be perceived from the outside?
 - Media

Legal Process

- Decision to go to court
- Suitability of process to solve disagreements
 - Impact on relationship with families
 - Impact on working environment

1. Satisfaction with the way things are

- The local process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently

- Barriers to doing things differently
- The legal process
 - Level of satisfaction
 - Strength and defects of the process
 - Suggestions for doing things differently
 - Barriers to doing things differently
-

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

1.9 Topic guide - Clinical ethics committee v1

Jean Frédéric Ménard
 PhD Candidate
 Faculty of Laws
 University College London

Exploring and Improving the Normativity of Neonatal Care

Topic guide – London (CEC)

v1 24 March 2015

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology.

Ethics:

Info sheet / Consent form
 Confidentiality / Anonymization

Format:

60 minutes
 Can stop anytime
 Don't have to answer every question.
 Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Age
- Personal circumstances
 - Children
 - Personal experience of paediatric care (yourself, as parent or as relative)
 - Influence on decision to work in the field, or on any specific professional interest?
- Training and professional experience (length, context, etc.)
 - Previous experience
 - Reason for involvement
- Current role
 - Status
 - Specific duties
 - Other involvement with the hospital

1. The clinical ethics committee

Aim: To explore the role of the ethics committee

Procedural perspective

- The committee
 - Role
 - Besides case-by-case advice
 - Eg policy on smacking
 - Education (annual conference)
 - Membership
 - Philosopher?
 - Institutional status
- Referrals to the CEC
 - The ethics consult procedure
 - The rapid-response procedure
 - Only obvious cases go to CEC?
 - Connection with the court process

Relationships/interactions of the committee

- With parents
- With hospital administration / board
- With clinical teams
 - With NICU/PICU in particular
 - Co-chair
 - With departments of other clinical members
- With the legal team
- With the public and the press
 - Daily Mail

- Evolution of those relationships over time

The reasoning process

Exploring the factors considered in assessing an ethical question/dilemma

- Best interest
 - meaning
- Quality of life
 - Level of handicap
 - Cognitive / motor
 - Social considerations
- Parental views
 - Authority of parents
 - Challenging parental views
- Past patients/past decisions
- Coherence over time
- Money-matters : cost, funding, financing
 - Is this a new situation?
- Other relevant factors
- Resources and processes, eg:
 - Second clinical opinions
 - Trust solicitors
 - Experienced member of the team
 - Ethics committee
 - Internal guidelines
 - National guidelines

- Medical ethics literature
- Other?

1. Satisfaction with the way things are

Something that works particularly well? Something to be proud of?

Something that could be improved?

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

2. Topic guides for discussion groups

2.1 Topic guide - Discussion Group - Consultants v1

Jean Frédéric Ménard
PhD Candidate
Faculty of Laws
University College London

Exploring and Improving the Normativity of Neonatal Care

Topic guide – London – Discussion Groups – Consultants

v1 11 December 2016

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in the NICU. Main focus will be on withdrawal of treatment.

Questions are informed by several interviews with HCPs in the unit and in the hospital. Two goals: 1) validate/flesh out findings from the interviews and 2) have a discussion about the ethical implications of these findings and potential improvements. Participant sense of what is right and wrong is very relevant. Feel free to disagree.

Ethics:

Info sheet / Consent form

Confidentiality / Anonymization

Format:

60 minutes

Can stop anytime

Don't have to answer every question.

Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

Short intro: Current role in the unit

1. “Setting the frame of reference” and managing expectations

- Finding from the study (‘FoS’): Important to set the tone of discussion / frame of reference / establish trusting relationship with parents.
 - NICU consultant perceived as primarily responsible for that
 - Giving hope/ Giving false hope
- FoS: Consultant of the week model: lack of consistency in style and personal beliefs in setting and managing expectations from week to week.
 - Lead consultant
- Defining expectations/common position within the interdisciplinary team
 - System by system approach
 - Other teams “passing the buck”
- Developing a concerted “unit view” (i.e. unit policy)
 - More coherence / more transparency in approaching EoL issues
 - “Putting your cards on the table”
 - Would be easier to share with families and rest of staff ahead of time

1. Withdrawing treatment “Getting there with the parents”

- FoS: Two typical situations where withdrawing is contemplated:
 - 1) Withdrawing when expected quality of life is very low
 - 2) Withdrawing when the chances of survival are perceived to be low
 - Frequency
 - Ethical challenges
- FoS: Withdrawing in the second case is perceived to be more difficult.
- FoS: Ethical dilemma between parental autonomy and best interest of the child
 - Can't withdraw without parental permission; yet goes against the interest of the child to continue aggressive life-supporting treatments and investigations in these situations
 - Interests of parents trump interest of the child?
 - Double displacement of the end in favour of the means adopted to achieve it: first parental autonomy becomes the end and then process of obtaining parental permission becomes the end.
- FoS: Process of obtaining consent to withdrawal from patient is sometimes perceived as a process of convincing or persuading the parents that they should consent to withdrawing.
 - The mean chosen to protect and enable the autonomy of parents is divorced from its finality
- FoS: Ethical Dilemma: Great weight given to parental autonomy, yet high level of scepticism re: justification for parental autonomy. “Asking too much of parents”
 - Flawed assessment of:
 - Future QoL
 - Burdens of treatments
 - Likelihood of meaningful recovery
 - Signals given by the baby (e.g. seeing a smile where there isn't one).
 - Parents as incapable to make right decision
 - Religious belief
 - Nature/Biological factor
 - Stress
- Ethical questions:
 - Longing for the paternalism of days gone by
 - Should unit/hospital be more proactive in recognising that the process

consent has failed. Should there be more efforts to identify potentially intractable disagreements.

1. Going to court

- FoS: Widespread dissatisfaction
 - Slow
 - Redundant
 - Expense of professional capital
- FoS: Conservative / risk-management approach to going to court
- Ethical questions:
 - Should the unit/the hospital be more proactive in going to court?
 - If you only bring the cases that the legal team is confident the hospital will win, that can skew the process
 - Elaborating a policy (whose responsibility is it? When? Why? Role of the CEC)
 - Streamlining the process:
 - Build a checklist of what is needed to go to court and standard forms for certain elements, e.g. the second opinions.
 - Judicial mediation/expedited process
- Comparative questions:
 - French 'collegial procedure': Ethics MDT for the purpose of deciding if a given treatment constitutes "unreasonable obstinacy"
 - Ontarian (Canadian) Consent and Capacity Boards: Administrative tribunal (with possibility of an appeal to the High Court).

1. If time permits...

- ***Working at the miracle factory II reputation and outside pressures***
 - Daily Mail

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

2.2 Topic guide - Discussion Groups - Nurses - v1

Jean Frédéric Ménard
PhD Candidate
Faculty of Laws
University College London

Exploring and Improving the Normativity of Neonatal Care

Topic guide – London – Discussion Groups

v1 17 January 2016

Introduction

The aim of this research is to explore the way legal and ethical issues are understood, approached, and resolved in neonatology. Main focus will be on withdrawal of treatment.

Questions are informed by several interviews with HCPs in the unit and in the hospital. Two goals: 1) validate/flesh out findings from the interviews and 2) have a discussion about the ethical implications of these findings. Participant sense of what is right and wrong is very relevant.

Ethics:

Info sheet / Consent form
Confidentiality / Anonymization

Format:

60 minutes
Can stop anytime
Don't have to answer every question.

Using a topic guide – Will be making little notes

1. Background, professional and personal circumstances

Aim: Introduce participant and highlight any key background issue that might influence their attitude toward the case and ethical and legal issues in general

- Short intro: Current role in the unit

1. Contemplating withdrawal of treatment

Aim: To explore the participant's experience of the decision to withdraw treatment from a patient.

Assessing the best interest of the child

- Broad agreement on “putting the child first”
- Single answer / objective best interest?
- Range of answers / Diversity of views
- Same meaning for parents, nurses and consultants?
- Reaching the very best outcome vs avoiding the worst outcomes

Components of best interest

Primary:

Clinical aspect / illness trajectory “disease that decides”

Survival expectancy

Quality of the life experience of the child / Balance of benefits and burdens

- Positive: possibility for interactions with family and environment; living a normal life.
- Negative: Prolonged invasive treatment, frequent hospital admissions; chronic pain and discomfort; dependence on medical and support care (“not being able to feed yourself”, “being a double incontinent”); severe disability (“won’t see, won’t talk, won’t hear”; learning disability; motor disability)

Secondary:

Preferences of the parents

Feasibility of the preferred option: strength of parental commitment, level of care after discharge, availability of support resources (ought implies can).

Excluded:

Distribution of resources issues (“getting another kid in”).

- Pull is felt – conscious effort to exclude it.

Division of labour / roles, rights and responsibilities

Nurses’ perspective – “12 hours a day at the bedside”

- Main concern: avoiding unnecessary pain for the child
- Sentinel holding guard
- Given sufficient weight?
- Responsibility to speak up when things are not progressing in the right direction?

Parents’ contribution/perspective

- “It’s their child”
- “Doing things for the parents”

Consultants

- Consultant of the week model

- Continuity vs starting over

“Getting there with the parents”

Interviews have indicated that a significant amount of effort has to be expended to bring the parents to the point where they understand and agree that withdrawal of care is the best thing for their child. Lots of discussion, need to repeat the same information more than once. Giving parents time.

- Where is it that we want to bring the parents when we say “getting there”?

In certain circumstances, it is not in the baby’s best interest to be kept alive by technology, either because death is inevitable or because the quality of life upon discharge from the unit will be poor and/or death will remain a relatively imminent threat.

AND/OR

The baby falls into that general category

Is it the role of HCPs to take parents to this conclusion?

“Tug of war” Applying too much pressure?

- Impact on nurses – “stuck in the middle”

“Not getting there”

- Being able to tell when the parents will not get there
- Predicting breakdown in relationships
- Relaying the message to the consultants

Tension between the BIC standard and parental authority

-- Fitness of parents to make such decisions / “Asking too much of parents”

1. Next steps

When the disagreement appears intractable – what to do next

Ethics liaison nurse appointment

- Awareness
- Role
- Usefulness
- Improvement

The Clinical Ethics Committee

- Usefulness (in withdrawal cases particularly)

The legal process – “going to court”

Level of nurse involvement

Taking to much time?

- Strength and defects of the process
- Suggestions for doing things differently
- Barriers to doing things differently

1. Conclusion

- Anything else they would like to say?
- Reminder re: confidentiality

Thank you!

Appendix D: Summary presented to CEC

1. Outline – CEC Discussion Group

Jean Frédéric Ménard
PhD candidate UCL Laws
20 January 2016

Outline – CEC Discussion Group

Doctoral project: Ethics of neonatal care in two NICU in London and Paris. I'm primarily interested in understanding the way things are done in practice and identifying the issues that might arise from there.

London case study:

- Observed CEC meetings for a year
- Observed various activities in the NICU: psychosocial rounds, teaching sessions, morning rounds;
- Interviewed 17 healthcare professionals (NICU consultants, nurses, surgeons, psychosocial professionals)
- In the present phase of discussion groups, there will be at least 6 discussion groups with approx. 35 people.

Aims of today's discussion:

- Present 'emerging normative model' of decision-making concerning withdrawal of treatment in the NICU.
- Withdrawal has emerged from interviews as a key issue in the unit.
 - Validate (or refute) preliminary analysis.
 - Explore participants' views and intuitions on certain ethical issues arising from the emerging normative model.
 -

I – London Paediatric Hospital **Emerging normative model**

Part ideal, part practice, one limitation is that it is difficult for me to tell the two apart based on interviews and focus groups.

The best interest of the child is viewed as the central ethical norm governing neonatal care. Not surprising, matches ethical guidelines and law. More interesting question: how is it used, what meaning is it given in the NICU?

A) Factors of best interest

Divided between primary factors, which lead to the elaboration of a *prima facie* view of best interest and secondary factors, which then modulate the *prima facie* view. I have also identified factors that are explicitly excluded from the assessment of the best interest of the child.

Primary factors (“medical best interest⁵⁰⁴” / “what would you do if the parents weren't there”):

- “Putting the child first”
- Clinical aspect / illness trajectory “disease that decides”
- Survival expectancy
- Projected quality of the life experience of the child / Balance of benefits and burdens
- Benefits: possibilities for interactions with family and environment; living a “normal life” (“play, go to school”); “a life that contains [suffering or] pleasure”
- Burdens: Prolonged invasive treatment, frequent hospital admissions; chronic pain and discomfort (“constant seizures”); dependence on medical and support care (“not being able to feed yourself”, “being a double incontinent”); severe disability (“won't see, won't talk”); learning disability; motor disability “being trapped in a wheelchair”).
 - Bottom line: In certain situation, death is the most desirable option.
- “And we try to be open and honest about whether that might be something that you can imagine someone wishing for rather than death – because that is often the balance”

Secondary factors (“wider best interest”; ‘family's best interest’; “looking at the

⁵⁰⁴ Double quotes (“ ”) indicate a direct citation from interview transcript or a close paraphrase. As all quotes are from people working in this hospital, I have not linked them to the profession of the interviewee to limit the risk of identification.

big picture”):

- Preferences and views of the parents (religious beliefs, values)
- Projected impact on family and feasibility of the preferred option:
- Strength of parental commitment
- Level of care required after discharge
- Availability of support resources
- “your resulting quality of life is very much dependent on the family’s quality of life”
- Excluded factors:
 - Allocation of resources (“getting another kid in”)
 - Protecting the reputation of the hospital
 - In both cases, the pull is felt – conscious effort to exclude it.

B) Limitations of best interest of the child standard in the NICU

“I think it’s a terrible test, but it’s better than everything else we have. [Laugh]”

- Shrouded in uncertainty/indeterminacy:
 - About the future experience of the child
 - About the actual level and concrete impact of disability
 - “We don’t know if they will be absolutely perfectly fine, or if they will be very disabled mentally and bodily”
 - About the capacity of either HCPs or parents to reach the right decision
- Some of the elements that are relevant for older children are not available “neonates are different”:
 - No prior level of functioning as a basis for comparison
 - Baby doesn’t have a “voice”, a “history”, no knowledge of “personality” or likes and dislikes.
 - More “potential” than actuality
 - Relevant to note that vast majority of NICU consultants also work in the PICU.

C) “Getting there with the parents”: outline of the process surrounding decision-making

- a) Establishing a trusting relationship with the parents
- Opening lines of communication
 - Transmit medical information to parents; ensure understanding
 - Offer support (psychosocial, spiritual, etc.)
 - Defining what is possible and what is not (“managing expectations”, “setting boundaries”, establish “frame of reference”)
 - Parental views seen as determinant
 - “So the biggest determinant is the family’s expectation and view of what is a good life. And the variance in that, you would not believe until you’ve been there”
 - Give parents time to assimilate information
 - Repeat – understanding not achieved in one meeting; often nurses

have to go through information several times with parents

-
- b) Defining a treatment plan; considering options
 - Default treatment plan is always “full-cure”
 - Change of direction requires team consensus (surgeon, other specialities involved, nursing, psychosocial, etc.)
 - “I can’t imagine a situation where we would deviate from full-cure conception without a sit-down to think it through and get this right type of conversation”
- c) Reaching a conclusion
 - “But when you start talking about withdrawing ICU, it’s only because as a physician you’ve already been through the journey, and you come to the conclusion that you should be stopping. It’s only then that you start having the discussion with the family and you negotiate.”
 - Healthcare professionals “get there first”, often they can “see the end from the beginning”
 - Professional experience and expertise
- d) Discussing treatment plan with parents
 - Obtain assent of parents to proposed plan
 - “It is very clear in our hospital, that you can’t stop treatments without a family’s agreement”
 - Keep communication lines open
 - Give time: “perhaps teams will always be on a slightly different time scale from parents with the decision-making. I think parents will always want more time to know what’s best for their child, and to if need be, say goodbye to their child. [...] I think they need to see, to have a bit more time to see that their child is still not getting better. We can’t expect parents to just accept that straight away.”
 - Repeat: “Well usually what you’d say is ‘I’m really sorry to hear that.’ It’s in steps, so there’s never an end point to these conversations. You’d say ‘ok, that’s fine, we respect your views, and let’s go away and think about it over the weekend,’ or ‘go and talk to whomever, the important people in your life.’”
- e) “Getting there with the parents”
 - Because they see themselves as being bound to respect parental decisions, the discussion process is geared towards guiding the parents to assent to team’s conclusion.
 - While supporting the parents in the ordeal they are going through is also seen as a central duty by HCPs, notably nurses and allied professionals, and a significant part of the support being offered to parents is aimed at helping them “getting there”
- f) “Not getting there”: going to court to obtain permission for withdrawal of

- intensive care
 - Breakdown in team relationship with the parents
 - Sense of professional failure
- Efforts from the legal team to dispel this perception
 - Onerous process
- Lengthy
- Obtaining second opinions
- Expense of social/professional capital: need to rely on colleagues from other hospitals
- Need to go to CEC first?
- Pace of the legal system
 - Redundancy of the process: court usually side with HCPs
- Or no, let me word this correctly: we already have a huge decision-making influence, but it's interesting that hospitals and society expect us to seek court support, given that when we go to court, it's deferent to professionals often.

D) Limitations of the “Getting there with the parents approach”

- Should be noted at the outset that the process described appears largely in line with ethical recommendations. Nonetheless, some questions can be raised.
- Framing and direction of the discussion is dependent on the people involved
 - “And so by definition, because there is no clear answer to those questions, and we don't know where on the spectrum of badness this child will fall, you end up kind of negotiating it with your colleagues and the parents, and you can come up with a different answer depending on which parents you're dealing with, and which colleagues you're dealing with”
 - “Consultant of the week model” may also lead to lack of coherence
 - Some parents might never “get there”
 - The premise that death is sometimes preferable is incompatible with certain value systems, notably religious beliefs.
 - Can take a lot of time
 - Baby might be experiencing significant pain or discomfort
 - Might be argued that the state the baby is in is undignified:
 - “I was just heartbroken to see her with... She was so tiny, and she looked so pale, and almost grey. Her skin started being already a bit kind of like... not normal baby skin anymore. All these wires and tubes, and she was oedematous. I think she had several bruises from canulation and things like that. She just looked bruised and battered, and she didn't even look alive to me anymore”
 - Moral distress for HCPs, notably nurses:
 - “And I know that someone once said, “That's what we do,” and I thought no, that's not what I do. I do not torture babies. I make them better, but I don't want to torture them. And that's what it felt like to me in the end.”
 - Process may deviate from its ethical finality:
 - Might be experienced as coercive by the parents

- “The clinicians have – particularly at a place like this, where you have such well trained and experienced... and the best, among the best. So, there’s a huge gap there. And you can’t drag the parents along; but at the same time, they can’t drag the clinicians back. And so you get this tension, where it’s almost like having a tug of war over a huge valley, and one of you is going to fall into it”
 - Perception that some things are offered to appease the parents rather than in the best interest of the child.

When is it time to shift gears and go to court?

E) Questioning the capacity of parents to assess the best interest of their child

Another underlying trend in the interviews with HCPs is that many are uncomfortable with parental discretion/authority. Everyone agrees that taking parental views into account is crucial, but many questions are raised, challenging the authority of parental views:

- Parents may underestimate the burden of treatments on their child:
 - “So for example, the research would actually back me up that parents are in many [cases] and quite often more likely to underestimate the burden on a child, despite the fact that it’s their child – because they are suffused with hope – than a clinician or the nursing staff”
 - “And you sometimes feel when people make requests, or seem to diminish or downplay that part of the experience, assessing the quality of life thing... whether they are just using a coping mechanism, denial or... to believe it, or whether they see themselves as slightly heroic, or whether... You sometimes hear phrases you know you’ve heard in movies or on television, and you feel people are saying what they feel they ought to say; and I just worry sometimes that people don’t really know”
 - Parents may overestimate the future quality of life of their child:
 - “And... either they don’t understand, they’re not ready to understand the ramifications of “if we do this, the life of your child would be mentally damaged. And you’re going to have... that child will grow, and you’ll have a very disabled child.” And the future... they don’t look to the future; they just see this tiny teeny little baby, and want everything done for that child”
 - Parents may overestimate the possibility of a meaningful recovery:
 - “I think sometimes they just don’t see how severe the situation is. “They think the baby can recover, they just need to start tolerating their feed; but they don’t see that the kidneys are still not working. Or even... they think if the kidneys start working again, that’s fine. Yes, but your baby is still ventilated, and we haven’t managed to get it off the ventilator. It’s not tolerating its feed, and actually it also has a bleed in the brain. And we don’t know what effect that will have on the later life. But you probably can’t expect parents to see the whole picture and to look into the future as well”
 - Parents may have difficulty interpreting the signals the baby gives:
 - ““Oh, but didn’t you see them smile?’ Well, it’s something that people are kind of

seeing, but which isn't really there, and shows a certain lack of capacity. Yet at the same time they're advocating for this child who they believe is doing this [...]

