

*A critical realist study of neonatal
intensive care in Mexico*

By

Rosa Maria Mendizabal-Espinosa

UCL Institute of Education

Thesis submitted for the Degree of Doctor of Philosophy in
Sociology

'I, Rosa Maria Mendizabal-Espinosa 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

Neonatal intensive care units (NICU) aim not only to reduce mortality and morbidity but also to promote babies' future well-being and health. Baby-led (evidence-based) practices take into account babies' physical and emotional needs. They also consider parents' needs and, when possible, encourage parental participation.

Based on ethnographic field work over the course of ten months, the study examined interactions among healthcare professionals, parents and babies in two Mexican NICUs. Dialectic critical realism underpinned the analysis of data while ideas taken from the new sociology of childhood contributed to an investigation about babies as service users of healthcare facilities in their own right.

This thesis contributes to an understanding of why preterm babies in Mexico are cared for as they are and opens ways forward towards changes in practice. Three overarching themes, moral and physical hygiene, dignity and well-being, illuminated discussion of results. I identify theory/practice inconsistencies that arise when discourses about sanitation, breastfeeding and babies' best interests are used to control and oppress service users of public hospitals (babies and their parents) rather than to protect them. I have found evidence that relationships between healthcare staff and service users were influenced by prejudices about social class, gender and ethnicity, which resulted in deficient care and disrespect of basic human rights. I consider how wider structures such as neoliberal policies, Catholic practices, poverty, corruption and violence influenced the day-to-day life in these hospitals.

The thesis concludes by identifying three ways in which practice might be improved: a) to consider nurses as agents of transformational change; b) to create multi-disciplinary teamwork, including parents and babies, in order to enhance communication at all levels; and c) to develop routine procedures and practices in the NICU informed by research evidence of high standards of care. Finally, I identify implications and steps for further research.

Acknowledgments

I would like to thank the National Council of Science and Technology of Mexico (CONACYT) for the generous studentship they awarded and that made this study possible.

A very special thanks to babies, parents and staff from MDH and JDH who participated in this study and to the group of healthcare professionals who generously offered help and advice.

I am indebted to my supervisor Professor Priscilla Alderson whose advice, patience, encouragement and never ending support were invaluable throughout my studies.

My sincere thanks to Inga Warren and Cherry Bond, who taught me to always 'listen' to babies.

My heart-felt appreciation goes to my husband David whose support and encouragement has been invaluable and to my daughter Valentina who continuously teaches me about love and joy.

List of abbreviations

AAP – The American Academy of Pediatrics

CPS – Canadian Pediatric Society

CR – Critical Realism

FCC – Family Centred Care

GA – Gestational age (refers to the time the baby spent in-utero)

GDP – Gross Domestic Product

IMF – International Monetary Fund

INEGI – National Institute of Statistics and Geography in Mexico

JDH – Juan Dautt Hospital

MDH – Mercedes Duron Hospital

OECD – Organisation for Economic Co-operation and Development

NAFTA – North American Free Trade Agreement

NBAS – Neonatal Behavioural Assessment Scale

NICU – Neonatal Intensive Care Unit

NIDCAP – Newborn Individualized Developmental Care Assessment Program

ROP – Retinopathy of Prematurity

UNCRC – United Nations Convention on the Rights of the Child

WB – World Bank

Table of contents

Chapter 1 Introduction.....	12
1.1 My motivations.....	12
1.2 Context of the study	15
1.2.1 Neoliberal Mexico.....	16
1.2.2 The Mexican healthcare system: past and present	19
1.2.3 Women in Mexico.....	21
1.2.4 Children in Mexico	23
1.3 Structure of the thesis	24
Chapter 2 Preterm babies, women and health: a theoretical background	27
2.1 Introduction	27
2.2 Preterm babies and neonatal care	29
2.2.1 New understanding of babies as persons	31
2.2.2 The parent-infant relationship mediated by the NICU experience	34
2.3 New understanding of children in sociology.....	36
2