- Parents may know what is in the best interest of their child without being able to consent to it
- And actually the court application was to stop, and it was granted. And rather than any kind of upset at the process for the father, who was a very religious man, he was grateful. What it meant was that it allowed him to behave in a way that consistent with his faith, and not make a decision that he would be criticized for; and yet also, what happened he knew inside was probably the best for his child, but he didn't have to make that decision.
 - Parents' judgement may be altered by the situation they are in:
- "And even though you may have most intelligent parents, when they are stressed because their child is ill, they don't necessarily act in rational ways, or hear all the information; they'll pick up on certain pieces of information"
- "And I think that's really hard, because when you say "your child might have a severe neurological impairment" to a parent, they don't always understand quite what you mean by that, and it's very difficult to frame that with upset traumatised people; to kind of get them to the place where they understand what that is like. You know, your child won't ever talk, won't ever walk, will be in a wheelchair, those kinds of things"
 - Nature may take over rational thinking:
- "And I think it's very hard for parents to – especially initially – to remotely think that what is best for my child is letting them die. There is naturally a protective side, which thinks, 'Surely what is in my child's best interest is to keep trying everything possible in order for them to survive'"

Relatedly, some participants wonder if the paternalism of the past was not a better way of promoting best interest of the child:

- So, um, in some ways I think we have done ourselves harm by losing a little of the paternalistic aspect of us. I know that's an unpopular phrase often, but in these circumstances we have no other... point. There is no other role we are serving other than trying to do the best for the child, and we have no other reason other than that to make a decision. So it would seem logical to me that 15 years ago an adult intensive care doctor wouldn't even have considered going to court. They would have just made a decision on the day, and you know, "if you want to see your father again, come tomorrow morning," sort of thing! [Laugh] We're almost defensive in our medicine, and I think we may lose something from that.

II – Potential interventions

- Be more transparent, earlier in the process about the principles that are applied in decision-making in the NICU
- Documenting in more details interactions with parents with a view to proactively anticipate intractable disagreements.
- Elaborating and implementing a policy on going to court (Who? Why?)

When?)

- Further integrate ethical discussion in clinical team meetings
- “I think possibly having more open ethics discussions about patient management, where different teams are involved, would be useful. [...] If it’s more available and more a part of our practice, then it won’t be seen as such a big thing to have an ethics discussion about what we’re doing; rather than seeing it as a major issue and people get all defensive about it once you mention ethics”
 - Invite the judiciary to a task force on speeding up the process for withdrawal orders
- Consider a standard form or procedure for second opinions required by the court
 - Advocating for creation of an expert tribunal on the model of the Ontario Capacity and Consent Board
 - Advocating for creation of an expedited mediation process
- Judicial mediation or not

Many thanks for your participation

Comments more than welcome: j.menard.12@ucl.ac.uk

Appendix E: Sample interview transcripts

1. Interview with Physician #1

Interview with Physician #1

Date: 6 March 2015
Location: London Hospital
Conducted by: Jean-Frédéric Ménard ('JFM')
Duration: 75 minutes
Transcription : Geneviève Cocke (6 April 2015)

JFM: So you have seen the information sheet? You have signed the consent form?

Physician #1: Yes.

JFM: So this is approximately 60 minutes. I'm going to keep an eye on the time, and we can stop at any time. If there are any questions you don't want to answer, we can skip ahead. Everything you are going to say is going to be confidential. I'm going to make efforts to anonymize you and to blur things as much as possible. Obviously the closer people are to you, the more chances they have to recognise you.

The topic of my research is decision-making in neonatology. I'm going to start by asking you a couple of general background questions, and then we'll get into the main topic. And at the end I will ask you for ideas for possible improvements.

Ph#1: OK.

JFM: Maybe I can say from the start, I know that here you do both NICU and PICU.

Ph#1: Yes.

JFM: I'm interested in NICU, but of course any kind of comparative insight you might have is very relevant; so I am interested in that as well.

Ph#1: OK.

JFM: So can I start by asking you your age?

Ph#1: I'm [omitted to protect confidentiality].

JFM: Thank you. Can I ask if you have children yourself?

Ph#1: I do; I have a 9 and an 8 year-old.

JFM: Great. And do you have any personal experience of intensive care? I mean, as opposed to professional – yourself, your family...

Ph#1: Um...no. Certainly hospitals, but not high-dependency. Not intensive care.

JFM: OK. Now I would like to ask you about your training and professional experience so far.

Ph#1: OK. So I qualified in 1989. I did standard medical and surgical house jobs. I then did a year of adult medicine, as my first job outside of house jobs – which is an important context, because not every paediatrician or neonatologist does that. I then spend a few years, two years doing some paediatrics and getting exams before coming to [London Hospital] in 1993, I think. I was an immunologist first, and then an intensivist, in 1994. And I have been in this department since 1994, in various forms. Firstly as a registrar, for 18 months, and then as a research fellow and lecturer for about 5 years; and then I was a consultant appointment.

Although I had done some adult intensive care as a medical junior – adult medical junior – and I had done some paediatric intensive care as a paediatric trainee elsewhere, as in neonatology, the vast exposure to my intensive care is in this institution. So I was appointed as a consultant in 2000, and I've been through various forms of that job, but since... 2009, is that right? Yes... I had an academic appointment; so my clinical time has reduced, has been replaced by a significant academic workload. So I do slightly less frontline clinical work.

JFM: OK. Can you tell me a little bit about your research, you academic work?

Ph#1: My academic work started as some basic science solo work about immunity and trying to relate that to clinical problems; but it slowly over the years has become much more clinical and clinical trials work, and particularly around acute information, septic shock, sometimes trauma. But a lot of it is about trying to use

laboratory techniques or monitoring techniques to classify our patients better. Like I said, knowing a little bit more, we have these great big groups of patients... septic, respiratory failure, or whatever, you know, huge bins of patients. But actually each one of course has a huge individual signature about what's happening; and so much of my research is about defining a fina type if you like, for an individual patient. Sometimes that translates all the way through to designing – trying to design treatments for those at high risk, or at least mis-stratification. So... yeah, that's what occupies most of my time now.

JFM: Good. Thank you. And what is your official title or post?

Ph#1: [Omitted to protect confidentiality]

JFM: [Omitted to protect confidentiality]

Ph#1: [Omitted to protect confidentiality]

JFM: Can you tell me a little about what you are doing when you're on the clinical side?

Ph#1: There's one bit I do which is the transport service, but that's perhaps not directly relevant to this. But the rest of it is, as the senior doctor on service, for either 24 or 48 hours; and that involves two wards rounds a day, predominantly planning the strategic direction for individual cases. There's often something a bit more operational about how you are going to get that strategy, and sometimes there's technical stuff about delivering those strategies. But most of the time it's trying to plan what's going to happen to this patient in the next 24 to 48 hours, with your team. And there's usually a team of at least another consultant and at least 6 or 7 junior medical staff... and a huge group of nursing staff. And so it's very much sort of a management of the team and the patient, is the main role.

JFM: All right. And can you give me an idea of the type of babies that you have in the NICU?

Ph#1: In the NICU? OK. It's not a standard neonatal unit; you have seen that. It is only children who have been referred here for something that is not typically offered in a neonatal unit attached to a maternity hospital. So we don't see children with just prematurity. We would only see them with a complication of prematurity that perhaps requires a surgical input.

A common example of that is congenital malformation needing surgery – so something to the gut in particular, or atresia of the gut, or acquired disease, often in

the very premature, inflammatory gut disease, something called NEC, which I'm sure you are familiar with. So those are the biggest part.

There are children who come for other diagnostic and investigative stuff; perhaps metabolic disease, perhaps neurosurgical or neurosurgical conditions. But it's always that... am I fair to say always? Almost always to a speciality here that we are facilitating their opinion. There are also many who come I suppose for specific intensive care skills that we have – but those are often around the very, very sick early newborn term infants, with pulmonary hypertension or a similar problem. They may come as a referral for the [inaudible] service across from the CICU, but we would often try and rescue them beforehand with other treatments that aren't always available. So it's very much specialist neonates rather than routine neonates.

JFM: One of your colleagues has explained to me in a previous interview that another way in which this NICU is non-standard is that it doesn't have neonatologists, or...

Ph#1: That's right. Well, until recently – although all of us have done neonatology, we've not taken that through to specialist accreditation neonatologist. Apart from one colleague, Dr. [Name], who had gone down that route before she did PICU; most of us have done predominantly PICU, with some neonatology.

In the last six months we have had a formal neonatologist appointed, and that's the direction of travel of greater specialisation that occurs with time anyway. But it's also a recognition that perhaps newborn infants around the hospital weren't getting access to neonatology expertise; so I think that's been a good thing. But it's... we have often discussed if it would be more appropriate to call our neonatology unit an infant ICU, because the routine neonatology, which is predominantly premature infants, is not part of our practice.

JFM: Now if we turn to the ethics of your practice... I'm going to start with more general questions. The first one I have is: in terms of ethics and law – though mostly ethics – is there something you feel that works particularly well? Is there a process that is especially good in your department?

Ph#1: Oh, so, not my own view?

JFM: In your own view. Something that...

Ph#1: Well, OK, there is an obvious statement. We are incredibly lucky in the number and seniority of staff we have around. I think because of the complexity of many of the cases, we are able to have a relatively sophisticated debate about

what's correct for an individual child.

We are relatively... familiar, having been to court on a number of occasions, we know many of the arguments. So, you know, what is the best interest, how can you assess the quality of life? If assessment is so subjective how do you do it, especially when someone is sick? All of those things we do talk about on a reasonably regular basis; so I think that's a strength.

I think one of the challenges – I wouldn't say it's a disadvantage, because you couldn't do... these problems wouldn't arise in a different system. And one of the challenges is that those discussions often happen infrequently, with many specialist teams. So it's not like we are always having a discussion with another... with say the surgeons, because it may not be their problem or speciality that the issue arises out of. I think it's a strength within our team that we are familiar, and there are people who have opinions, and they are varied and I think that's a strength; but it's a challenge that there are some many specialists, I think there are 30 in the hospital, and individually they have many specialists. So the whole experience could get very quickly diffused if you like, once you get away from where the problems often present themselves, which is on the ICU.

JFM: And I would suppose that for most of the patients there is going to be one or many other teams that are involved?

Ph#1: Yes. It would be very unusual, in the NICU in particular, to be less than two; there would be ourselves and at least one speciality. And if you have more than two, then you often have five or seven. Once you tip over from a single problem plus intensive care, support need is often multiple.

Yes so that's a specific issue for us. And because people here are so specialised, it's not uncommon we hear responses like, "well the heart itself is manageable," or "the kidneys shouldn't lead your decision-making – because they're manageable." But actually the challenge becomes integration of all these problems, which can be difficult.

JFM: Would it be fair to say that it sort of becomes the intensivist's responsibility to integrate?

Ph#1: Well I think... to some extent, yes. Is that fair? Yes, I mean I think we often pride ourselves on being relatively generalists. You can take two approaches as an intensivist, it seems to me: you can be all diseases that are bad enough to need intensive care, or you can treat yourself as a technician if you like – an expert in the support mechanisms. And if you take the former example of, you know, a sick child

specialist, then you are in a good position to integrate lots of information. That process can be long though, and one of the challenges for us is the fact that we work on a rotational system. And so to consistently have the same debates, the same words and the same people until we all understand each other can be a challenge.

JFM: The flipside of my first question: what would be, according to you, the most difficult situations that arise from an ethics perspective?

Ph#1: OK, so... Well, difficulties arise when some members of the team have a view that is so far outside of what the rest of the team thinks – and I'm including parents as a member of that team, or a speciality. The situations where the problem becomes intractable, when that opinion is not based on evidence, fact, reason, or whatever you want to call it... You know, the obvious example to focus on is when someone believes a religious intervention is going to change something for their child, and that's not up for discussion, and it's not going to be changed by the child becoming sicker or less sick.

So that's a particular example. That's a sort of extreme form. You may well have a surgeon who feels they can do something, or want... See something as a professional challenge, and wants to achieve something, and finds it distracting from the other details that are more complicated. For example, this is a very small infant with a common malformation. Could we do, even though this infant is say 560 grams, could we do the operation that is technically difficult even when they are 2 kilos? Because if I can, that's a technical achievement that people will recognise, or opens up other possibilities.

So there are all kinds of agendas that start to come into play. Although I think we don't struggle with huge surgical egos as much as many people like to pretend we do. There's a stereotype about that but I'm not sure it's really very true. You just have to bear in mind that there are other things in people's minds when they are making decisions like that.

JFM: That's interesting. When you mention that it can be the parents, or it can be some of your other colleagues. Do you have any other examples of situations like that?

Ph#1: Well, I can remember examples of experimental therapies. So, in infant rather than newborn, but experimental enzyme replacement therapy – which is incredibly appealing in a child with congenital metabolic disease that gives it an abnormally shaped heart muscle, heart failure and respiratory failure, respiratory muscle... So there is a protein made that is the same thing that the child is missing, and getting it is a beautiful, neat, physiological solution, and everybody feels that

should work, although the trial clinical evidence at the time it's being offered is limited. And I've seen examples where optimism has, in my view, been translated into unrealistic expectations for the family; to the point where no decisions could really be made, because views that were so far from being realistic had gotten well established early on, and months and months pass, and the child still hasn't improved; but maybe another year will be better. And you know, time has passed and the child has suffered in the meantime. So that's an example of extreme form, but one that many of us will remember! [Laugh]

JFM: And this discussion process, or this consultation process within the team, how does it unfold, how does it happen?

Ph#1: Well I think it can happen any number of ways, depending how readily there is consensus. For many or the vast majority of our conversations with another speciality team or with the family, where you all look at the facts, and discuss what we think, and everybody can see a sensible path; and that path might be, I'm uncertain what this means but if things haven't changed in a day or two, or a week or something, they are going to change. So, a combination of information and time passing to firm up the information is often the easiest to get a consensus. That's... In practice that's how it happens most of the time. But your question was, how does it work in practice? Or how does... Sorry, I've lost the thread.

JFM: Yes, how does it work in practice – like, at what point are you going to talk with the other specialist, and in which context? And the same thing for the parents...

Ph#1: So the answer could be anything. OK? Depending on what's happening and where. The theory is that every child's family should have an update at least daily during the week, and certainly if there is a problem over the weekend. And often these conversations start as part of a routine update. Obviously if there is something more serious happening, they will be spoken to at the time, and many of those – again, the question every family wants to ask you is, "will this be OK," and how confident you are in answering that question opens the whole discussion about ethics and appropriateness every time.

So it could be in any form. The timing of when a speciality team is involved is completely dependent on the individual child. If the child has come from the hospital ward, then they are involved at the time; and they should make the actual referral to us, so we'll know at the time. We'll discuss if this is a situation where we're confident this is recoverable. Is it a, "we need to wait and see?" Or is this a very high risk and we need to... So it's that sort of information would normally be part of the referral conversation. If it's a child from outside coming from home, then it might not be recognisable until a day or two or three into the illness which speciality team should

be involved. So it could look like anything.

JFM: And is it more likely to take the form of an informal discussion or a formal meeting?

Ph#1: So, again, it could be either. Most commonly, you've got some information and you ask a speciality. Let's just take an example of a child referred from home. So you will say, I wonder if this might be something like that? Are we sure we've excluded a rheumatology diagnosis? Could we ask them down? And often a junior doctor would come down, and then call back the consultant who would come later, perhaps the same day, perhaps the next morning, and there would be a very quick discussion about... very informally on the ward, standing up, "what do you think? Is this...?" It's usually a, "Let's try this, let's see what that shows; It's possible, it's probable, I think it might be..." You know, all those kinds of things might come out.

The formal sit down meetings usually mean there is a problem. It's not on the established pathway. All it means is that we're considering a change in direction from what is the obvious. And the obvious track is always full treatment, trying to go for a cure, and so on. So I can't imagine a situation where we would deviate from full-cure conception without a sit-down to think it through and get this right type of conversation.

I'm just trying to imagine... I suppose there might be, if someone had such a catastrophic event, a cardiac event type. But everybody knows what the determinants of survival are after that, so... yeah.

JFM: And if we think of the sit-down meeting, would the parents be typically involved?

Ph#1: So, there are two models to that meeting. One is, we think we know what's going on, and we're going to share it with the family and everybody is going to catch up and we're going to think about next steps. And the family will obviously be there from the start. The other is in the face of greater uncertainty, is let's sit down us and maybe a speciality or more, and talk through what we think is going on here, and get our best hypothesis together, and then share that with the family. And I think both occur; it's just sensitive to the details of what the question is at the time.

Would we do it without the family at all? Not deliberately. We might do, you know, because of what information is available, and if there is really no new information you might not specifically involve the family. So I think that's probably how it plays out.

JFM: All right. Now if we move on to the reasoning process. So in the

previous answer you mentioned best interest, quality of life... I'm interested in what is taken into account when you're thinking about changing direction, or...

Ph#1: So specifically in neonates?

JFM: Yes.

Ph#1: I think in neonates – they're clearly distinct from older children, because the child doesn't express an opinion. So that's one thing we can put aside.

JFM: **Would they be different in any other ways?**

Ph#1: I think in older children, the child's prior level of functioning, and things they say about their life, a perception of whether they enjoy their life or not is all discussed, yes. And how any future life would compare to their previous life, all that stuff is always discussed. That's not really relevant for a newborn, because... you know, obviously.

So the biggest determinant is the family's expectation and view of what is a good life. And the variance in that, you would not believe until you've been there. I've heard families say, "If you can't guarantee he could go to university I think we should stop." And I've had families say, "we'll take him if he can breathe." The absolute opposite ends of the spectrum. So that absolutely sets the frame of reference for the conversation. And then I think the next discussion is... well, there are a number of factors: there is prognosis in terms of just life lived, you know, today he's alive; there is the possible experience of what that life would be; and the two main parts of that are, is it likely it would include some sort of interaction with the world? Or, would it be a life that contains suffering or pleasure?

So, both something about consciousness and something about experience, I think. I've probably never put it into those terms before we had that conversation, but that's how you think about it. [Laugh]

So... how long might they live for? And what would that look like, in terms of them as an individual? But also, their level of suffering or pleasure. And elements of that include how much time would they spend in hospital, how many operations they are likely to have – all of those discussions are part of your view about what their experiences would be. But keeping in mind that the framing for those discussions can be as broad as I started with, it's a very exploratory discussion.

One of the issues is that... There is always anxiety on my part that if a family is for very active treatment in a situation where you feel that maybe average person

wouldn't... I'm anxious that people could make that decision as informed as possible, because... I wonder if people really know what it means to be in tracheotomy through the night, or having a ventilator, or some of these more intensive interventions, until they do it. I'm not sure I do, you know, and I've done this for 20 years. I have a rough idea that it must be incredibly hard work... but it would be all the time!

And you sometimes feel when people make requests, or seem to diminish or downplay that part of the experience, assessing the quality of life thing... whether they are just using a coping mechanism, denial or... to believe it, or whether they see themselves as slightly heroic, or whether... You sometimes hear phrases you know you've heard in movies or on television, and you feel people are saying what they feel they ought to say; and I just worry sometimes that people don't really know. And that becomes a challenge, because then the balance between allowing people to make a genuinely informed decision, and appearing to direct them, is a... well it's a fine line, actually. And fortunately, fortunately, most people... you know, this is not a decision we have to make today, this is over days and weeks and sometimes months; it becomes more obvious whether this is sustainable or not. And so that decision evolves.

But it would be fascinating to know how many people who were at that decision point really deep down wish they had made a different decision, sometime later.

JFM: And do you have any tools or resources that you can provide them with?

Ph#1: It depends on the situation. For disease-specific stuff, it's relatively easy and they are often in contact with the specialist for the specific disease. Or there are speciality nurses who work in a particular area or with a particular technology support like chronic ventilator or tracheostomy... you know, things that we often do, who have fabulous resources to talk it through.

But I get the impression that most of the decisions that the families make come from inside, not from outside. And so you always have to accept that there are whole proportions of patients and families for whom you are irrelevant to the decision. There are many who, whatever you say, "that would be an unacceptable life and we're not going to consider it. And I'd like you to keep him comfortable." That's fine. And there are many who say, "we can't even have this conversation, and it doesn't matter what you say, we're going to keep going until it's obvious, or God says," or whatever test they want to put. And it's only with those in the middle that there is actually a genuine discussion about...

And often you don't know! You may have a feeling. And I think the right thing to do is to say, "I am uncertain, but... this is what I'm feeling the issue is; and if for example the gut doesn't work, we're trying it now but doesn't work this week, and if in another week or two the gut isn't working we have to be honest, that's going to be a terrible situation." On top of the other problems, for example.

So the examples when it feels like it goes well are when we were all honest about how little we know at this point, but how that information would evolve with time. And families understand that that's a decision-making process.

JFM: And what would be the relevance of the social situation of the family?

Ph#1: Wow... Um, gosh, what a good question... I mean, in many ways it shouldn't make a difference. It depends what you mean about social situation. You know, you can go all the way from a very wealthy family for whom 24-hour care is not an issue, and the child will have whatever technology is available. So of course that makes a difference, and that is one end. And the other end is – because London, as mixed as it is, you sometimes have... recently we had some [inaudible] from Afghanistan. And their residency links to the child being on [inaudible]. So there is a spectrum. So of course it's relevant.

I think our view is largely to try and look at the bits that are irrelevant of all that background noise. Of course the quality of the debate, discussion, information exchange you have with the family depends on how articulate they are, whether they speak English, whether... you know, all the other things that play into that information.

And their prior view of medical staff, whether they trust doctors and nurses, whether they think they are arrogant, or pseudo-religious, or all these things. So yes, it makes a huge difference; but I think we like to think it makes less difference than it does! [Laugh]

JFM: So you said that the views of the parents would frame the debate.

Ph#1: Yes.

JFM: Are there any situations where you would not accept this sort of initial framing?

Ph#1: OK, so... Yes, of course there are. They are few and far between, but... so there are various ways of talking about this. There is clearly an area around which the multidisciplinary team is comfortable with parents having discretion. But there are

limits to that, in both directions.

And so, a few years ago we had a child with a CHARGE association, which is not particularly unusual, but it has a complex [inaudible] malformation that includes major gut abnormalities, minor heart abnormality, some swallowing difficulties related to brain, but many of them live – the majority of them live through childhood; some have some very difficult respiratory function related to their poor swallowing and that kind of aspiration. But there hadn't really ever been a debate as far as I can remember about whether we would support a child with a CHARGE association; unless their heart was terrible, or... And we had a family who said – it was an unexpected diagnosis – they saw the child, they did a bit of reading, they said, "We want you not to feed the child. Let it die." And that was outside of what the team felt it was OK to do.

But actually, that challenges you. Actually, it wasn't so unreasonable, because if you then start to count up what a child like that would require, who was coming into the hospital many times... so it wasn't, you know... I think initially it was a big surprise to people, but it wasn't completely crazy. So there was a negotiated, not very aggressive but moderate incremental plan made that everybody seemed to feel comfortable with. And actually the child did die relatively young, at two or three or four years.

So yes there are examples, both ways, but equally there are examples for... requests for treatment would be completely beyond what any medical or nursing staff would feel is... but it can go both ways, so... At one end, if you have performed resuscitation for 20 minutes or half an hour or whatever limit you want to apply, even if a family is screaming at me and insisting, I would not continue.

Similarly, there are children I would not refer because... so there are some extremes at one end that there is no parental discretion around. Where the bottom of that limit of that parental discretion is, is a subject of constant debate; and occasionally recourse to the law, as I'm sure you are aware.

But yes, so I think Hedley talked about four zones in child [Inaudible]: be asked to do something that you think is unconscionable, or not do something that you think is unconscionable. In the middle though is being asked to do something that is a little bit more than you are comfortable with, but you're prepared to do it; and events the other way around. So there is an extreme and a middle ground.

And the skill perhaps is picking apart what's behind those requests. Is it a clear understanding of what's going on, with a different set of hopes or beliefs? Or is it a misunderstanding of the facts, or an over-emphasis on one fact that they perceive as

positive compared to others that they don't necessarily have the background to know how important those facts might be, for example? So we obviously spend a lot of time on trying to define that framing – the limits of the discretion, if you like.

JFM: So would you feel it's part of your responsibility, of your role to sort of... once you've identified what is sort of leading to that perhaps unusual or eventually unacceptable position, to try to discuss or to try even to convince families to change their views?

Ph#1: I think it's our responsibility to share our experience, to help everybody make the best decision. Now, if somebody chooses to ignore our experience, that's fine. You have to put aside any sort of professional pride around that. But then you have to consider, I don't want this for any other reason than I want the right thing to happen, or what I perceive the right thing to happen. And how – to what extent does parental view trump professional experience? I think we're always wrestling with that. And there is discretion, and there is too much. If a family says, "I don't want you to give antibiotics for pneumonia," it doesn't matter what they say; we're going to do it. Well, provided certain criteria are met, certainly.

So... but society is very inconsistent about this. You know, we allow families not to immunise their children, which strikes me as absolute barking, when it has changed the world in terms of... anyways! [Laugh] So there is an inconsistent message about the status of science versus individuality or professionalism, in all sorts of environments. We are relatively privileged, in that we often have lots of data, lots of investigation, lots of observational data, lots of speciality opinion, and it's usually very up to date, and it's changing constantly.

So the best way, in my view, to manage those kinds of disputes is to seek further evidence. And sometimes you're wrong, and the further evidence pops something up that you are not expecting, and that's helpful. And sometimes it just continues to confirm... But what is interesting is that there is an asymmetry in the kind of evidence that persuades non-clinicians. So often, visible evidence, maybe an x-ray or maybe how a child is behaving is much more powerful than laboratory evidence.

So you have to sort of build in how effective some of the evidence is, when you show it. So for example, if you are having trouble explaining to a family, or having trouble communicating with a family about severity of a brain injury, say, two things are often useful: sometimes looking at a scan is useful, and showing a normal scan next to the child in question's scan; but also, watching the child very carefully with the family, or comparing them to another child of a similar age is very powerful information. I think that's especially true in young children, where the whole development is going on. But if you as a parent are just focused on the child and it

looks the same as yesterday and that's okay, you're missing the trajectory; you're missing important information.

We had a case until last month of a child who was here for the first year of her life. Towards the end she behaved at about a six-week developmental level, and the parents were celebrating that. She hadn't grown, she hadn't... there was nothing else that had changed, until... I don't think the family could stand back enough to recognise that every day she was actually falling further behind what her potential could have been. So... when you can't consider those things, using evidence... but being aware that some kinds of evidence translate better than other.

But sorry... but also a part of that... so the next level of sophistication to that is considering that it shouldn't feel like a persuasion conversation for the family. OK? I think we should try to make it a "let's understand what's going on here" conversation with the family. I think as soon as you're getting in a situation where you are formally asking for permission for something which is a real challenge for any parent to consider, then I think you have... failed is too strong, but I think that's not a great strategy for a clinician. Because every parent has a deep-rooted response to protect their child, or it should be a... if you're making a difficult description of a prognosis, you should be making recommendations, you should take a lot of that decision-making responsibility. I'm not sure if this translates, but there is something slightly different between asking formally for consent, and just assenting to the information that we're sharing together. It's a "disease that decides" sort of conversation. Do you follow my argument, rather than what do you think we should do now – which I think is an almost impossible question for most parents.

JFM: Excellent. You mentioned that the intention is to do what is best for the child. Earlier on you mentioned the obvious best interest sort of formula.

Ph#1: Yes.

JFM: Can I ask you what you think about it, and what it means to you?

Ph#1: I think it's a terrible test, but it's better than everything else we have. [Laugh] In the sense that we are obviously making a series of assessments of what would be an unpleasant experience, and what would be potentially a pleasant experience, and trying to balance them. And we try to be open and honest about whether that might be something that you can imagine someone wishing for rather than death – because that is often the balance.

But you clearly have to consider all sorts of things – especially for a young child; they may never have known anything else. And our understanding of really what they

experience is a huge, and unknowable challenge. So yes, you try and think about how unpleasant is such, for example, a tracheostomised and ventilated child, you could describe as very unpleasant. Is it so unpleasant that it's worse than not having a tracheostomy and being dead from an airway obstruction? Probably not! [Laugh] You know, so these kinds of debates are naturally rather crude. But yes, in short you try to make a list of what's good and what's bad, and size it up. Sounds terribly crude. [Laugh] But that is it!

JFM: You mentioned and described the inconsistency of the social message. Related to that, I'd be interested to know... How do you feel about the social message you get from the court and all sorts of sources, about what is and what isn't permissible, and how comfortable are you with what I would call the normative situation you are in?

Ph#1: I think I understand the question. I think... Um, I'm always a little disappointed with what comes out of the courts. But then if you think about it for a moment longer, I could see why it can't be any other way. I can see that the court, perhaps in contrast to the society in general, puts a huge weight on professionalism and experience. And therefore, it's extraordinarily rare for a court to go against a recommendation from... a properly constructed and thought-through and evidenced recommendation from a professional team. That's obvious.

But the court limits itself to the case in front of it, pretty much. There are a few general comments, but what pretty much always seems to be the theme of these judgments is almost a little hint of "why have you come?" [Laugh] In a sense that... Because professionalism is so important, and no one... As long as you've done the process properly, there can't be a better recommendation that that done by a team of properly trained professionals with a second opinion. So the court is going to agree, unless there is something extraordinarily wrong with how you have come to that opinion.

So... it doesn't make a lot of sense to me that we don't give professionals a little bit more decision-making... Or no, let me word this correctly: we already have a huge decision-making influence, but it's interesting that hospitals and society expect us to seek court support, given that when we go to court, it's deferent to professionals often. So, um, in some ways I think we have done ourselves harm by losing a little of the paternalistic aspect of us. I know that's an unpopular phrase often, but in these circumstances we have no other... point. There is no other role we are serving other than trying to do the best for the child, and we have no other reason other than that to make a decision. So it would seem logical to me that 15 years ago an adult intensive care doctor wouldn't even have considered going to court. They would have just made a decision on the day, and you know, "if you want

to see your father again, come tomorrow morning,” sort of thing! [Laugh] We’re almost defensive in our medicine, and I think we may lose something from that.

JFM: Um... I’m just trying to put my questions in the right order. Well maybe as a follow-up question: you mention that a well put-together case to the court would necessarily include a second opinion.

Ph#1: Yes.

JFM: And from your point of view is it always necessary?

Ph#1: Well, not always, because there are extreme examples concerning cardiac resuscitation... they are so extreme that essentially the profession makes known what its second opinion is. It’s so... But I think in situations where there is genuine uncertainty, but a recommendation about the next step, then I think a second opinion is often very useful.

But... in most circumstances the second opinion meets the same response from a family as the first opinion! I can’t remember a last occasion where somebody has said, “oh, well if that doctor also thinks the same, then you know what, you were probably right in the first place!” [Laugh] But I think it’s a useful check and balance on our practice. And actually, you know, occasionally you do find something that you should have thought of, or tried for a bit longer, or tried in a different dose, or whatever. So I think it’s a good practice to do. But it’s interesting how little effect – it has more effect on the medical staff than it does on the families, if they’re in disagreement.

JFM: OK. Another question I wanted to ask you: do you ever feel there is a sort of pressure coming from the outside in terms of what you do? For instance, I think that this hospital in particular is very much in the public eye.

Ph#1: Yes.

JFM: Do you feel that?

Ph#1: OK, so, I feel pressure from outside to manage my resources to do the best for the most. That’s perhaps a pressure I create, and create for myself, but it also comes from the fact that I still have a role in the transport service. So I’m constantly aware of the number of referrals and how few actually make it in. And so one of the considerations I have – so maybe not the pressure that you might perceive behind your question – but I perceive a sort of utilitarian issue about, if that child can’t survive, then actually they are doing harm by being here, in the sense that

they are denying an opportunity to another child. Now, there is obviously huge leeway about that; it doesn't mean you stop on that child now, but it's one of the things that make you... If this can't work, it's better that it doesn't work today rather than it doesn't work in a month's time.

What's behind your question is something about publicity and... perhaps more so now... I'm relatively unconcerned by that sort of public... and the reason for that is that having done adult medicine as a junior doctor, I have a very strong feeling that the UK public are very sensible. OK, the number of conversations I have had as a junior doctor about people's elderly relatives and them dying or being very sick – the majority of families understand what that means and are not unreasonable. [Inaudible] 20 years ago or a bit more. But I think there is a story that comes out from here, with a family saying something outrageous like, "they wouldn't support our child in the situation," versus specialist opinions saying, "actually we tried lots and it has not worked," I'm pretty clear that that would be understood by the general public to be what it really is. You get a few people who wouldn't, but... so I'm not too worried about that. I much more acutely feel the pressure to use the resources.

JFM: And do you feel that that is relatively new, or you have always felt it?

Ph#1: About the resources?

JFM: Yes.

Ph#1: Yes. Always. So the demand has... as our capacities increase, the demand has increased. It has always been similar.

JFM: OK. We have been going for almost an hour now...

Ph#1: I'm all right for a bit.

JFM: OK, good. So, can I ask you to talk a little bit more about your interaction with the legal system?

Ph#1: OK.

JFM: Maybe I can start with asking you, when does it feel like you're going to have to go to court?

Ph#1: Oh, interesting. So, um... when does it feel like it, or when... OK, so, I think you can often spot the families quite early on in whom evidence is not relevant to the position they're in. OK? So, they didn't get to their position through reason,

and therefore reason or time or evidence is not going to change their opinion. That's often clear early, you know, within a couple of weeks of admission.

The situation when you need to go to court is when that is combined with a child who is neither deteriorating nor improving. So you end up with an ongoing uncertainty about decision-making. And the next thing you have to factor in is how willing the institution is or isn't to go to court on such an issue; or whether they would fear... so I think the institution fears the public opinion more than the individual doctors do.

So there are kind of those three things. In the case that was here for a year until recently, we knew at six months for sure for sure that we were going to be in court. We didn't know what the terms would be, and whether it would be required around an end of life issue or whether she would deteriorate to the point where... it would be something along the process that would come out. But yes, we knew, and...

But you are always hoping, I think, once you recognise that, you are hoping that either some new information comes along that either improves or clarifies the prognosis. Or, that... and therefore the family's opinion updates and you get consensus.

Oh, there was something else I was going to say, but you were waiting for... oh yes! And the other issue is that some of these cases are so complex that it's... there is a practical issue about what we're going to court about. "What should we do next on this child" is not an appropriate order to seek. "I want permission not to do this individual treatment on this day" is much credible, I think. So it often takes a while for the [inaudible] to the sort of core order if you like, the application you might make to become clear. Although you know the overall thing isn't going right, which bit are you going to pick as being manageable for the court as a coherent argument? And that was very much the case with the child from last month.

JFM: And maybe just for the record, this child you are talking about was in PICU?

Ph#1: Was in PICU, yes; started on NICU.

JFM: OK. I know which child you are talking about, but I just... OK. So, trying to find the right court order to ask for, is that... Who would you have this discussion with?

Ph#1: We would with either the trust solicitors, or depending on their workload, the [inaudible] sister. But in my experience, it has been me that has suggested what

we make, and then they said if that is possible or not possible, rather than the other way around; but that makes sense, because I know what is both relevant and significant.

JFM: Can you say a little something about your perception or your understanding of the role of the trust solicitors, and your working relationship?

Ph#1: Yes. The trust solicitors work very hard. They have a lot on their plate, and they are trying to manage often very complicated cases; and to trade off I suspect three or four priorities: one of them being the best interest of the child, the other being the public view of... you know, a big hospital taking a poor family to court is a public relations time bomb if you get it wrong. There is the cost and the resources implication of going to court, but also of not solving these problems. And with that comes the staff involvement... you know, people who spend a huge amount of their time on these complex cases from their disputes. I'm imagining the costs of the legal proceedings also.

So I think they are juggling all of these considerations. I am not convinced... so they have a different view than the clinical staff. They have other priorities that aren't just the best interests – although that's going to be the biggest one; they've got other things to consider. That's my view; they might say differently, but that's what I think.

JFM: Have you been to court yourself?

Ph#1: Yes. Both as an expert for elsewhere, a few times I have done that... family, criminal, and as a professional witness. Actually both in family and criminal, so I don't know, 20 times?

JFM: OK. Can you tell me what you think of the court process, especially when it's your patient and you're going there asking for a specific order, or...

Ph#1: You know, much to my surprise I was impressed. The majority of the time, I think both the lawyers and especially the judges are able to distill an awful lot of information incredible quickly, and come to the summary points. And... the vast majority of times I have been – not all – I have thought, well, you know, these are smart people who are especially skilful with words and the way they express themselves, and often do a better job of describing the issues in a way that is relevant to society. You know, we are slightly nerdy scientists in comparison to these very literate, articulate people, and I think they often put it in a wider context much better than we do.

Having said that, there is... the other priority of the court is clearly not to be too different to anything that has been said before; and so there is often a feeling of looking for compromise. And the more I do it, the more I understand that. I think generally there is a bit of a game in what the application consists of. You know... if you need three things you ask for four or five, if you need two you ask for three, or whatever. [Laugh] So there is some sort of... everybody can feel there is some sort of equity, but there is always a compromise, it seems to me, in the law. And as a scientist that just doesn't make sense to me. There are facts, there is a right and a wrong, and let's just get on with it. But as a person, I can understand that that's the way people communicate; I just find it a little strange.

JFM: And do you feel it's a good way of solving those disagreements?

Ph#1: Um... Often, yes. OK, I know I said earlier I think it's a mistake that we have taken away some of the paternalism. But there are other cases where there is genuine uncertainty about what should happen; when precedent isn't set or there is such strong objection that... for example, we had a child a few years ago who had a congenital metabolic disease, and who nobody thought had a chance in the world, and nothing positive on the quality of life scale at all, but the family were very resistant to stopping. And actually the court application was to stop, and it was granted. And rather than any kind of upset at the process for the father, who was a very religious man, he was grateful. What it meant was that it allowed him to behave in a way that consistent with his faith, and not make a decision that he would be criticised for; and yet also, what happened he knew inside was probably the best for his child, but he didn't have to make that decision.

Interesting that people are comfortable with the courts taking that responsibility, but not the medical staff taking that responsibility; even if... But, you know, that's obviously the process. He pushed it as far as it could go, the law takes over and everybody can walk away satisfied. The tragedy of that is that it takes six months of the child's life for everything to come together, during which time he's had no pleasure, and significant suffering.

So that is the other comment about the law, is how long it takes. It always takes along time. [Laugh] And you know, for good reason because you need proper information, but... that grates for an intensive care doctor. We are used to, "I have the information, I'm making the decision." We work on a relatively short loop. So it seems terribly slow to say, "Can we come back next Wednesday and talk about it again"? [Laugh]

JFM: In this example, you said it had its six months through the...

Ph#1: I maybe exaggerated, but you know, certainly months. Once reports and opinions were prepared, and we're sure we haven't given this for a month, and let's just see if it makes any difference...

JFM: So the fact that the court process is relatively slow has a direct impact on the children.

Ph#1: Yes. For sure. I mean, there are moments in the application that are often heard very quickly, but they are necessarily narrow. That is sometimes enough for what you immediately need; and I am actually impressed at how quickly those can be done. But... it doesn't take for it to be much more complicated and the whole thing slows down exponentially. As soon as there is a little more information needed, the whole thing takes weeks rather than minutes.

JFM: So in terms of the legal process, would you see things that could be done differently and would improve...

Ph#1: Part of the discussion that was interesting about one of the most recent cases was the role of Cafcass, the child's advocate person, and whether there is a possibility of someone acting in that role earlier in a dispute, before the courts are formally involved.

Now, clearly that has all sorts of issues for parental responsibility, but you just wonder if we couldn't have independent opinions... I don't know whether they would be seen as independent opinions or if there is already a conflict... but I just wondered about that. I can't see a simple way of changing it, but there is a caution I suppose that sometimes people feel when there is a clinical decision-making process going on, there is sometimes pressure to use a child protection mechanism. And I think we have to be careful about that mismatch. Just because you don't agree with them actually doesn't mean it's a protection issue. Sometimes it so clearly is, because it's outside of what we do. But if you accept it's within the zone of parental discretion, then you've accepted that it's not a child protection issue, and there is a discussion about what should happen next. Um... yeah, so it's very tricky.

JFM: And what about locally? I guess for the majority of cases we don't go to court; there might be a disagreement that will arise, but it will be solved...

Ph#1: I think clinical ethics in house is a useful step. Um... I wonder if our case selection is correct, under the threshold to going to a clinical committee is too high, such that we only do it with cases that are on their way to court, and therefore a gentle bit of advice or consideration from the ethics committee doesn't change anything, because we're already in such an established...

I think the principle is right, but I'm not sure we've got the practice entirely right. And there's a huge resource implication to that – there are often 15 or 20 people in the room for two hours; so you can't do it with every case, but I can't help thinking that... Currently it's too late, but... You could almost not do half the ones that we do, because they are so clearly on their way to court, but a clinical committee is not going to touch it, so... Maybe you could use some of that resource for something a little less... where there is an established [inaudible] to work through some of the issues.

JFM: Do you have a sense of where you would see that threshold, if you think it should be a bit lower?

Ph#1: I would like it more – actually not necessarily in the parent versus medical staff discussion, but in the speciality versus speciality discussion about.... I think we are not that candid about how often we disagree with our colleagues. [Laugh] I wonder if we should be doing that more. For example, we have conjoined twins in the hospital now. And they are just there, and nobody is really sure what's going to happen. Whatever happens, there's going to be an issue arising from it. We should be talking about that in front of the committee now, before the damage.

JFM: So if we talk about this case... like, there hasn't been a consultation or...

Ph#1: No, last I heard there hadn't been. But the children are not on ICU – the [inaudible] on ICU that might be seen as a reasonable thing to do, because without it, who is going to know what's next? And just to define what some of the issues are, I think that would be very sensible. Rather than waiting until the family says, "No, you're not operating," or, "Yes you must," or you know, "do it at this stage and let's work at it."

JFM: Which would also, if we relate it back to what you were saying, it would probably – it might influence the way the information is transmitted, sort of on a day-to-day basis, if people have a clearer sense of where they want to go.

Ph#1: Yes.

JFM: All right. I think that very much covers everything I wanted to ask you. Is there anything you would like to add?

Ph#1: No, I think that's good... Good structure! You got most of my opinions out

of me! [Laugh] Does [Name] get to hear the tape?

JFM: Not if you don't want to...

Ph#1: No, that's all right. He's heard it all before. [Laugh]

[End of part 1]

[Conversation continued informally - Ph#1 accepted to start recording again]

[Beginning of part 2]

Ph#1: So, I was just saying... When a family feels that the arguments are building up – perhaps it is a technical opinion, perhaps it is speciality consensus – that there aren't any other options, one of the last strategies that you often hear from families that are resisting the message, that it's futile and we shouldn't carry on, is "not yet."

So time is used as a delaying tactic, but also as a... So the medics often use it to try to increase the certainty of their case. "I made this statement today, I'll make it again tomorrow, I'll make it again the day after that." And if the picture is repeated, then clearly it has a greater certainty. That's often a very powerful tool. But when a family is in absolute dispute and isn't listening to you, the response is "not yet." It doesn't matter what you tell me, because maybe tomorrow it will be different. Whichever day tomorrow is that we are talking about. And that's fascinating.

Every now and then you can unlock a family's resistance by saying, "OK this is my honest opinion, that if nothing has changed in two weeks from today, and what I mean by not change, let's write it down together what that is, then it's not going to work. And I'm perfectly willing to go all out up until that point, but I will tell you for sure for sure, if I think it can't work."

And sometimes if you have that conversation and say "I will honestly tell you if I think this can't work," and then you come and say, "you know when I told you at the start I would say if I can't work? We're there now."

Sometimes – not infrequently, actually – that's quite a powerful assist to making decisions. I'm effectively telling you what's happening, because on the basis of my experience, there is a strong recommendation. In fact I can only think of once when that didn't change the way people thought. Which is the case we've been talking about! [Laugh] But anyway...

JFM: Well, thank you so much.

[End]

2. Interview with Senior Nurse #2

Interview with Senior Nurse #2

Date: 26 January 2015

Location: London Hospital

Conducted by: Jean-Frédéric Ménard ('JFM')

Duration: 72 minutes

Transcription : Geneviève Cocke (3 February 2015)

JFM: Thank you very much for taking part in this. You've seen the information sheet. Do you have any questions about the research? [Silence] OK.

So everything you're going to say is going to be confidential. I'm not going to use your name in anything that I write; and I always try, as much as I can, to be broad enough so that you won't be recognized by your job title or something like that. I'm going to ask you about what you do, and then we'll try to find a generic term we can use that would be acceptable.

The point of departure for this discussion is a specific case, a difficult case that happened in the unit last fall. I'm sure you know which one I'm talking about. We're using that as a point of departure. So we're going to talk about that, but anything more general or about other cases that you want to talk about, I am very interested in; so please don't restrict yourself to this specific case.

If there is any question you don't want to answer, just tell me. We'll move on to something else. And if at any point you want to stop, we can stop as well. All right?

I would like to start with a couple of background questions. Can I ask you about your background and training?

SrN#2: I'm a trained children's nurse. I was trained in [European Country], and I came to the U.K. in 20[0X], and started working on this neonatal unit. Since then, I have done additional training. I have done the Pediatric Intensive Care course, and two years ago I then became a senior nurse, from a Junior Band 5 to a Senior 6.

JFM: Did you work in [European Country] before coming here?

SrN#2: I did work in Germany; my training was three years and then I worked for about 7.5 years on a general pediatric ward – nothing to do with intensive care,

nothing to do with neonatal. So that was a big change.

JFM: Can I ask you why you changed?

SrN#2: I just needed a change in my life and work, and I was always interested in neonatal and intensive care. A friend of mine who had trained with me was working here, so I just applied. And then they gave me the job.

JFM: Can I ask you your age, if you don't mind?

SrN#2: I'm 39.

JFM: Thank you. Can you tell me a little about what you do here?

SrN#2: Like I said, since three years I'm a senior nurse, a Band 6 nurse. About a year ago I started my in-charge training. So now this year I work either as a bedside nurse, or I have a patient, or just on my own, or I might have a patient together with a new start or a student. Or I'm the in-charge nurse, so that I overlook the whole unit. Or I'm the floor nurse to support the in-charge nurse and/or the other nurses. So it's quite...

JFM: I'm not familiar with the in-charge position, can you tell me a little more about that?

SrN#2: So, every shift, one of the nurses – it's always a Band 6 nurse or a Band 7 nurse – is in charge of the whole unit. She doesn't have a patient, and she will do the ward rounds with the doctors, and she will organize transfers in or out of the unit; so a little more organizing and overlooking.

But she will also intervene, for example if a doctor and a nurse have maybe a different opinion about what they would do with a patient or treatment, what would be right, or to withdraw or if there are any discrepancies, the nurse in charge can intervene and say, "No, actually I do agree with the nurse," or "No, I do agree with the doctor," or say, "Well actually, let's get a consultant in." So she has a bit more power as well.

JFM: OK. And do you often have to use it? Do you often have to intervene in situations like that?

SrN#2: No. Not very often, no. Not in my experience.

JFM: Do you have any other professional affiliations, or are you a member of an outside body? Are you involved with any kind of a working group?

SrN#2: No, I'm not. No.

JFM: Do you have children yourself?

SrN#2: No.

JFM: Do you have any personal experience of intensive care – either yourself, or family?

SrN#2: No, not really. No... My aunt has been very unwell. She didn't need to be intensive care, but the doctors gave her six months with chemotherapy or half a year without, so she was quite unwell.

My mom has been in intensive care just for one or two days, but I wasn't there at that time, because I was living here and she was obviously in [European Country]. But she came out of it. It was just post-surgery that she had to stay a couple of days, but otherwise not long-term experience with intensive care.

JFM: And when that happened to your mother, you were already working here?

SrN#2: I was already working here, and we knew she had a surgery and there might be a possibility she might have to stay in intensive care after. So it was not [Inaudible].

JFM: So there is no connection between your personal experience and what you do now? So what brought you to intensive care?

SrN#2: [Pause] Um... Intensive care... during my training we had this little bit of going through different wards and units, and I also had a replacement on the neonatal intensive care unit at my hospital. But I would say compared to this, it was only a level 2, not a level 3. So it's not that intense, and they didn't do any surgery. But yes, I liked the environment, and I liked the little babies. So yes, I was always interested in intensive care and neonatal, and I just tried. And it was difficult in Germany to get a job in neonatal intensive care without any experience. So that was probably one of the reasons why I said, actually, why not try it in a different country?

JFM: All right. Now we will turn to this specific case. Can I just ask you tell me about it?

SrN#2: So I guess we're talking about [patient]?

JFM: Yes.

SrN#2: I actually admitted her. And she wasn't that unwell when she came. She was tiny and she was, I think, a 26-weeker. She was small, and the whole history now, looking back, I think she was very small still, and she was very pale. She was a very pale baby, but probably her natural colour. And she didn't look that unwell initially. I don't know if the surgeon waited too long to do her surgery, if they maybe should

have gone in earlier or not. But yes, I think from then on, she just deteriorated after her surgery, and I think it just went on too long.

I didn't... because I have been in charge, or floored a lot in the last year, I did not look after her that frequently. In that whole time she was here – she was here 91 days – I probably looked after her for five or six shifts; but they were all towards the end, towards the time where I think most of the team were at the point where, like, “enough is enough, we should not resuscitate, we should not increase the treatment any more, we shouldn't restart the inotropes.” In times where she had very wobbly days, and senior people had to look after her to make sure that everything happened that needed to happen, that everything was on time and we knew what we were doing, not to confront junior people and junior nurses with this stress, and with the parents. We tend to say they were difficult parents, but I don't think they were that difficult. But for me it was difficult to understand why they wanted us to keep going after such a long time, and after being told several times that she could not make it.

JFM: You said you were taking care of her for a couple of shifts towards the end. Can you just tell me what that would have involved? Then you would have been the bedside nurse? So what would you do in the course of the day, or the shift?

SrN#2: The shift, yes. I remember one night shift. I think that was actually the last shift I ever looked after her. But I had a few day shifts previous, with people together, so they did more of the work and I just overlooked it.

During a day shift it will involve to assess her in the morning to see how she looks and how her state is – if it needs intervening or if we can just carry on with routine care. It will involve throughout the shift, giving medication that had been prescribed by the doctors, making sure that the infusions are running correctly, that the pumps are programmed correctly. That would be right at the beginning of the shift ideally, together with the previous shift, to see if the pumps and infusions have been set up correctly.

And then yes, give medication, attend to her care, change the nappy if needed, dressing changes if needed. And also then talking to the parents, try to involve the parents as much as possible, encourage them to either help with change the nappy or at least – some parents are really afraid of touching their babies when they are so unwell. To encourage them still to at least hold their hand, or...

And during night shift it's more or less the same. There is a little bit less workload from that point of view. During the day we would change the infusion, change all the medical infusions like inotropes, morphine, [Inaudible], all these things we would change throughout the day shift, so we don't have to do that during the night shift. Unless there are obvious changes, and the doctor says, “No, actually I want this [Inaudible] and not this one.” Then we have to make it up. And parents are not usually around during the night, so this is in some cases definitely a stress factor

taken away.

JFM: When you say the fact that the parents are not there is a stress factor taken away, would you say that that is in general, or in that specific case?

SrN#2: I think it's in general. Parents are not always a stress factor, but they're always a factor that you have to incorporate in your routine, your care, what you do and what you say. If parents are around, you have to be careful.

It might just be the parents in the bed space next door, but you still have to be careful what you say in your bed space about your patient, because the parents next door might have big ears, and listen in. Parents on the unit – not that I'm saying they shouldn't be here, but it's easily forgotten that there are parents on the unit, and that what we say or what we think, and how we react is always a bit... Yes, we have to be a bit more careful, I think.

JFM: Can you describe your relationship with these parents, the parents of this baby?

SrN#2: Mmm... I remember that when the mom came on the day she was admitted, I got on quite well with her, she was very open and she was very understanding about the fact that we – that because she was very little and was NEC, that was the initial admission reason, that she had NEC – that it might be that she might not survive. The mom was quite aware of it, especially because she was very little. So I had the impression that the mom knew that she still had a long road ahead with her daughter. And I never really met the dad until later on, and I've never really had long conversations with him.

My first close encounter with him was actually after a shift where his daughter had been very unwell, and actually had an arrest the day before. She was still quite unwell and we weren't sure if she was going to make it through the night. So I spoke to the parents about it and said that she was still quite unwell and we didn't know if she would make it. I can't remember exactly but I said something about – I think I said, "Maybe we have to let her go." And the mom was like, "What do you mean by that?" And I thought, "Hmm, she has been here quite a long while, she should know what that means." So I said, "Well maybe if she arrests again, we might not be able to resuscitate her, and we would stop doing it." The mom didn't say much, but the dad, when I spoke of her being unwell, he almost shouted at me and said, "We don't need to hear that anymore. We've been told that enough. That's not helping."

He did apologize later, and I apologized as well. I said, "I know you've been hearing that, but we just want to make sure that you are aware." But yes, that was my first close encounter with the dad, him shouting at me. [Laughs]

JFM: You suggested that perhaps it might be advisable to let her go. Do you see that as being part of your role, to have that kind of conversation or to raise

that kind of point with the parents?

SrN#2: Not if it's the very first time, but if it has been... If the doctor has spoken to the parents already beforehand, and said, "We are in a situation where we don't know where it's going, and if she has an arrest again, we might not be able to resuscitate and get her back," then I feel it is my part, because I'm there the whole time, for 12 hours, whereas the doctor, especially the consultant who normally has the conversation, might not even be at the hospital at the time when it happens.

I feel that it's my role to make the parents aware. Because I know that sometimes in the conversation with the doctors they are so shocked that the information might not sink in. I sometimes feel – and parents do ask, "What did the doctor actually mean by this?" or "What did the doctor mean by that?" or "I don't understand what he's saying." Sometimes they ask later on, way back after the conversation, what was actually said. Not just specifically in these cases but in other situations as well. For example for consent for a surgery, they'll say, "What exactly did they mean by this, or what does that mean?" So I think it is part of my role to then tell the parents, "This is what they mean," or "If this and this happens, then we probably have to do this and this."

I always feel safer if I set at the beginning of my shift – if I have such an unwell patient that I say to the parents, "I am very worried about your baby, and I don't know if it's making it through the night." Because I don't want to be in the situation where I might have to call them at 2:00 in the morning, and they'll be like, "But you didn't tell us that my baby is that unwell." So I think it's yes, part of our role to kind of remind them that their baby is very, very unwell, and that it might not survive.

But yes, I think in their case, in that short period of time they were maybe told too often by the previous nurse, and then I started straight away in my shift saying again, "She might not make it through the night," so that that was maybe the reason why the dad...

And I think they had had previous... because that was probably towards past 60 days that she was with us, that there were episodes before where they had been told she might not survive, and then she pulled through. And then again, they are told she might not survive, and again she pulled through this very critical situation. And I think she had at least three or four of them until she finally passed away.

JFM: At what point did you come to the realization that... You said, it went on for too long. At what point did you start to feel uneasy? I don't know if that's the right way to describe, it, but...

SrN#2: I don't know. I mean, probably after... It's difficult to say. After four weeks, six weeks? I think up to four weeks is still kind of like where we say, okay, she had the surgery for NEC, she's a pre-term baby anyway, they do get a lot of sepsis and [Inaudible] after. Then she developed chylothorax, unfortunately. Then she also

developed kidney failure and needed PD and dialysis. So there were just things coming on, but everything was something that could have been reversed, that could have been... or, we tried to treat it, but then at one point, especially with kidney failure, it just didn't recover, really. I don't know, probably at four weeks or six weeks, around that time.

JFM: So is there a specific point, or a specific event, or it's more the accumulation?

SrN#2: No, it's just the ongoing thing. I remember when the parents came in and where like, "Oh how is she?" and I kept saying, "Well, she's static." To parents, static is good, but I think at a certain point, for us static is not good anymore. It's bad. Because it's not getting better.

And I don't know why, but for some reason I have the number 64 – because on the computer we have how many days she has been with us. It might not always be correct, because sometimes people don't change it, but for some reason I have this point of like 60 days, and that's already actually two months. So I think from that point, around 60 days, for me, I saw it as enough is enough. It was just... I don't know. I think no one here was very positive and hopeful that she would recover from this.

JFM: Can you expand a little bit on that, "it went on for too long, enough is enough?"

SrN#2: Um... You've probably never seen her, have you?

JFM: Yes. Briefly.

SrN#2: Mmm. How did you feel when you saw her?

JFM: For me it was very punctual. It was while during the rounds one morning. There probably wasn't anything... It was difficult to see... But you could tell that this baby was different, because there was a moment where people... You know, people are very matter-of-fact about what went on, and then there was this kind of pause. And then you felt there was a kind of shift in the discussion.

SrN#2: Yes. I just... I remember the last shift I looked after her. I think I went on annual leave after or something like that, so that's why I didn't look after her after that.

I was just heartbroken to see her with... She was so tiny, and she looked so pale, and almost grey. Her skin started being already a bit kind of like... not normal baby skin anymore. All these wires and tubes, and she was edematous. I think she had several bruises from canulation and things like that. She just looked bruised and

battered, and she didn't even look alive to me anymore.

It just broke my heart, and I thought, if it breaks my heart, why doesn't it break the parents' hearts? And it probably did, but in a different way. For me it was just the way, like, "We should not do this to this poor child anymore." Even though she is on medication, pain relief and muscle relaxants, do we know how much they do feel or not feel, if they are in pain or not? We should not do this anymore. I think she suffered. We don't know. I don't know if she suffered or not. But if you get tubes stuck into your body – even if it's a tiny canular – it's painful. And I don't think that morphine does the trick anymore after 60 or 70 days. But then she was not showing signs of pain – because I don't think she was able anymore.

And I know that someone once said, "That's what we do," and I thought no, that's not what I do. I do not torture babies. I make them better, but I don't want to torture them. And that's what it felt like to me in the end.

JFM: Do you have any sense of what the... Is there a line between what you're supposed to do, and when it's going too far or going on for too long?

SrN#2: I don't know if there's a clear-cut line. I think it's probably very, kind of like... yes, kind of a blurry zone. It's more... If something goes on for such a long time and nothing changes for the better, then it just starts... And then if there have been arrest situations as well, where the baby is kind of saying, "I've had enough, my heart is stopping now, I had enough, leave me alone," and we keep going, and we resuscitate, and give drugs, and do compressions and everything we can do – if that's the right thing to do? And if it happens twice or three times, and you still see no improvement, then that may be the line.

I don't think there's way to say, "Oh if that patient had one arrest, the second arrest we're not resuscitating anymore." There are probably patients where you resuscitate three or four times, and then they come out of it absolutely fine. But I think her underlying condition, all the problems she had, there was just... I don't know... and I remember, I think at one point we were actually close to a DNR, to not resuscitate anymore, and then the parents withdrew this decision again. I'm not sure if it was with these parents or others, but we have had these situations. And if you have a DNR in place and then it's withdrawn, there must have been a reason why someone decided to suggest that. And then to withdraw it... I think then the line has been crossed already.

JFM: So... was this a situation that was being discussed with the rest of the staff, amongst your colleagues? Was that something you would be talking about?

SrN#2: About DNR?

JFM: No, no, in general. As time went on, and there was no improvement... you

said very clearly how you felt about it. Did you talk about it with your colleagues as well? Did some people come to you?

SrN#2: I don't think that someone came to me, but I know that after that one shift – the last shift I looked after her – the next night I said, "I'm not looking after her. I'll do whatever you want, but I'm not looking after [patient] anymore." I did speak to some people. Because I remember that night, the nurse in charge spoke to the parents. And I was quite grateful for that, because I wasn't in a state to speak with them. I was actually angry... angry, and disappointed, and sad, and, I don't know... I was almost in tears that night. And the nurse who was in charge that night said something like "I would want everything done for my child if that was my child. I would want everything done for her." It was kind of like saying, before she had a child, she was thinking differently; but since she had a child, she would want everything done. And I just thought, is it really that way, that if you don't have kids of your own that it's easier for you to say I would withdraw?

I also felt a bit – I don't know what the word is, but like I'm not as worthy as someone who has children, because I don't have, so I don't understand. But I'm still – I'm a daughter, I'm a sister, I still might have a very close person in that situation, so... And I wouldn't want that for my mother or my sister, or even for one of my friends, to be in an intensive care for such a long time, with no perspective. And with these tiny neonates, I think we always have to think, what will be the outcome? We don't know if they will be absolutely perfectly fine, or if they will be very disabled mentally and bodily.

So I did ask a few colleagues that have children. I know that I definitely asked two. And one of them said as well, "No, I would do the same, I would want everything done for my child." And the other one actually said, "No, if this was my daughter, I would have stopped a long time ago." And that made me feel a little bit better. I thought, I'm not the only one that thinks there is a limit, and it's not just parents who want to keep going. Even parents might want to stop and say enough is enough.

So yes, I think we did kind of speak about it in smaller groups, but I still think mainly kind of like, "enough is enough." I don't know. But there was never a meeting where we said we should let the nurses come together and sit down and... And even if the whole team had said we don't want to keep going, that's not our say. It's in the end the say of the parents. And then it's the say of the doctors if they want to take it to court or not, if the parents say no.

But I guess if we start saying "We are actually not able to look after her anymore," then maybe it will kind of like support the doctors to make a decision if they want to take it to court, or to take the parents to court. Just because we say we don't want to look after her any more. In the end, yes, that's my job; I have to look after her. If I want to or don't want to, if I think it's right or not.

JFM: We talked quite a bit about the interaction with the parents. What were

your interactions with the doctors, in terms of – how does it usually go, do they explain what they're doing?

SrN#2: Just in general, or specific to her?

I think in general it depends. Some doctors just describe things, or prescribe things, or say, "We're going to do this or to do that." Sometimes I do understand anyway why they want that, or where it's coming from. And often during the ward round there is a discussion to say "OK, the plan for today is this, this and this."

But sometimes I don't really think this is the right think to do. Why do we need a long line, or why do I need to put a catheter if she is peeing anyway? Things like that, where I am like, is that really necessary? And if I ask, then normally they will explain. In most cases they will explain it in that way where I am like, "OK I will do it that way if I am informed so well." Even though I might not agree with it, go ahead then.

And I think in her case, in the end it was just... I think it's a doctor's... my impression was, and I said it to [consultant]...was that her doctor's name? He said he did agree with us, and said, "I'm supporting you, I know, but it's the parents' decision. There is nothing I can do about it." And I think they even tried – I didn't realize it until we had to debrief, that the parents, especially the mom, was very religious, and that even one of the chaplains tried to approach them from a religious point of view, and said, "God has decided to let her," kind of... "It's time for her to go. To let her die a natural way, not attached to all these wires and machines and so on." But the dad wouldn't have it.

So I think we tried everything in this...But I haven't been in conversations with the parents, so... but my impression is, from what I hear and from what I have read on what the doctors have written down, that they tried everything to... yeah, bring across that it might be the best way for [patient] to stop the treatment; that she very unlikely would pull through.

JFM: You mentioned the possibility of going to court.

SrN#2: I'm actually not sure if they were starting to get things ready to take her case to court, but I know that there have been cases previously, and that there are cases ongoing where the doctors will take a case to court so that they can overrule the parents' decision of not withdrawing care. But I can't remember if they actually did with her. I think they were preparing, weren't they? Yes.

JFM: And whose responsibility is it to bring a case to court?

SrN#2: I think it's the consultant's responsibility. But to be honest I am not sure.

JFM: Is it something that is being discussed, or that perhaps you or one of your colleagues might decide to raise with the consultant?

SrN#2: Um... I don't remember that any of us... I don't know [Inaudible] sisters, but the sisters might approach one of the doctors or consultants and say, "Look, do you think this is wise?" But I'm not aware whether any nurse has approached doctors and said "Is it not time to take it to court?" In the end it's the doctors' decision to do or not to do, no matter how many people have approached them, but... I'm not aware of that. Maybe there has been a group sitting down and saying, "Should we take it to the consultant and ask him to take it to court?" I'm not aware of that. I'm also not in the path where we have been going to the doctor and saying, "Look this is the time to take it to court."

JFM: No?

SrN#2: Not that I am aware.

[Pause] But I think in the six years I have been here, on our side, I would say maybe two years and this might have been the third, or eventually the fourth case we've taken to court, anyway. So I don't think it happens that often. Either because the parents in the end decide to actually withdraw, or unfortunately – well, yes, in most of the cases the patient deteriorates that much and passes away; makes the decision themselves.

JFM: In a difficult case like that, what other resources do you see being available to try to deal with the case, or to make it progress, or to try to solve it in any way?

SrN#2: For the nurses, or for the parents?

JFM: In general, but of course I'm interested in your own perspective.

SrN#2: So, I think from the parent's point of view, they always have the possibility to talk to the doctors, and discuss things with them. If needed we have an interpreter, we have the chaplains – no matter what the religion, I think we can provide whatever is needed. Then we have [inaudible] psychologist, and... but I think that is more for support. But then, probably also, if – like I said the chaplain tried to approach the whole situation from a religious point of view. It could have worked, and the parents could have agreed and said, "Actually we kind of agree, and if you... you might be right."

And for the nurses to deal with situations ongoing... well one thing is that we are quite a lot of people. We only work like three or four shifts a week, so there is always a bit of rotation. Yes, we try to do continuous care and say okay, it's good for us, it's good for the patient and for the parents if one nurse looks after the same patient a few shifts in a row, or again and again. But then also, it's quite easy to say, "I can't deal with this today, I'm having a different patient across the unit." And so you can step away from that. But it doesn't mean necessarily... it's not out of the way

completely, but you can have a little bit of a break.

We can talk to each other, with each other. We have the senior nurses, and if we really struggle we can talk to the sisters. We also can talk to [psychologist] if you want to. But yes, if you're at work, it always is present – especially during the big ward round, our morning handover. So all of us nurses will sit in that room next door, and the nurse in charge from the previous shift will give a quick handover of every single patient. And then we get allocated to the patient. And then the nurse in charge will hand a bit more detail about every single patient.

So during that ward round, or that handover, you always will get reminded of that one patient that is on the unit. And if something like an arrest has happened on that previous shift, that will be mentioned, and you will be like, "Why?" But yes, you can step away a little bit and say, "I'm not looking after her." On some days you might be the only person that is capable of looking after a patient like this, and then you have to.

JFM: What about the ethics committee?

SrN#2: I've actually never been. I don't know what they do or where they are!
[Laugh]

JFM: [Laugh] OK!

SrN#2: I know that [Consultant] is in it, isn't he? He's one of the... yeah. I remember that he did once – when I did the intensive care course, he had a lesson about ethics and law, and... a long time ago! [Laugh]

JFM: OK. [Pause] So in your view, when we are trying to decide what to do in a case like that, what should come into consideration? Any principles or standards you have in mind, any sort of guiding principle, or...

SrN#2: I think it's probably very difficult, because every patient is different. And the reason why the patient is in a situation where you might think, "Hmm, is it reasonable to carry on with the treatment, or would it be more reasonable to not escalate the treatment anymore, or maybe even completely withdraw the treatment?"

Because there are many different ways – sometimes they just say, "We do not escalate the treatment anymore. If the patient needs more medication or a different infusion, we won't start it." Or sometimes the doctors decide, "Actually, we should withdraw right now; we should stop everything, and not just let it happen." And sometimes the patient just arrests and then you have to decide, or the consultant has to decide if we should do resuscitation or not.

It's probably very difficult to draw a line, but... that's my personal opinion, but I think you should consider what will be the outcome... if a patient has renal failure in that

way, that the kidneys will never recover and the patient will need kidney transplant, but needs to reach 10 kilograms before it can have a kidney transplant, and the patient is 1.2 kilograms, how are you going to reach this? It's not reasonable to have this child in the hospital for what, two or three years before it can have its transplant? Is that fair for the baby, the child, and the family? And all the complications that would come with a hospital stay that long. Because we know that a lot of our babies get unwell because of being intubated, because of having lines inserted; they get infections because they have lines inserted, and then they get septic and it's all around septic, and not the initial NEC that was the problem or whatever they came for... PD ligation, and then they just got septic. And that's just because they are in the hospital. And then if they then have to stay in the hospital for another I don't know how many months or years to get to a certain point for a transplant or for another surgery, but they have to grow for another surgery, and they're in a situation where they are that unwell that they wouldn't survive without all the support...

It's sometimes... when... I think it's mainly from a religious point of view when parents say God or Allah or whoever has to make the decision, where I think, he actually has made the decision already, because your baby is on life support. Without that, it wouldn't live anymore. And that's... I know, I don't have children, so I might sound completely different talking if I had my own children, but sometimes to me it seems... Is it... irrational? If they say that God has to make the decision? Well he has made the decision to make the patient that ill, your baby that ill, that it needs all this man-made support. I don't know. I think it's very difficult.

There could probably be some sort of guidelines saying, "If something goes on for that long it should be considered... thinking of withdrawing treatment. Or if this condition plus this condition and further hospital of more than three months, or six months, and the patient is that unwell that it wouldn't survive without this and this and this medication, consider withdrawing."

I don't know. It's probably very, very complicated, and then it will be that blurry that you could decide, "Well we don't have that so we don't have to do this." I think it's probably impossible to make guidelines, but... I don't know. Maybe it's not.

JFM: Do you think this case has had an impact on unit on the way people work, on the way people care for their patients? Do you think it has a sort of lasting impact?

SrN#2: I don't know. It's possible, on some. I definitely had... I don't know if it's that case alone, but I'm actually... I always loved being a nurse, I like my job, but at the moment I'm not very happy in my job. I don't want to pin it down to that case, but that case probably has contributed to my... unhappiness? Not being satisfied anymore?

But as I said, there are many other... I can tell you, I do not like being in charge. So... [Laugh] That does not help. But yes, I think it has made some of us maybe sensible to... difficult parents? And it's obvious, because – well we had two cases

more or less at the same time that were, um, yes very complicated history and outcome. And I think in the end they actually withdrew on that patient, while [patient] was here as well. And I think within a week after [patient] had passed away, we had a new patient in the same bed space with PD, and everyone was just like, “Oh my God. Oh my God.”

It was very difficult for us to... We were just reminded constantly – and she was actually not in that bed space initially. My colleague wanted to move her, and I said, “I’m not moving her into that bed space. I’m not moving that patient in my bed space.” And she was like, “But you have to.” And I said, No!

So yes, I think with every new baby that reminds us of [patient] we will probably be like, “Oh my God, not again.” I don’t know... I don’t know if it has changed the way people care for babies in general, but maybe a little bit... about... if what we do is always right or not; and if we should keep going that long or not.

JFM: So you see yourself sort of going back to the case, and making comparisons or thinking about it when you’re working?

SrN#2: Mmm... Yes, I think because first there was [patient] and this other baby at the same time, so that was kind of like, “Who is going which way, and who is going first?” Literally, they came within, I don’t know – in ten days of each other? And then that baby probably passed away after... I don’t know, four weeks? I think she was here for four weeks, or six weeks maybe. And then, yeah, I think just because [patient] had gone, a new baby came with very similar problems, and it was just like, “Oh my God not another one of these, we can’t deal with this, we need a break!”

I don’t know if maybe it has to do as well with... A lot of our patients, they come in, they have the surgery, and they go back to the hospital. We very rarely have patients staying much longer than three, maybe four weeks, if at all. Sometimes they’re here for a week and then they’re gone – maybe two weeks. I would say that probably 10 days to 14 days is an average time. I might be wrong, but that’s what I feel. They’re not here very long. And then when we have a patient that’s here for three or four weeks, it gets to the point where “Oh my God, this baby is still here?” And then if it gets to three months... We don’t have them often.

JFM: So would you say it was more of an exceptional case?

SrN#2: Yes. I think so, yes. Yes.

In my whole career here, for me personally, I would say yes. Yes, we had other patients that were very unwell, and maybe the one or the other where you saw we really need to stop. But it didn’t go on for so long. That’s my impression.

I mean I do remember when we were still on the other side... When I started he was a long-term patient, but he wasn’t unwell. He was just long-term ventilated, and

couldn't go anywhere. But most of the time he wasn't that unwell, but he obviously had his [Inaudible] every now or then; and I think his condition was just incompatible with life, but the parents didn't want to stop treatment. I think that was taken to court, but I was really junior so I wasn't really involved in that.

And I remember another patient where we kept going quite a long time, but it wasn't that long. I remember one little Jewish triplet where the parents... the parents actually did agree at one point. They said, "OK, but we need to ask our rabbi." And their rabbi was on holiday so they asked another one. And he was like "Well I'm not your rabbi so I can't decide, so you can't stop." So it was a bit... we got to that point where even these parents did agree, but they wanted the support from their community and didn't get it. In the end that baby unfortunately passed away as well; and we did keep going for quite a while as well. But I still think it wasn't that long. I can't remember another baby that was here for three months.

JFM: Do you have any sense of what could have been done differently in that case?

SrN#2: Well, maybe if she had had surgery much earlier – I think she had been with us for three or four days before she finally had surgery. I don't know if that maybe would have made a difference; if they had actually done surgery earlier.

But even if she had surgery earlier, would she have developed the chylothorax? Would she have developed kidney failure? She might have had that anyway, and I guess in the end these things were the problems. The kidney failure and... I don't know if we ever found out what the problem was with her lungs where we could never get her off the ventilator – even when she was fairly okay, we never got her off the ventilator. I think she had two failed extubations, at the beginning when she did recover. So I don't know, maybe she had underlying problems anyway. But I think she actually came on cpap. I admitted her on cpap, so she was able to breathe on her own.

I don't know. I don't know if that would have made a difference, because all the complications she had afterwards were possibly triggered by the surgery anyway. So maybe if she never had surgery nothing would have happened. I don't know.

JFM: And in terms of the ethics, or the management of the parents, or the management of the decision to withdraw or take it to court, in general do you think that something else could have been done, or is there a way of avoiding going that long?

SrN#2: I don't think so. I don't know if there is like a guideline on how long things have to go on before the doctors are allowed to take it to court, or if it has to be a specific situation; but I think the parents had conversations again and again. They had been made aware of the situation. And then they had been made aware of the possibility that the doctors might take it to court.

And I could imagine that for some parents that might be a bit of a threat, and also a bit like, “Whoa, it’s that serious that the doctors want to take it to court? Maybe I should rethink what my decision is, and maybe I’ll change my mind, because I don’t want to be in court while my baby is still on intensive care.” But I think with some parents it’s just... and I don’t think that doctors would use it like that, or should use it like that. Like, “We’re going to court now if you don’t agree with us.” I think that would be wrong, but if it gets to the point where the doctors, and we as advocates for the baby as well, think it’s better to not keep going, then it has to be addressed. And if it helps the parents to change their mind, then fair enough. But I think if they would be able, or wanting to withdraw, then they don’t need a board decision or this idea of going to court. I don’t know. It’s...

I think even though we as nurses – or I as a nurse, I’m not necessarily aware of what’s going on behind or outside the unit, what the doctors actually talk about in certain meetings, or other consultants maybe with each other. Like, “This case is giving me a headache, what should we do, should we take it to court?” I don’t know what is going on, as I said I’ve never been to an ethics meeting. I think that it’s probably handled very well, and I’m not necessarily aware of it.

Maybe in some cases it should be passed on better, to say, “Actually we are thinking of taking this case to court, and this is the progress now, so you need to start documenting even better.” That’s when we kind of get made aware of it – when people start saying, “Make sure you document everything. Document what the parents said, document what you said, and document what happened.” Then we’re kind of like, “Oh, there is something going on.”

JFM: In a situation like you describe, where there would seem to be a consensus between the nursing staff and the consultant that something ought to be done, or that in that case treatment should be withdrawn, do you feel it’s right that parents have the last word?

SrN#2: At the end it’s their child, isn’t it? So from my point of view yes, but from a medical point of view, maybe no... because I think parents are – they don’t see the whole picture. They see that moment, but they maybe see that... We do try and treat the kidneys, but they don’t see that. Yes, they might recover, but... I think they don’t see the whole picture, and often don’t understand the whole picture. And sometimes the questions parents ask, you just think... “You do not really understand what’s going on here right now, do you?”

So from that point of view... And even if doctors explain it to them, I don’t think they grasp it, because they don’t have the medical training. And the little bit – unfortunately they can look things up on the Internet, and that doesn’t necessarily help. So from that point, maybe they shouldn’t, but in the end it’s their child.

So... I don’t know. It’s difficult. I think sometimes they just don’t see how severe the

situation is. They think the baby can recover, they just need to start tolerating their feed; but they don't see that the kidneys are still not working. Or even... they think if the kidneys start working again, that's fine. Yes, but your baby is still ventilated, and we haven't managed to get it off the ventilator. It's not tolerating its feed, and actually it also has a bleed in the brain. And we don't know what effect that will have on the later life. But you probably can't expect parents to see the whole picture and to look into the future as well. What that might bring.

I remember a situation where a consultant had gone into the conversation and said to the parents, "There's nothing we can do, we have to stop." It was a long time ago, probably three or four years ago. Yes, at least four years ago. And the parents were shocked, but they did agree. And I'm wondering now if maybe it's the way she said it, because she said, "there is nothing we can do, we have to stop," that the parents were just like, "OK then, well then, stop." Whereas other doctors say, "There is not much we can do, she might or might not pull through..." They are a bit more vague, and they give parents the option and possibility to say, "No, if you say she might pull through then we are not stopping."

I don't know if there should be... if it helps, or if it's right to actually... If you very clearly say, "There is nothing we can do; from a doctor's point of view, we think you should stop the treatment," and not say, "Well maybe we could try this..." That doesn't help! If the doctors feel that strongly, if they have the feeling there is something we can do, then yes, of course, keep going.

I remember another patient that was here for quite along time, where I asked the consultant, "Why?" And she said, "Well we can treat PD, we can ligate it, and hopefully improve the flow to the gut, and we can do this and hopefully improve the situation, and then he might pull through." And I was like, "That makes sense, okay." We need to fix this and this, and if then he doesn't recover, we can withdraw. It made sense, what she was explaining.

In that case it was actually the parents, mainly the dad, who were actually kind of wanting to withdraw. They were like, "We don't want our baby to suffer any more." Also, the dad was saying, "I don't want a disabled child." So they were like... they were not saying we don't want this baby, but we don't want him to go through all this, and we don't want this any more. Where we were kind of like –well, the doctors were like, "Well we can do this, and we need to try this, and we need to try this." And I was just like, "But why? Look at this poor baby, do we really have to do this?"

In the end he didn't make it. It was just the other way around, and I would have agreed with the parents. I would have said, "OK, is that what you want?" Then why another surgery, why another...

JFM: This attitude you just described, being hesitant to have a disabled child, is that something you encounter a lot as well?

SrN#2: That was the very first time that I had parents saying, or mainly the dad kind of like saying, “I do not want a disabled child.” That was the very first time.

Most of the time I think parents do not think about that, but... These parents were quite intelligent as well, the dad was an IT something high consultant and the mom was very... So I think he already had very high expectation in his child. Both of them were Chinese, so maybe it was a cultural thing as well, to try to get the... I mean, if they live in this country they don't have to have only one child, but to have very high expectation in the only child. So that probably contributed, in dad's case especially, to say no. Because even if he hadn't had all these complications, he was a 26-weeker; you never know what comes out of that. But it's very rare that parents are aware – that's my impression, that they were like, “Oh yes, I know that my child might be disabled anyway.” Learning difficulties, not able to walk or talk... We don't know what the end result will be.

JFM: OK, I think that pretty much covers all of the questions that I had. Is there anything you would like to add?

SrN#2: No.

JFM: Well thank you very much for taking the time, I know it's not necessarily an easy topic to discuss. Thank you.

SrN#2: You're welcome. [End]

Appendix F: Sample focus group transcripts

1. Discussion group with nurses #3

Discussion group with nurses #3

Date: 21 January 2016

Location: London Hospital

Conducted by: Jean-Frédéric Ménard ('JFM')

Duration: 61 minutes

Transcription: Geneviève Cocke (19 March 2016)

JFM: Thank you very much for participating. As I have explained, you have seen the consent form, and you have signed the consent sheet. Does anyone have any questions at this stage?

Multiple: No...

JFM: OK So... I should say as well that in my discussions with your colleagues, there is a specific theme that has emerged, which is the question of withdrawal of intensive care, which was seen as particularly difficult to deal with. So that is the lead I am following in my research. So many of my questions will be around withdrawal as well, so I should mention that. I am interested of course in your whole experience, and I am interested if you have worked in different places as well. If you can make a comparison between the place where you used to work and here, that is always useful as well.

Oh, and I didn't say anything about confidentiality, and that's very important. I'm going to be using quotes from our discussion in my work, but I will never attribute them obviously to your name, and I am always using very general categories. So I mean, you would all be identified as nurses, for instance. I always say it's a bit more difficult with nurses, but you know, if I talk about a consultant I'm not going to say if it's a man or a woman; so, same thing here. For instance I gave a presentation at the ethics committee yesterday. Because it was so close, you know, I was talking to people from here, so I didn't even say what jobs people had. I just said, "Someone said this and that," just so that people don't start guessing, you know, "who might have said that?" So I cannot guarantee completely that you will remain anonymous, and that someone who knows you very well might not be able to say, "Oh I know that's what she thinks. She might have said that." But I am going to make all efforts to protect your anonymity. And in my transcript I never use names; the person who does the transcription for me removes them right away. So we don't keep any track of your name.

So could I ask you first to just briefly introduce yourself? If you are comfortable using your first name that is fine; like I said, it will be removed from the transcript. So just a brief introduction, your name if you're comfortable, what you do here, and a little bit of background. Someone wants to start with that?

N#1: I could start. My name is [Name]. I'm 29 years old. I came from [European Country] 2 years ago, and I have been a nurse for 6 years. Anything else?

JFM: No, that's good! Thank you.

N#2: I'm [Name]. I have been a nurse... I qualified in 2001, and I have been predominantly in intensive care since then. I was first in [English City] in PICU, and then I have been here for the last 10-ish years.

JFM: Only on NICU?

N#2: Just NICU, yes; but PICU in [English City].

JFM: Very good.

N#3: I'm [Name], and I have been qualified for 30 years [Smile]. I worked in adult care at first, and did a lot of various jobs. I migrated to neonates. I worked in [African Country] for a very long period of time. And I have been here for 13 years.

JFM: OK Can I ask each of you, what is your specific role? Are you all bedside nurses?

N#3: Yes.

N#1: Yes.

JFM: OK Thank you.

N#1: I forgot to say, my background is with adults too. I'm not sure if that's important.

JFM: OK Well, everything can be relevant. So my first question is: when we are making decisions, when we are thinking what is the right kind of care to offer to a baby here, what would be the main consideration? Or, how would we be thinking about it, from an ethical / legal perspective?

N#1: Humanized care, individualized care... [Pause]

JFM: OK...

N#2: Excellence of care...

JFM: OK... And if I say best interest of the child, what does that make you think of? What is your reaction to that phrase?

N#2: It's not always... That is what we would aim for, but it is not always what is actually carried out.

JFM: OK Would you mind explaining a little bit, or maybe giving me examples?

N#2: Well, when a child is actually suffering, we try our utmost to actually prevent that from ever happening. But when a child actually gets to a state of where there would be no reprieve, there would be no turning back from, we sometimes don't always put the child first. We actually put the parents first.

JFM: OK And what would that mean, putting the parents first?

N#2: Um... We have to give the parents time to come to terms... maybe they don't have an understanding. Maybe they have religious beliefs... Maybe they are actually going through the grieving process anyway, and are at the stage of anger towards

us; so they are not looking at their own child's best interest.

JFM: OK [Asking others] How would you react to that? Does that...

N#1: I do agree.

JFM: You do agree?

N#1: I do agree. I do think we sometimes prolong situations too much... because we are thinking about the parents, and how the parents are going to deal with it, and then the child ends up suffering for days; because there is nothing else we can do for them. And we know that. But sometimes the decision... we try to work as a team, but ultimately the decision is not ours. And sometimes I feel there is this idea that we want to put an end to that child's suffering, and we have the feeling that other members of the team are like, "Okay, but we need to give parents a chance to..." You know, talk with the parents and see how they feel about this. And sometimes we end up prolonging the child's suffering.

N#2: There is also – I am speaking all the time, but – there is also not a degree of uniformity throughout different consultants. [Construction noise]

JFM: OK...

N#2: One consultant can actually give that tiny little glimmer of hope, which the parents will pick up on; and the other consultant will be able to actually direct it as the situation, how it is. And you get a little bit of seesawing; and that goes on for days, not just hours. And that actually puts everybody in a difficult situation. And it's not only consultants here. It's also different teams. That is the problem. [Construction noise]

JFM: There are many things to follow up on in what you said. So you said that it's not a matter of hours, it can be several days.

N#3: Especially if the parents aren't quite ready for the final ending.

JFM: And so when parents are not ready, what can be done, or what is being done to help them come to terms, like you said? You mentioned talking to them, trying to get their views...

N#1: Well, the consultants have – and we can when we are present too – have meetings with the parents to try to explain the situation. But then we have the problem that [Name] just said, that sometimes some consultants just... you know, they see the situation, but then they give them something that might make them think, "well maybe there is still hope," and then we can go on for a while. We also have a psychologist that tries to follow up with parents; when we have harder situations she is more frequently with them, and in itself that helps them to deal with

the situation too. But sometimes parents are just in denial of what is happening with their child, and they just want to have their child with them, and not let her go.

JFM: So is there a sense that nothing... like, in a situation like you said where there is no turning back, there is no possibility of a recovery, is there... how can I put it... Is there a sense that you always need to get the agreement of the parents before something is done, before we consider for instance withdrawing intensive care treatment?

N#2: It never used to be... I mean, you were around as well [to other nurse], it always used to be that – well not always, but the majority of the time – it was that the consultants basically led, and basically said, “There is nothing else that we can actually do for your child.” And I have found during years gone by, parents seemed to actually get to a situation where they were ready for their child not to suffer any more. Whereas here, at this moment in time – and I think it is to do with the degree of court cases that have gone on and progressively; there is a lot more litigation now than what there ever used to be. Then consultants are very cautious on – some consultants are very cautious; some consultants are still very much... they actually can say those things. “Leave it with the parents, and then let the parents actually come to terms.” And in those cases, they come to terms much quicker than by saying, “Well we’ll see, another 24 hours, and we’ll see, another 24 hours.” In those cases, we are the ones actually dealing with those children; and the only thing you can actually do is give them an excellence of care during that time. But it’s very difficult to actually sit and try to be positive with the parents at a bed space when the parents are on a high and you are there for the full 12 hours with them.

JFM: What do you mean by “the parents are on a high?”

N#2: Well, because they have been given that glimmer of hope...

JFM: OK, yes...

N#2: That we are leaving it another... to see whether they recover... if spontaneously a miracle has happened. [Construction noise] And obviously a lot of parents will actually turn toward religion. I’m not [Inaudible, noise] about religion, but what I’m trying to say is that you would actually... you would grasp at anything at those stages. [Construction noise] And a lot have never, ever gone through a bereavement – let alone of their child, but of their parents, or of their grandparents before. And it’s a very, very hard thing to accept. But in a lot of cases, if you actually had somebody who... This is just coming from me, but if I actually had somebody who was medical, and I was a layperson, and if they said to me, “There is nothing else we can actually do,” then I would feel as though that weight had actually been lifted from my shoulders. Because I don’t want to be the person who says, “No, you need to stop.” It’s a guilt thing that the parents will be left with.

N#1: Yes, I think so too.

N#3: Yes. Quite a lot of the consultants – not just the consultants, but the doctors are quite... they try to let the parents come to the decision themselves. Rather than just being very blunt, they try to be fluffy, and fluff around, and say, “Well, there is this last little thing that we could maybe try, and it might make a difference, but it probably won’t. We’ll try it, and then leave it for 48 hours and then see what happens...” Rather than just saying, “No, that’s it.” They just don’t put a full stop. They sort of keep...

N#1: And who is the parent that is going to say, “That’s enough, don’t do it anymore?” I mean, if the parent can see that the child is suffering... but it takes so long for the parents to actually be able to have the courage... I mean, I’m a mother now, and I know that... I want to believe that if I saw my child suffering like that and there is nothing I knew they could do, that I would be able to say no, stop it. But maybe I would not be, you know, because you just want to keep your child there with you. And if there is not a doctor that tells you, “No, there is nothing we can do. He is just suffering and he is not going to turn around.” It’s what they were saying, it’s like the parents feel that they have to make the decision, and it’s really unfair for them, I think.

JFM: Do you have a sense of why doctors don't put a full stop, like you said?

N#2: I think it’s a very difficult situation for them at the end of the day, and their emotions also need to come into being. But... again, you have different personalities in the amount of consultants that we actually have. And I sometimes feel that the teams who are actually not within intensive care do say things of which they don’t realize the consequences of what they have just said. The impact that they actually have on... because they would give false hope for certain cases. And you sometimes think it’s fine because you are just walking away, and you are now just leaving these parents with us, with this false hope. And then it’s actually up to the intensivist to have to basically be a bearer of bad news. And I don’t think that’s right. I think that is actually... it is passing the buck, to be quite honest. They don’t take cognizance of their own actions.

N#1: And I think it also confuses the parents sometimes.

N#2: Yes.

N#1: Because our doctors will be saying, “There is nothing else we can do, there is nothing else we can do.” And then somebody else will come in and go, “Oh, they don’t look too bad. Try this, or... have you done this, or have you done that?” It makes the parents not believe us, and then it makes our doctors’ job harder; because then parents turn around and go, “Yes, but such and such said that they have seen this before, and this worked,” and things like that.

JFM: Just so that I have a clearer picture: so would specialists from other

teams... do they talk directly to parents as well?

Multiple: Yes.

JFM: So basically, let's say the... I don't know, the kidney specialist will come in, see the child, do a couple of tests, and then it will be that doctor who will talk directly to the parents?

N#3: Yes. Although, if they can, all the doctors get together and speak to the parents together.

JFM: Yes.

N#2: But then they don't always have a meeting beforehand...

N#3: Yes.

N#2: So then you will get our consultants, who look over the whole picture; you will see them sort of back pedaling on what the other consultant said, to try to make it be as bleak as it should be, rather than having that positivity. So you can see them trying to go, "Yes but, yes but, yes but..." And because the other consultant tends to only look at one system, they don't tend to always look at the whole, then as [Name] says, you get that little glimmer of hope, for the parents... [Interruption, someone walks in] Sorry. [Laughter]

JFM: All right. So you were saying, sorry?

N#2: Yes, so they get that little glimmer of hope that our doctors then have to solve; going, "Yes, but this is the whole picture. Yes, this might look a little better today, but in general this bit isn't very good, and this bit is more important than this bit." So you can see them doing it when you sit in and listen to them. [Pause, whispering.]

JFM: Okay, so that's very interesting. Can I ask you to tell me a bit about how it is taking care of these kids? You know, in this period you describe, where you have the impression or the belief that there is no coming back, but then we are not yet at the point where we are going to stop treatment?

N#3: I think it's quite hard; because although you know what is happening, you don't want to be really, really negative to the parents. You just can't take every single little... I know we were saying about the doctors not giving them hope, but you can't just dash everything to them when you are speaking to them...

N#1: Because if they say something to them, you can't say, "Oh no, they are wrong. There is nothing else we can do for your child." We can't do that.

N#3: Yes. Because you are there for 11.5 hours; so you can't be negative all the

time.

N#2: What I end up doing... well, I have a psychological pathway that kind of blocks me off from it; but I have developed that over the years. Once a baby goes, I cannot remember the baby's name, come hell or high water. Don't ask me. I can tell you what bed space they were in, and what condition they had wrong with them, but I can't remember their names at all. But I find that... what I have to do is concentrate on one tiny thing that I can relay to the parents that is actually a good thing. Like pain, "Well, we know they are not in pain because..." and then go into that. Or, "Oh look, he has had a poo." Ridiculous things; but it is positive for them, and those are the things... You know, his gas may be absolutely atrocious, and he may be on the highest settings possible with inotropes where you cannot go up anymore. But you are actually having to find the tiny little aspect where you can relate, and have it be positive for the parents, so you don't look like the bearer of doom and gloom constantly for the 12.5 hours shift.

N#3: Or you end up saying things like, "Yes, he is really sick, but he is stable."

N#2: Yes.

N#3: Because for all intents and purposes, they are stable; they are not going to die any second. But they are so sick that there is nothing else you can do. So you end up saying, "Yes, he is really sick, but he is stable," which they take as a positive. Which it isn't, necessarily...

JFM: Yes...

N#1: But it is very frustrating for us, I think. Because you know that... you know that anything that you do is not going to change the baby's outcome. But we still do blood tests; we still have to prick their heel to do blood tests sometimes. We still have to do things that we know are going to be painful for them; and there is no point in doing that, because we are not going to change the situation. But because they are here, we need to do something, because we cannot be... we can't not give them the care that they need. But we know... and we give them the care to keep them alive; and so we control things and get on top of things; but we know that those bloods are not going to make any difference. You know that the treatment is not going to make any difference. So what is the point of making that baby suffer just a tiny bit more every day?

Because when a baby is that sick, even a nappy change is painful. There are so edematous, most of them, that even touching them must be painful; and we are aware of that. Even though they are sedated most of the time, we don't know what they are feeling, and we are making them suffer anyway. So it's very frustrating to have to do that – with a smile on our face, because the parents are there. The doctors come and ask us to do something, and we cannot say, "Why? There is no point!" because the parents are there and they just told them that there might be a

chance that they can do something for him.

So it's very frustrating; because especially, as they were saying, we are the people who are with the patients most of the time. We are the ones who are there, and whom the parents are going to be asking questions to once the doctors are gone. A lot of parents at that point have been here for a while, so they test us. They will ask the same question to [Name]; I come around when [Name] is gone, they will ask the same question to me. That's fair enough; they are trying to understand if we are consistent. And most of the time we are, because we are aware of what is happening. But these kinds of situations, for us, are very stressful and frustrating, I think.

JFM: Would it be possible to... Is there a way of communicating that frustration, of relaying it back to the consultant for instance?

N#2: Well, the majority of consultants do actually pick up on what we are going through.

N#3: But I think it is also quite hard to speak to the consultant when parents are there.

N#2: Yes.

JFM: Yes.

N#3: The only time we can do that is first thing in the morning ward round, by which time we haven't really met the parents, so you are just going on hearsay of what other people are saying. But quite often, the consultants, because they are around every day, Monday to Friday, they get to know the parents, especially by the end of the week. And they have heard mutterings from the nurse in charge and from us, that this is what is happening with the parents... and things... and I think the family liaison nurses as well...

N#2: Yes, they are a very, very good support on that side.

N#3: Yes. They are a very good support for the parents; and then they will go away and speak to the consultant, and explain what is happening, and things.

JFM: Do you also speak to the family liaison nurse, to...

N#2: Well they actually work closely with us, really.

N#3: Yes.

N#2: Anything that we need to discuss, to do with the families, then we relay to them and they will go chat with the families.

N#3: Yes. And again, sometimes it's just about getting to speak with them when the family isn't next to you; which is sometimes a bit difficult when you have a really sick child.

N#2: But on that side we kind of work as a team. There is just... I mean, like you were saying [to other nurse], you know, because there is no do not resuscitate in the notes... Or, you get... which we have had recently, where there was a part do not resuscitate; well, what is a partial do not resuscitate? Well, they put it down specifically: if the tube blocks off, then you actually have to react. But if... even though the child is deteriorating and deteriorating, and you have sacs that go down 10 each day, you're still giving things like antibiotics. And you may be giving a lot of antibiotics in a day. So your workload continues to be exactly the same as it would be when you are actually treating... Now, I know that sounds as though you're being lazy, but it's not... You're giving these antibiotics to a child who is never, ever going to actually recover from an infection that has just riddled his body. And... [Pause] Sorry, it's a waste of resources.

N#3: It's true.

N#2: And they are not cheap.

N#3: And every blood test we send is not cheap. And yet we still...

JFM: So do you feel that, the sense that resources are wasted? You just said, with regards to the...

N#3: Well I think, I probably... I don't know about you [to other nurse], but when I worked in [African Country]... I worked in a busy neonatal clinic, and it was attached to an infertility clinic. So you had multiple births that came in. And this was a private clinic. So you had patients on a conversion aspect back then – which would be the... not only would you pay 2,500 pounds, like you do over here, if they had to pay that per day for your bed in an intensive care unit. You could be escalating to possibly 20,000 a day in cash for the things that you were actually delivering: X-rays, lines put in, antibiotics, drugs being given. And I do look at these babies and I think, "What are we doing? Why are we..." Parents would never be able to afford this care. And I have sat in front of parents in the same situations over there, and they have actually said, "We're through child, because one, we can't afford it." They had to put a second mortgage on their house to actually pay for the basic care. For one of their triplets, let alone the three of their triplets. But they would actually turn around, because they knew that situation. They knew, and it had been made aware to them that even if remotely this child actually had a chance of living, the quality of life of this child would be horrendous. And that is never, ever put over to these parents, at all, at [Name of the Hospital].

N#2: And I think not just that, but it's quite frustrating as well, when you are in charge

and you have children cuing up to come in, and you have a couple of babies on the unit that you know you are not going to be able to help; but you might be able to help these other two that are waiting to come in... It's also very frustrating from that point of view. It's like, well, we're stuck with these children, we can't help them, but they are here and we just have to keep going. But this one that needs this surgery that could save their lives, we can't do anything. We can't make them better, because we've got these babies here that... are here.

N#3: Well they're bed blockers, aren't they?

N#2: So that can get very frustrating at times.

JFM: And is there any way of addressing that? Would that ever be... How can I put it... Would people sort of do something about it, in a case like that? Do you feel that the consultant might want to push things a little more knowing that there is a queue for the bed?

N#3: No...

N#2: No.

JFM: No?

N#2: They just go, "Whoever is outside the hospital is not our concern. The babies here are our concern." Which is true...

N#3: Yes...

N#2: They are, but...

N#1: But then if there is nothing you can do for them, what are they doing here?

JFM: Yes.

N#1: But it's not good for the parents, too. It's not good for the child, and it's not good for the parents. It's prolonging a suffering. We know they are going to suffer in the end, because they are not going to have their child; but we are prolonging their stay here, which is even more painful, on a hope that it can get better in the end; but we know that is not going to happen. And a lot of them are spending a lot of money on traveling here; a lot of them are staying in hotels and everything. We have places for parents to stay, but a lot of them are here for so long that they end up getting fed up of being in the accommodations, and they go to friends' places. For parents it's also very bad, because they spend all their days here, around a child for which there is not any hope. So what is the point of prolonging all of that?

N#3: And also some children within the family are kind of neglected, because they

are with grandparents... those situations, I mean, because you have... How can I put it... Because you feel that your attention needs to be bestowed on your sick child at the moment, what happens to the other siblings? It's never really taken into account, because of your intensity. And it is, it's human nature; we are selfish as humans, because we don't want to let go. And you can fully understand that. But if things are put and actually told to you a lot more basic – because the majority of these people are very lay people. They have no idea what is anything to do with systems or medicine or anything like that. They do a lot of googling on the Internet, which is the worse thing they could possibly do. But they need things to be explained to them; but by the time some things get explained to them, they are at that blanket stage, where they can't take information in whatsoever. And unfortunately, that could have happened over a weekend, where you have one consultant over the weekend that can be fluffy, and then by the time Monday morning comes you have a consultant who can actually speak to them, but those shutters have already come down.

N#1: I think what you said before is really important too. If these parents got explained, "If your child survived, you will probably end up with a child that is never going to walk, never going to talk; he is going to be in bed and you are for the rest of your life going to be taking care of a child that is not..." it's not disabled, because there are some disabilities you are okay with, but it's just that probably it's going to be a child that is not going to have any quality of life – neither the child, neither the parents, neither their whole family. And I think most of the parents are not aware of what they may be facing, if we push that baby too much. Because we in neonatal medicine have been progressing so quickly that we are not even sure... we are saving babies who are 23 weeks old gestation-wise, and then we are not sure what will happen to them 20 years from now! We are still at that stage, aren't we? So we are starting to see that now. But we are not sure... and when they are that small with the brain hemorrhages and stuff, we are not sure what outcome that child is going to have. But we know that some of them are going to have a really bad one if they survive. So is there any point in making that child suffer for the rest of their life, and that family suffer for the rest of their life, just because we didn't want to make that decision of putting an end to it, because there was still hope? Because one thing is surviving, and another thing is having a quality of life, for the child and for the whole family... And I don't think that is ever...

N#3: No, it's never discussed...

N#1: ...discussed here.

N#3: And it's okay changing a nappy now on a baby who is 2, 3 or 4 kilos. It's a bit different changing a nappy on a child that is 12 years old and needing 24-hour care. And that, a lot of times, is not actually provided by the parents themselves. You'll be lucky if mom and dad actually even stay together; because there is such a high incidence of divorce rates for people who have handicapped children.

N#1: But they cannot picture that.

N#3: No.

N#1: You know, nobody can picture that child 12 years from now, and what is going to happen to them. And if they are not told this, they are never going to be thinking of it. They just think about their baby that is there now, and what can we do for him? They don't think, well, we can make you survive, but then you will stay in your bed for the rest of your life; you won't go to school, you won't have any friends, you won't... you know. And they don't think about it, and nobody tells them about it.

N#3: I think in neonatal units, if you actually have a baby who is born at 23 or 24 weeks and their consultant... I think it's the obstetrician who actually comes to them and says, "Your baby's survival rate will be 40-60 % at 23 weeks, 50-50 % at 24 weeks, and the incidence of them not having any problems when they get..." They are the ones that give those ratios. And I know there are probably a lot who are actually saying, "Let's just try." But those seeds are planted in those moms' brains, or in the dads' brains, even if it's just for a second, because a lot of the time it probably is. "What would you do if your baby is actually... we are now in labour, your baby is going to be born and its chance of survival is this and this. We have to make you aware. Do you want us to go ahead and do things, and resuscitate?" But a seed is planted... Now if it goes back to it at the end of the day, they may actually regret their decision, but that seed is there. And there are some parents that would actually say, "If my baby is handicapped, I don't really want... I can't go any further... I would not be able to cope with that at all." Again, we are going down to lay people, who have no idea about that!

JFM: If I understand correctly, if we are just talking about prematurity, it's one thing. But then the babies who would be admitted here, as premature, they would have further complications. So the stats are not the same anymore.

N#3: Well they have actually gone into that grey area, because they have gone into the area where they have developed their NECs, and then unfortunately you are then going on to the NEC... sorry, do you know what NEC is?

JFM: Yes. [Smile]

N#3: OK [Laughter] And then that has turned into, "No, you actually have gut syndrome." And what does that actually... And some parents will come to you and say, "Well how long are they going to be in the hospital for?" And they will always say to us, how long will they be in the hospital for? And you say, "Well, I can't tell you. It depends on this, it depends on this, and they might not reach this..." And you can actually say that at that stage. But when it comes to end of life, us as nurses can't really have any input whatsoever with it.

N#1: And I don't think it helps either with the media and all their miracle stories. "My baby was born like this, and this happened and that happened, and look, they're

fine!" So parents...

N#2: That's the 1% who are fine, isn't it?

N#1: Exactly.

N#2: It's like that 1% that was fine, that was in the newspaper... do you remember the one that they actually showed? Oh I can't remember, it was ages ago, it was in the Metro. And all the nurses came here at work and said, "Yes but that child had a tracheo!" Nobody else would have seen that, because it had something covering it! [Laugh] And then you go out and say, "Well, that child may have a tracheo for the rest of its life." But the rest of the public don't know that...

N#3: Yes, so I think sometimes the media has a lot to answer for, because people have unrealistic expectations of... Especially here, because people think [Hospital Name] is the best of the best...

N#2: Yes...

N#3: And is wonderful and brilliant. So they have slightly higher expectations of us being able to do something.

N#1: Yes...

JFM: Well if they are here, it is because the situation is very difficult to deal with.

N#2: It's grave, yes. Yes.

N#3: But they think that because they come here, we are going to fix their child. You get that quite often, people turning around and going, "I'm so glad to be here now, you are going to do something." And it's like, "Not really, no..." We just happen to have the surgeons and specialties that you don't have at your hospitals, and that we have here.

N#2: Yes.

N#1: And sometimes they come from really far. Remember that patient that we had, coming from Kuwait or something like that, to be investigated respiratory-wise? They came here from Kuwait. We realized he had a neurological condition that he would never be able to breathe on his own. So why did he come here? They knew what the problem was; but they came here for nothing [Laugh], because there is nothing we can do and that child is never going to breathe on their own.

N#3: Yes, but... That was a political thing, because...

N#1: Oh, okay...

N#3: He actually was a member of the Saudi government; and therefore he had obviously gotten the Saudi government to sponsor him to bring him over here, for us to give him the same diagnosis. That was actually money for the hospital, at the end of the day.

N#1: [Laugh] Yes, but for the child! He was just transferred from Kuwait to here for nothing?

N#3: Yes.

N#1: For absolutely nothing!

N#3: Yes.

N#1: [Laugh] Because he didn't come here for... They didn't find out anything that they didn't know back there. And is that in the best interest of this child? No! For sure it is not! The best interest would be to stay where he was and give him the best care that they can there, because that's his home. Not coming here and then going back... you know, for the child, it's not fair.

[Pause]

JFM: I want to ask you, coming back to something that was mentioned before: you said that very often these children are suffering. I would be interested in hearing... It might sound like a bit of a dumb question, but how can you tell that they are suffering? What signs do they give you?

N#3: Well, if you were 500 grams, and you had fluid in your tissues that registered to 600 grams – that is double your body size that you actually are now. Do you think us being able to deliver pain relief for that would actually be effective, considering these babies have probably been on the same drug for quite a while, by the time they get to that stage... I don't know if your wife has ever had a baby and had swollen ankles, and she said, "Oh my god, my feet are absolutely killing me." Well, that is actually on a baby's body from head to toe. They are like Michelin. They are so swollen... if you actually put a cannula in, they leak like a watering can.

N#2: Yes. And even when you reposition them, they actually lie with their arms out like this. You can't put their arms anywhere. You can't roll them over, you can't do anything. And if they are awake and we haven't gotten them paralyzed, they sometimes just look at you as if to say, "What are you doing? Just leave me alone."

N#3: Yes.

N#2: "Go away."

N#1: You can tell by their eyes. You can see the suffering. Even with all the painkillers you can give. And we do things to them, to be fair, that we wouldn't do to an adult.

N#2: No.

N#1: You wouldn't have an adult incubated awake. Never. Immediately the adult will take out the tube, and that's it. Nobody can stand having a tube on their throat... how many times...

N#3: We do, do... we actually do give, but the neonatal units don't. The neonatal units never, ever give sedation...

N#1: Yes. In Portugal, we didn't use to give...

N#3: They never, ever give sedation.

N#1: We give sedation to intubate them and everything; but how many babies do you have that are intubed and awake? Whereas an adult, as soon as they wake up...

N#3: Yes. They pull it...

N#1: ...they pull out the tube, because it's unbearable to have it there. And we keep them like this for days if we need, awake with a tube down their throat.

N#3: And chest rings in...

N#1: Exactly. Things that, if you could imagine... We always say that they are so strong, these small creatures. They are so strong; because you could never cope with these kinds of things that we do to them; because they cannot say what they are feeling – because if they could say what they are feeling, we would think twice before doing some things. But because they cannot express themselves other than frowning, or you know, looking at us in a different way, then we keep pushing and pushing and pushing a bit more. Because they are not really saying... because if you have a 5 year old who will scream at you, or you know, pull your hair down [Laugh] and make you understand... These babies we can't... actually so sometimes we need to be the ones that say, "It's enough. He can't take it anymore."

N#2: Sometimes the junior doctors will just go... when the lines are being put in, they will just carry on, and carry on, and carry on. "Oh, he's fine, his heart rate has not gone up, or his blood pressure has not gone up. He's not desaturating." Well, the possibility being is that those systems can't do that. We don't know whether those systems react in that way in a child who is actually so edematous, he just does not... he cannot move, cannot do anything. It will basically just be... you have two little

eyes in a body. But what is your brain doing? You can't actually... Nobody can actually say that. And unfortunately we have one consultant as well that comes around and turns the morphine off, and says, "Oh, he has morphine in his tissues. He doesn't that morphine carried on." Now how does he know that?

[Pause]

N#1: It's just because sometimes if you say to them, "Try to get someone to put a cannula on your hand." Because if you ever have felt that, you would think twice before trying three or four times to cannulate a child, not leaving her to rest a bit and have a bit of quiet time. Because it's very, very painful; and if you've had it in your life, you know it's painful. [Smile] And just having the cannula there, even if you take the needle out, is painful. So... but sometimes they don't think about it; especially the junior doctors, because they are trying to get their skills improved and stuff, so they just do it, and go ahead and do it. And then we need to be the ones to say, "Okay, can you please stop and give the baby a rest, and we try it later? Because he needs to be quiet for a while." Because everything for these babies is stressful: the light is stressful, the sound is stressful. We are in a very loud unit. Most of the time it's very loud. Lights everywhere, beeping monitors everywhere; just that is so stressful. Coping with that, plus, people sticking needles on you... And sometimes it's two of them, one trying their arm, the other trying their leg. I mean, it's not... you can't have this. It's not fair for them. I spoke about humanized care, right, first thing. Sometimes we don't do it, because we're thinking about the medical stuff. We're not thinking about the patient itself.

N#2: We actually had a documentary a couple of years ago, and one nurse who worked on – not this unit, another unit – actually said on camera... it was to do I think with ethics actually. And she said on camera, "You would never treat an animal like this." It's very true at times.

N#1: it is.

N#2: You would actually be prosecuted. If you treated an animal like that. And that's not just the cannula; but sometimes the things we actually do to children that should not be... they should just be left to die.

N#1: I'm really sorry but I will need to go soon.

JFM: Yes, okay. Do you need to go now, or do you have a few minutes?

N#1: I have a few minutes, if it's a few minutes.

JFM: OK So I'm just going to ask you, maybe to conclude. We have already said it I think, but maybe there are other things you can think of. What could be done differently to avoid these very difficult situations that you have described?

N#3: I think consultants need to lead, rather than... So they need to be more forceful, I think, about...

N#2: Yes.

N#3: I'm not saying telling the parents exactly what to do, but I think they need to have a more definite line.

N#2: And a direct... approach.

N#3: A direct approach. And say, "We have done everything, there is nothing else we can do."

N#2: And actually say, "These organs have actually gotten to their limit. Even if anything occurred, it would be irreparable. The damage that has occurred on these children would leave lasting damage at the end of the day, to your son or daughter."

N#3: Yes. I think they need to be more blunt, rather than trying to say things nicely. I think they need to be more blunt sometimes. I mean, some of them are.

N#2: Yes, some of them are. And also, to actually try to get the other teams on board; I mean, the cardiac team are probably not too bad; but it's like, teams like your renal team, who don't deal with death every day; your metabolic teams, and your urology teams...

[Interruption, someone comes in and exits.]

N#2: And to try to actually get them on board, to realize what they have actually... it doesn't even need to be that. Sometimes it's the anesthetist, when they are going to theatre... we had one last week, "Oh don't worry about it. He will be fine when he comes back." Well...

N#1: [Laugh] No.

N#2: Well... no! This is not actually going down, because he'll be that fine when he comes back. I don't remember what was wrong with him, but it was actually going down because this was helping him to get to his next... Oh, I know what this was! It was the renal patient that was going for a transplant. Why would someone say a ridiculous thing like that? [Laughter] The child is going to need a kidney transplant. He's not going to be fine just because he has gone down to have a catheter put in. Just actually... all the multi-discipline routines to be aware that what is coming out of your mouth, think about it before it comes out.

N#3: Yes, I think it is things that we wouldn't take as positives as such. If somebody said, "Oh, they'll be fine when they come back," we will just say, "Oh, that means they shouldn't be too rocky, they should be quite stable when they come back." Not

the fact that they are going to be better, whereas the parents can take it in a positive light, I think.

N#1: And you see patients that went to quite basic surgeries, and they come back and they die afterwards. And nobody was expecting that, because the problems they had before are not going to help. And so basic surgery for them or for anybody else, it's not a basic surgery for them. It's a surgery, it's anesthetics, it is intubation – you know, all those things that for them, that had underlying problems before, really bad ones, it can be their death. And we cannot say that to parents, "It's going to be fine." Maybe it's not, you know? I'll never forget that patient that went for a choanal atresia. Do you know what that is?

JFM: Yes.

N#1: That baby went in for a choanal atresia repair; she died two days later, and nobody was expecting that. But the problem she had before caused a lot of different problems after the surgery. And everybody was shocked that that had happened. Even we were very surprised that that happened. But it can happen. So you know, we can't promise that kind of thing. "Oh, your baby is going to be fine." No, we don't know that. We can't give them that hope. It's not fair for them.

N#2: And also I think we have had a lot...

[Interruption, N#1 exits.]

N#1: I have to go now. Is that okay? I'm really sorry. Thank you very much.

JFM: Thank you.

N#2: We have had a lot of cases where there has actually been... the prolonged final care for the patient has actually been because of religious... and that is really hard, definitely. Because they actually get family members sitting at the bed space, who... we get family members or people from their church, or people from the synagogue or wherever, who sit at the bed space representing the parents. One gentleman was playing poker on his phone!

JFM: They are kind of keeping watch, or something like that?

N#2: They must be representatives, while their parents or family are at home. But to me that is the most highest, disrespectful thing that you could possibly do! I can understand that... if, you know, it's a very stressful situation. But then don't volunteer for it! And therefore come and sit and read; but don't do something so disrespectful like that, at the end of the day. And that poor child suffered probably more than I had ever seen a child suffer before. That child decomposed in the bed; that is actually how traumatic it was. And it is the Jewish community, and unfortunately it is the Muslim community, because of their beliefs; and I can understand that, but... In

some of these cases, they actually ring their families up in other countries, and ask them for their opinions. Give them the history over the phone; and I don't know whether those people are psychic or not, but then they give a positive outcome to the child at the end of the day.

N#3: Although... we do sometimes get quite lucky with... you get the religious leaders of their church or synagogue, who turn around and go, "It's okay to stop."

N#2: Yes. Some do.

N#3: Very few and far between, but we do get them every now and again. Especially the ones that work in this hospital, they will talk to their respective colleagues and community, and...

N#2: But that's if we're lucky.

JFM: **And... one last question. What about going to court with these cases? Does that ever happen, is that an option? How does that play out?**

N#3: That is hard. It's really, really hard.

N#2: Hard. Yes.

N#3: It's very... because I had to go to court with one of them a few years ago, and that was really hard; because I didn't even know why the parents wanted me to go there, apart from the fact that they get to look and everything that has ever been written on the child, they get to look at [Inaudible] of you. Lawyers get to look at it, and barristers, and they just literally plucked people out that had said something a little bit positive. And you have to go and sit on this stand, and... You haven't looked after them for months, but because you once said, "The baby smiled at me," or something like that...

N#2: That is why the nurses' documentation is so crucial to being impartial; because what you put down as your possible interpretation of something, some of these girls, actually, their career was swiped through the floor, and they actually left.

N#3: And as you know, being from a law background, it is really hard to be sat there and cross-examined on every little bit...

N#2: You probably couldn't even remember...

N#3: It was about a year since I had looked after the child. I had been around, but because I was in charge of doing various different things, I hadn't looked after that child for a long time since they were tiny. And yeah, that's really hard. Really hard.

JFM: **Well, thank you very much. I think we could have gone on for much**

longer, because you had such interesting things to say. Thank you very much.

N#3: Okay, thank you.

JFM: Take a cookie for the road, please. Thank you.

N#3: Oh, I will. [To nurse] I'll have yours. [To JFM] Do you want me to send the next one?

JFM: That would be great, thank you.

[End]

2. Discussion group with consultants

Discussion group with consultants

Date: 13 December 2016

Location: London Hospital

Conducted by: Jean-Frédéric Ménard ('JFM')

Duration: 44 minutes

Transcription: Geneviève Cocke (19 March 2016)

JFM: So, basically, the idea is to have a discussion. I'm going to be raising a couple of themes. I'm going to let you speak. I am very interested in what you think; I am very interested also in your moral or your ethical response to these things. You may notice that I might sometimes sound a bit more "leading" than you would expect in an interview. It's because I'm trying to present the results – to reflect the results of the previous interviews – and you know, what are the emerging themes from the interviews I have conducted before. And if you disagree, please go ahead and say it. It's just going to make the data richer.

So can we go around the room and can you very briefly introduce yourself? If you don't mind saying your name, it makes transcription easier; but then we won't keep it in the final transcription. So the transcriptions are completely anonymous. [Pause, someone jokes].

Also, as a further layer of protection, I'm trying as much as I can to avoid using the name of the hospital, in my research and when I am publishing or anything. I just say "a tertiary pediatric teaching hospital in London". There is more than one of those. [Someone jokes, laughter].

Okay? So maybe we can start with you? Briefly introduce yourself.

Ph#1: I'm [name] I'm one of the intensive care consultants here, and I do ethics as well.

JFM: Thank you.

Ph#2: I'm [name] I'm another one of the intensive care consultants, but I'm also an academic.

Ph#3: [Name] [Inaudible, unclear pronunciation] the neonatal unit here.

Ph#4: I'm [name], I'm an intensivist here.

Ph#5: I'm [name], I'm an intensivist here.

Ph#6: [Name], intensivist.

JFM: Thank you very much.

So the first thing I would like to talk about is this theme of... your relationship with parents, with children in critical situations. Many have mentioned the importance of managing expectations and setting the frame of reference when you're engaging in a relationship with parents. So I would be interested in your thoughts about this idea. I don't know if it resonates with you?

Ph#4: I didn't understand that.

JFM: Okay. So, setting the frame of reference. Sort of laying down the options, having this discussion, so that when the child arrives... It's important to explain to the family what you do here, why the kid is here, what will be the options. Especially if you think about the possibility that you might end up in a situation where you might want to suggest withdrawing life sustaining therapies. So, I guess, the importance of dialogue at the beginning of the relationship.

Ph#2: The first [inaudible] is almost always what do you understand before, here. And that tells you where somebody is [inaudible] setting up expectations. And actually, usually in the first few sentences you know if you're likely to have a wild mismatch of expectations and reality, I think.

Ph#4: Except that some patients change.

Ph#2: Yes, true.

Ph#4: I mean like... Sometimes I just assume that the parents would be sensible and would agree, but...

Ph#2: Sure, you do get surprised. But it helps you calibrate.

Ph#3: I guess because we're a receiving unit, the patients aren't becoming sick here very often, they are either in the ward upstairs, or more come from the neonatal unit, so... [M2]'s point about finding out what they've been told up to now. And often they have had expectations they would have got from conversations about pushing somewhere else. So, some sort of feeling of what they understand, I would kind of start with that. Your first meeting is a bit about getting to know them as well. Trying to drop bombs like "we might switch the machines off" the first time you meet someone, unless there is an imminent catastrophe going on, is not likely.

Ph#2: But, having said that...

[Brief overlap, inaudible]

Ph#4: We are talking about neonates here, aren't we?

JFM: Yes, absolutely.

Ph#4: Then I think that's slightly different than the pediatric world... because most of the neonates that we get – not always, but most of them – have been in another unit for a period of time.

Ph#1: Yes.

Ph#3: Yes.

Ph#4: So the environment is a bit more... they are a bit more used to the sort of environment, and what we are doing, and all of the rest of it. Whereas in the pediatric population, you often have families that have never been to the hospital before. And so the whole thing is such a shock that you have a lot more work on your hands in terms of explaining, you know... "That's a ventilator."

Ph#2: Yes. And you have to information gather as well, because different places have different ethos. Depending where they come from, some places are much more likely to have been frank, and other places are much more likely to beat around the bush a bit more.

Ph#4: I presume, when you talk about neonates, you're not just restricting it to ex-premature babies?

JFM: No, no. Neonates. The neonates you see here.

Ph#4: We also get the neonates that are born and then have something unexpected that... they have never been in an ICU for ages.

Ph#6: Well... they are much rarer. And those ones tend to get better.

Ph#5: Again, I think what [W1] said is very important, because it's a series of conversations. So for me, it's like getting to know them and a very general feel of the situation.

Ph#6: But unfortunately, in the bigger part of the population, you don't always have the luxury of that.

Ph#2: Or even the neonatal population. I mean, quite frequently the first conversation I have with the family is, "I'm sorry, this is terrible news, we need to

plan for what comes next.” I mean, that’s not uncommon actually. I think that’s about a third of the conversations I have first up.

Ph#3: I mean, it’s definitely also the meeting. Because if your first contact with us is saying, sort of “death and destruction,” not infrequently the family starts hiding from you after that. But sometimes you can’t avoid it, you know?

Ph#2: Yes.

JFM: Something that has been mentioned in my interviews is the risk of giving “false hope” in this initial conversation.

Ph#6: I think...

Ph#3: Sometimes it’s too late. Because sometimes by coming here, there is false hope given.

Ph#6: Yes, yes... When you work in an institution like this, people tend to say, “Oh don’t worry, you’re going to go to Great Ormond Street. They’ll sort it out.” That tends to happen. So one of our rules is just to explain that, you know, that may not necessarily happen in that way. And even when you say to the clinicians, you know, “This doesn’t sound very good, I don’t think there’s anything we’re going to be able to do for this. Please explain to the family that they are going to come, but that things aren’t looking so good.” It doesn’t matter. They still get told, “Don’t worry, you’ll go to Great Ormond Street and they’ll sort it out.” So I think that’s a problem. [Short pause] Having said that, I don’t think that there’s any purpose to beating around the bush, you know? I think you need to be open and transparent with the information that you’ve got. And if the information is that they are very sick and I’m not sure we’re going to be able to help them, then that’s...

Ph#2: Yes, I think that’s... I couldn’t agree more. I often make a point of saying, “Your child may die.” I’m not saying “do badly” or “poor prognosis.” I’m actually using the word “death” in some form. And...

Ph#1: [Joking] And that’s for children who are visiting us!

Ph#2: [Laugh] Yes! And usually I’ll say, “I’m sorry to be blunt but I think it’s important to be clear.” Or something like that. And nearly everybody says, “Thank you for telling me.”

Ph#3: Yes.

Ph#2: Not.... Occasionally you get, “How dare you say that? He only has...”

Ph#4: And we always say, “We’d rather be honest with our parents and tell them things right from the start rather than hide it from you.” And most of them are grateful

that you're honest with them.

Ph#2: I think [W1]'s point about coming here... There is a very recent conversation that is vividly in my mind about that, where they come here thinking that we are going to fix it. [Short overlap. Laughter.] And I think, I do, that that is actually quite... not tricky, but it adds another dimension to the expectation.

JFM: That's a very specific... Oh no, sorry, go ahead.

Ph#5: In terms of... you mentioned about false hope... I think another important aspect to it is the specialties involved as well. Because probably they are a little bit more optimistic about their specialty but they don't look at the bigger picture. It probably happens more on the pediatric side, but it's quite relevant to the neonatal population as well.

JFM: That's also something that was mentioned in the interviews. Is there a way to avoid that? I know usually you try to have an interdisciplinary meeting before talking to the parents, or to get everybody on the same page. But it's also something I have been told, that sometimes the other consultants from the other specialties will say, "Oh, we can fix that bit," and the other one will say, "We can fix that bit too." Then it comes to you to say, "Hmmm."

Ph#6: I think it's a difficult one, because some of the surgeons really do believe that they are technicians. I've had several of them tell me, "You know, look, my role is to do what I do. I'm not there to decide whether it's the right thing to do or the wrong thing to do." Which is quite interesting, because the GMC would disagree with them, and say, "Actually, every consultant has an obligation to ensure that what they do is the right thing to do, and to think about what to do."

Ph#3: Well, they say they delegate that to the prior...

Ph#6: I know, but according to the GMC, they are not technicians. They are doctors; and doctors have a code of practice, and the GMC is very clear about the code of practice. [Inaudible] just spent the last 2 weeks going through it in detail. And it's a very clear code of practice – which I think a lot of people forget, particularly in a hospital like this, where they are pushing the boundaries on their little specialty. They often will want to do things, you know, because it's technically possible.

Ph#3: You're right, but there is a balancing sight that... sometimes the cases have so many specialties involved that any one can't, usually, see the picture. I'm thinking of the child with the endocrine disorder... Surgeons could repair the abdomen again, but actually it was only truly evident once you had a proper conversation with the endocrinologist and ourselves, and the [Inaudible] pharmacist, could you see that the whole picture wasn't manageable. So...

Ph#1: So your answer is getting everyone in the room talking at the same time,

[Inaudible] talking to families. That is much harder than it sounds. And some of that, I have to say I think is slightly deliberate at times. So people won't come sometimes to difficult conversations where you know you will bring things up that they won't like to hear.

Ph#5: And I think the word "death" is not preferred to be used by other people.

Ph#6: Certain specialties. It is quite interesting, the number of euphemisms for "death," or "dying," are fascinating. I mean, you'd almost think we shouldn't talk about it. [Brief overlap] Or actually, we should write a paper about it! And sometimes you're sitting there and you're listening, and they come up with, you know... they come up with these unbelievable... "angels," and "passing away"... and once a mother was like, "What's he talking about?" [Laughter] What's he saying? He's going to die! They use these things... and you just think to yourself, where did you get that language?

Ph#1: It's called [Inaudible].

Ph#2: But also, I think... another thing not to underestimate is also how intimidating some of these things can be to parents as well.

JFM: Yes.

Ph#2: That's something that strikes me more and more, is that if you've got every specialty there and there are 12 people in the room, the parents can really...

Ph#6: They don't like that.

Ph#2: No but the point is you need specialties to talk together and make a plan, I agree.

Ph#6: Yes. And then you should have one or two people partaking in the conversation with the parents. And that comes back over and over and over again...

Ph#2: From families, yes...

Ph#6: that they really find that very threatening. Is that when you have lots of quote unquote "experts" sitting around the table... And I think we need to be careful about that. Because sometimes in the hope of being inclusive, we forget what it feels like. So when you have the palliative care nurse, and the specialist nurse, and the...

Ph#2: Yes. Everybody has a good reason for being there, but actually the whole picture is kind of...

Ph#6: Yes. So I think we have to manage those situations and say to people, "We'll all get in a room together, we'll talk about it, and then one or maybe two of us will go

in and speak to them after.”

Ph#2: Because otherwise... And also the parents feel it's a *fait accompli* as well, that they are all already there...

Ph#3: But that's not always the case.

Ph#2: No, no, not always.

Ph#3: Sometimes you have really informed people who know their [inaudible] inside out, and actually they want to know the full...

Ph#2: I wouldn't say for everyone, but...

Ph#4: That, we get a lot feedback from parents about that. Of saying... And also, they call this room “the death room.”

JFM: Oh, yes. So that is where you get the talk.

Ph#1: To be fair, there are purple chairs, [W1]. To be fair.

Ph#4: And you know, no matter how you try and make it look nice, they say, “I hated that room. Every time you came up to me...” Sometimes I meet parents afterwards – because we run a party and then we have the sessions afterwards that we go to. And unfortunately some of them still send me Christmas cards and things like that, and I have met them afterwards. And when you start hearing from them, you know, five years have gone by and they can actually talk about it, they'd say things like, “You'd walk in with that look on your face, clicky-clicky heels, and I knew, Oh God, here we go. We are going to go into the death room.” And that's the way it was. So I think it's a difficult...

JFM: Maybe following up on something that has been mentioned before... the fact that people come here with a lot of expectations, that's a very specific issue with this place.

Ph#3: I don't know... I have to say, I think if you work anywhere where you were coming in from an environment to an augmented place, if you like. So I think other places do have that as well. I don't think it's necessarily just here, but I think it's worse here.

JFM: Yes.

Ph#3: Because of some of the stuff that's offered here; but the same things have happened in other places. Perhaps even Paris! [Smile]

JFM: [Smile] Okay. Related to that idea of setting a frame of reference, of

initiating the conversation with the parents, something that has been mentioned quite a bit as well is the fact that... the way work is organized for consultants on the NICU, you know, the week by week rotational organization, that could be seen as creating difficulties. That is often observed from the perspective of the nurses, who are there on the longer term, and who say, when you change consultants, the discourse changes as well.

Ph#3: So that's interesting. It's just a simple observation, that if you have more consultants who are sharing the conversation, it will regress to a mean... there will just be an average position. But if you're with any one person for a while, you obviously have greater continuity, but you also have the possibility that that is not an average view – which is kind of interesting. But we thought it would be better to have the same person, I think...

Ph#2: I've also heard the view that actually the nurses like the fact that it's the same person [Inaudible], so...

Ph#4: I thought it was that view; that they prefer to have the same person. Because...

Ph#2: [Overlap] Well there is both. [Inaudible]

Ph#4: NICU patients don't change very much, unlike the PICU patients. NICU patients stay there for a lot longer. And they don't like the fact that we change so often, and then the treatment options change...

Ph#3: But again, if you have... "Look, I've seen 8 ICU consultants, and they have all told me that this is not going to work." Actually that must be quite a powerful...

Ph#6: I'm fascinated that you actually think that they know we're consultants...

Ph#1: I've got my badge now! [Laugh]

Ph#6: Most of them don't even know... they actually can't tell the difference between us, in terms of junior doctors and senior doctors.

Ph#1: It's very similar.

Ph#6: It takes them a long time to get that.

JFM: You are talking about the parents?

Ph#6: The parents.

Ph#1: We're not talking about the nurses! [Laughter]

JFM: No, no, but I'm talking generally, because...

Ph#6: So they... they don't see it as a group of 8. They see it as a group of 45, you know, and...

Ph#3: Okay, interesting...

Ph#6: And they will often say to you, "Oh well you know, the person in charge today..." and you know you're the person in charge today. And you're like, "Oh, who's that?" [Laugh] And they're like, "Well they were there!" And you're like, "Oh, meet the medical student!" [Laugh] They really... they can't...

Ph#2: "That was the most sensible person I met!"

Ph#3: "They had such an air of authority!"

Ph#6: [Laugh] I think that part of our problem is we're not that autocratic, you know, and we aren't hierarchical.

Ph#3: Speak for yourself! [Laugh]

Ph#4: We aren't very hierarchical. And we wear normal clothes; and you know, so it is sometimes quite difficult for them to understand who is the person that is giving them the conversation.

Ph#3: But surely you say, "I am..." your name...

Ph#4: How much do you think they take out of a conversation? First of all as you're walking in the room, the room terrifies them. I've heard this from them when they come back to you. The room terrifies them. They have buzzing in their ears; they're looking around at all the different people. And you start talking. They say they don't hear the first 10 minutes of the conversation. So if you have anything important to say, I would suggest you wait 10 minutes.

Ph#1: That's not going to work, is it? [Smile]

Ph#4: No, not with you! [Smile]

Ph#3: Say it, say it again in the middle, and say it again...

Ph#4: Yeah.

JFM: Yes. I've also had people tell me that they only hear the first two sentences.

Ph#4: Yes.

Ph#3: But hang on, we can't win...

Ph#2: But also, that's a very specific thing about attending on the neonatal unit. I mean, that's the way it has felt for the last 2 years anyway, since I have [Inaudible]. And before that, that wasn't... it was a different setup. Other places use the same... I don't think that's very... That's quite a detailed point, I'm not sure how important that is really, to be quite frank. I mean at [name, inaudible] we used to do it...

Ph#5: You used to work there?

Ph#2: It's not dissimilar systems. So it's just getting used to a newish system as well, I think. That's [inaudible] reflected that too.

Ph#4: Well we had attending for a whole week before [name] came...

Ph#3: True.

Ph#2: That was last century! [Smile]

Ph#4: You've been attending, in...

Ph#6: It changed. It changed, about... what, how many years ago? 3 years ago?

Ph#2: Yes, 3 years ago.

Ph#1: So you used to do a week on...

Ph#4: Yes. On NICU.

Ph#6: On NICU.

M: [Inaudible][Overlapping chatter]

Ph#6: It was just before... [Overlap, laughter, chatter about timeline and comparing memories all at same time, about 15 seconds.]

Ph#2: Um... Back on topic? [Laughter]

JFM: Thank you so much! Okay... If we move on to the topic of withdrawing life-sustaining therapy... Something that has been an emerging theme in my research is this idea – it's been described in various ways, but always going back to this general idea of getting there with the parents. So, sort of bringing parents on board. Having repeated conversations with the consultants, with the nurses, with... So this idea that parents are somewhere, and you sort of have to take them to a place where they understand what's going on, and they

understand that it might be a situation where there is nothing else to do. Or... either there is nothing else to do, so, you know, the chances of survival are very low; or, even if survival is not necessarily an issue, the quality of life might become a problem.

Ph#4: I think that's partly our own fault. As technology has developed, the media has portrayed this sort of image of, you know, you can't die. And therefore...

Ph#3: Well if you do, someone is to blame.

Ph#4: Yes. It's like there is something wrong; it's not the normal process. And you know, death is not a normal issue anymore. You don't see people dying, whereas the generation before us did see people dying, and it was sort of a normal process that happened. That we're in a way making it... that's what we've left them with, you know? And actually a lot of parents probably think it's a good idea that – not a good idea, but they think it's the right for their child to die; they just didn't know that that's possible. You know, can that really happen, without it being wrong? Do you see what I mean? It's... the normality of death has gone.

Ph#1: And also I think, we're challenged recently by their distrust of experts as well, which seems to be coming in more and more, which I think is a real issue.

Ph#4: Yes, but that's because, again, because they sort of believe that... Death can only happen if something was wrong.

Ph#1: It's not that they... They're being *told* that it's wrong. I think it's a big thing here in society, is that...

Ph#4: Dr. Google is better than Dr. [name].

Ph#1: And the governments have spent some time pushing a referendum result, some of them. "The experts are wrong, we don't need experts." At least...

Ph#2: It's part of the democratization of information.

Ph#1: Yes...

Ph#2: It's everywhere. So people think they can find something and not reference it.

Ph#1: That's right.

Ph#2: So... that's a good thing and a bad thing.

Ph#1: It's not agreed by government.

Ph#2: Everyone thinks it's like Lorenzo's Oil. Everyone thinks it's going to be... the

doctors are going to...

Ph#1: The other thing is that we're pushing the miracle cure time and time again. You read the newspapers, the media... Most people who would never come to a place like this get their information... It's keeping the magic alive. "The doctors are wrong, we proved them wrong. They wanted to switch them off, but..."

Ph#6: But that's the point: that the normality of death is gone.

Ph#1: Yes. It's wrong to die.

Ph#6: [With emphasis] Everybody dies.

Ph#1: Yes, but in that documentary... that BBC documentary showed 3 deaths from here. And there was such a discussion about whether that was going to be possible. And there was quite a backlash, that it wasn't the "dream alive" outcome; it was the real world that shows that sometimes with multiple pathologies, sometimes they don't survive. It shouldn't be a surprise to anyone. But actually saying it is a threat.

Ph#3: 3 on 3 was pushing it. [Laugh]

Ph#6: One did survive. Although that one was a bit dodgy...

Ph#1: But it's not just the media, is it? It's the whole...

Ph#4: It's everybody!

Ph#1: You missed that earlier on...

Ph#6: Yes, and that's what I'm trying to say... You know, I have friends who will say to me, "I have never seen anybody die."

M: Yes!

JFM: Doctor friends, of course.

Ph#1: It's hidden.

Ph#6: Both! Some doctor friends, and some non-doctor friends.

JFM: Yes.

Ph#3: I had a consultant pediatrician on the phone. There was a child who had a long cardiac arrest in the hospital. There was no possible way they could survive. And I said, "What you need to do is say, this is where we are, and we need to stop." And she said, "I've never told a family that their child is going to die, and I'm not

going to start now.” And I’m a consultant pediatrician. I’m like... [Laugh]

Ph#6: [With emphasis] What? [Laugh]

Ph#1: Will you speak to all the families? [Laugh]

Ph#6: That’s what I’m trying to say. The normality of death has gone from our society.

Ph#5: I think the other thing is balance between patient and parents’ sort of input and independence, and the doctors’ views.

JFM: Yes.

Ph#5: Somewhere down the line that balance is a little bit off in some cases. They say, “I know my child.” Yes, that is very true to a certain extent, but you know, your judgment may be clouded by a lot of other factors, and you’ve got objective medical evidence. So that comes into play quite a lot of times.

Ph#4: But again, if they recognized that death was a normal process that does happen, then they wouldn’t... I think parents are in a very difficult position, because they seem to feel that they have to advocate for their children. That it’s part of their role to do. Which it is, but they couldn’t possibly allow their child to die. If they did, they would be a bad parent. And so they get into a position of having to go down a path, which I’m not sure they always want to do.

Ph#3: And part of that is that the kinds of things we are using to make a case that death would be better than life are *evidence*. And the family’s view is not based on evidence. It’s based on emotion and a perception of their role in society... So there is always a tension. Is there anything I could say that would convince you? Is there any test I could do that would convince you?

Ph#1: Technology is going to [inaudible]

Ph#3: Well, that’s the...

Ph#4: But, I mean, it’s really quite... I remember I had one mom and dad, and they were... She said to me, “What am I going to do with the nursery?” It was very sort of...

Ph#1: [Inaudible joke]

Ph#4: It was really like, what am I going to do? I got it all fixed, I painted it, you know, it was all ready. What am I going to do? And it’s just, you know... And you’re sort of thinking, fuck, there’s a lot worse you could be thinking. [Laughter] But actually, that was... that was a big deal, you know? For 9 months this is the focus that they’d had,

you know, and all of a sudden they have to go in a different direction.

Ph#3: [Name] is right that there should be different ways of deciding. Because there are... you know, we can't be emotional about every child who doesn't [inaudible].

Ph#2: I'm thinking that sometimes it goes incredibly well, and everyone agrees. And then other times it's just completely...

Ph#5: They are done...

Ph#2: And you forget those ones. But the ones that live in your mind are the ones that are incredibly traumatic.

Ph#1: And 1% are incredibly, incredibly traumatic.

Ph#3: Yes, indeed.

Ph#2: It is about that.

Ph#6: But even that 1%... I've met some of the parents of the 1% that have gone badly. And you bring them back sometimes 2 years later, and they say, "You know, I know I was really difficult... but I understand now that it was the right thing to do. But it was just that I had to get my head around it." And that's what I'm trying to say, is they have this sort of pump, of you know, "You've given her a child, it's going to be perfect, the room is going to be painted blue or pink..." And they are on that sort of train, and suddenly they have to get off.

JFM: Yes.

Ph#5: The other thing some suggest is that they are going to fight hard.

Ph#6: That's what I think! Because...

Ph#1: They can't stop.

Ph#6: Yes. "I have this child's advocate."

Ph#1: They can't get off that roller coaster. There is no...

Ph#6: Yes! It's a train!

Ph#1: There are different ways you show them, and sometimes they just can't take it. And even, we've had some families who end up going to the courts about it. And they just say very clearly, "The only person who can make me stop things is a judge." There is absolutely... nothing else could have happened before that stage. And the problem is, some of that is a learned narrative, and some of it is reflecting. But the

idea is that they come and say, “I fought as hard as I could. I couldn’t have fought any more, because that person has authority over me. You don’t.”

Ph#3: Although there are some [inaudible] ones, there are many in between where something happens in the passage of time that makes it clear.

Ph#1: I’m talking about the hard ones.

Ph#3: Sure. But you know, there are some who are in between, and you think, we are never going to come to the same plan here. And actually, when we wait for another few days, or a new scan, or... actually you do get to the point. But it’s about consistency of recommendation on some of them.

Ph#4: But I also think, as a society we have a responsibility to start talking about the fact that people die, you know. So even things like the guy who has cancer who is talking on [inaudible] and [inaudible] and all that sort of stuff... The fact is it’s starting to be okay to talk about this on media.

Ph#1: But doesn’t every cancer patient have a blog these days now? [Laugh] You know, it’s... there is lots of it there!

Ph#4: They do have blogs when they’re alive, but they don’t talk about the fact that they’re dying. This is the first time I’ve recognized that, actually everybody is, you know...

Ph#1: [Inaudible]

Ph#3: [Inaudible, chatting low, Overlap]

Ph#1: Even with children it’s out there. So the organ donor stories are there every so often of a child that dies; so that’s probably the best exposition people have to the idea that children die.

Ph#2: But just think of the illustration of this. The child who wanted herself frozen...

Ph#4: Yes!

Ph#2: That was fascinating... That’s an illustration of the sort of...

Ph#3: She didn’t want herself frozen – she was frozen.

Ph#2: Yes. She won the court case to become frozen.

Ph#3: She was frozen.

Ph#2: But before the case...

Ph#3: Yes.

Ph#5: I think the things we speak of, and then the media things in which, “They tried to stop treatment and look at how he is,” and there is a smiling baby, that kind of... It changes the whole trajectory of normality of death. “Look, these people were wrong and I was right, and look at him now,” kind of thing.

Ph#1: Yeah.

JFM: And... So I see that there is a bit of a... I don't know if it's the right way to put it, but like a latent ethical dilemma. Because on the one hand, I think there is a very strong belief that you don't do these things without the parental permission. But on the other hand, something I have just heard in this conversation and in previous interviews as well, is that often or sometimes, parents are kind of ill equipped to make these decisions – from, you know, the place where they start, the information they have.

Ph#1: It's not that they are ill equipped; it's just that sometimes they feel like they can't make...

Ph#3: Yes.

Ph#1: Between the two, it's that they feel they can't possibly have something that actually results in their baby's death.

Ph#4: Because then everybody else is going to think they failed!

JFM: Yes.

Ph#1: Exactly. And that they actually killed their child.

JFM: So in that case, is it... could it be fair to say that in certain situations, it might be too much to ask parents to give an actual permission?

Ph#1: Well, this is... we often talk about this, about whether the degree to which there is an open question or a closed question to the parents... Is it, “What would you like us to do?” or is it, “We have a very strong recommendation from the whole medical staff that we should do this. We might do it this afternoon, would you like to get your family around?”

Ph#4: You have to give them... you have to... so they have to be able to save face. It's a horrible thing to say, but to go back to the family, and “Oh no, this is what they told us we have to do.” So it's a balancing act of making sure that they are... Is it complicit? So that they are working *with* you. But this was definitely your idea, not mine.

JFM: So they are rather assenting to what is going on?

Ph#5: Yes.

Ph#4: It's even more important for Muslim families. Because they can't be seen to tell you to stop.

Ph#1: Yes.

Ph#4: So you say, "This is what we think is the right thing to be doing."

Ph#1: It's a sort of up-down versus [inaudible] question.

JFM: Yes.

Ph#1: It's a strong [inaudible] in one direction.

Ph#4: Obviously if you don't... If you really object to this, then we all rethink how we think, but this is what we think we want to do.

Ph#1: I don't think... I've actually had very few problems with Muslim families. I think if there is a strong religious thing, then that can often be [Inaudible].

Ph#3: But it can work either way. There is a sort of fatalism that is in God's hands, which is sometimes, you know, with Muslims in particular, but... there is also...

Ph#1: [Inaudible] published on that. Muslim families were not the problem here.

Ph#3: It can be the evangelical, or the Jewish, or...

Ph#1: From the King's area, I understand, [name], they are quite...

Ph#3: Quite vociferous!

Ph#4: It's how you say it... If you are being inclusive, but they get the impression that you are actually asking them for permission... And that is the wrong way to put it.

Ph#1: That's right.

JFM: And is there an influence of the way the legal system is set up, asking for active consent? If you go through the assent route, do you feel like you're – again, maybe too strong a word, but not respecting the law, of that it's just...

Ph#4: Does the legal system make us get consent for death? No...

Ph#1: You have get agreement with them before you stop life sustaining treatment

Ph#4: They have to assent.

Ph#1: Yes. It's very broad...

Ph#4: Assent.

Ph#3: But what happens is...

Ph#4: Assent is just not dissent.

JFM: Well there are degrees, I guess. Non-dissent is even weaker.

Ph#1: I think the problem is, in much of the [inaudible], consenting process has been formalized to such an extent that many people who do death infrequently are less comfortable with supporting the decision process that we use. Ok? And so you will often have... let's say a neurologist saying, "What do you want to do?" when he has made a compelling case that there is only one sensible choice for anybody. But then that last step... he feels he has to back away from directing. I find that really difficult.

Ph#4: And that's just experience. So those people who haven't done, you know, the death routine very often will shy away from that final nail. They just can't go there. And that's why you have to have people like us in the room.

Ph#5: Again, going on the theme of fatalism and for them to accept rather than consent as such, they need to hear things like, "We have done the best. This is all we can do, there is no other treatment."

Ph#1: Yes.

Ph#5: And if they hear that, I think it comes across very clearly.

Ph#3: Not always. I mean, I think it's a useful step, but sometimes, "You just have to give time for a miracle" is the phrase that you really worry about.

JFM: Sometimes the only option is going to court. That is the last theme I'd like to address. I'm interested in your thoughts on the interface between your work, the work of the hospital solicitor, the role of the court, and what you think about that process.

[Overlap, laughter]

Ph#4: I always think we have to work much better together, you know? I think that, as I said before, for some families it's the feeling that they have to be their child's advocate, and this is going to be the final end. And you can see that from the very

beginning. It's not a negative thing; you just have to let it ride, and dot the i's, cross the t's, and just get on with it. And support it as best you can. And that's what we have to do! I mean, it just costs a bit more money, but that's the way it is!

Ph#3: There is a special, unique combination of circumstances that ends up in court, slowly, which is the chronic, usually neurological [inaudible] condition. Because other things tend to be getting worse or are so unstable that actually there is never a sort of set point to stop and discuss. It's very rare for somebody with multiple organ failure to end up in court... I mean it has happened, but...

Ph#4: Just because, you know...

Ph#3: It's that unique bit of lack of time pressure, if you like.

Ph#2: And interesting, some families have been three times in High Court doing this. Sometimes it works... The family are just so intimidated, basically, by the whole law, going up to court, that that's enough for them. And others still don't accept, and they still... Even though they... the judgment has been done, it's still a fight. But that very much depends on...

Ph#1: But I can remember very clearly one of the... Where the court ruled in favour of removing life-sustaining therapy... and we did it, and the dad was grateful. I think it was that process of him being a champion for his child; he was pushing for [inaudible]. You could see that was the right thing to do, but he couldn't even assent to it.

Ph#4: So it took the court to say what the dad wanted. And thank you very much for having done that.

Ph#1: Well it's not to assume, I suppose, there is always...

Ph#4: But I think that's why we can't take it personally. Sometimes I think we do give... I think it's "Oh, here we go," you know? "Let's just give the lawyers a bit of money now, off we trot!" [Laugh]

JFM: Okay, full disclosure: I'm a lawyer. [Laughter]

[Overlap, brief banter.]

Ph#2: But it's still up to the coroner's court in some way, where the process by which the family at least feel like they've had justice, whatever that means, and they... They've had...

Ph#1: They've had their day in court.

Ph#2: They've had their day in court, yes. Sometimes that really helps, and

sometimes the anger goes on.

JFM: And so you've mentioned working better together, I guess with the court system or with the hospital solicitors. Is there anything that could be done specifically?

Ph#2: Well I guess one of my frustration is it always seems to take such a long time.

Ph#1: Yes.

Ph#4: Yes. You can predict it so much, you just feel like...

Ph#1: It really does.

Ph#4: Yes. You think, well what are we waiting for? Just get them in here!

Ph#2: So I think we've got... we know what the necessary prerequisites are: second opinion, ethics committee, multiple MDTs...

JFM: Yes.

Ph#2: We do that, as soon as we...

Ph#1: Stuff has already happened before, that's the thing that... I mean, there's a guy from Manchester talking to [inaudible] about trying to optimize how this goes. And the biggest miss by hospital solicitors, and ours, it would appear, [inaudible] other units are actually reasonable compared to them in terms of timing. Some of them start de novo, so even your second opinions have to be got again. Because now you're talking to the lawyers, and... so it can be really arduous and slow, and there's no set way this is done. My experience, the last time I did this was with a [inaudible] child. And actually it nearly killed me, because all of a sudden having asked people to get things sorted for 4, 5, 6 weeks, including meeting all the [inaudible] round... All of a sudden I have to do extra reports on Easter Sunday. You're joking? I've been asking this for 6 weeks. I did all the stuff, and now you want something because all of a sudden is happening in 2 days' time... Suddenly... It's nothing, nothing, nothing, and then [inaudible] all or nothing very quickly. It's my experience [inaudible] too...

Ph#4: And I think they are trying to save a bit of money, to be honest.

Ph#1: Possibly...

Ph#3: It is interesting to reflect on money. There is a... The way the hospital is funded for intensive care is per occupied bed. So there is no incentive for the hospital to finish a case and come to a resolution quicker.

JFM: While the money that is being paid to the barrister is coming from another place.

Ph#3: Yes. I don't think it's overt like that, but if it became a cost, I think things would move quicker.

Ph#2: The barrister is already paid for by the trust.

Ph#3: Yes.

Ph#6: No but then when you go to court, do they have more than just our barrister... They then have a proper...

Ph#4: And the difficulty is even if you go to court and end up, you know, resolving it... it's a withdrawal of life sustaining treatment. The barristers are picked up by either the trust – they usually will end up paying both sides, just as a sort of, you know...

JFM: Yes. Do you think it would make sense to... because again from what I observe, there is a fairly conservative approach to going to court. You know, usually only the cases where the hospital is very confident that they are going to win their case go ahead.

Ph#3: Yes. We've never lost.

JFM: You've never lost?

Ph#3: So therefore we can't be anywhere near the limit.

JFM: Yes. So would it make sense to sort of devise...

Ph#6: It costs a lot of money.

Ph#1: I think we're about to! [Laugh]

Ph#6: I mean, the reality is it's expensive. It is.

Ph#1: The other thing I find fascinating – it's one of the things that underlines where you're going with this – the hospital here will not go to court for anything if there is even slight disagreement among all of the medical team. So if you have 19 consultants who all think this about a child, but one person says, "No, I think there's a chance that one of those small cells in the brain might keep firing for [inaudible]," the hospital will not take legal resolution because they would say there is a difference of opinion; therefore you must carry on doing what you're doing. It's really hard.

Ph#3: I mean, it may feel like that some of the time, but the one I was talking about...

Ph#1: No, it's exactly... Hang on...

Ph#4: [Name]?

Ph#3: Yes.

Ph#1: They came around... by the end.

Ph#4: By the end of it, but it was...

Ph#1: By the end, that's right. So the only reason they went, the reason that it took 4 months from the first approach to get there is that they didn't approach until that person came around. Hence the reason it's been so long.

Ph#3: Okay... I have to leave to set up the next meeting.

Ph#1: [Inaudible] You have to have the entire trust agreement... that's a problem, I think. Because often you'll find something...

Ph#5: Yes.

Ph#4: I do have to go as well... thank you...

JFM: Ok. Well... Thank you very much.

Ph#1: We're done?

JFM: Yes, we're done. Thank you.

[End]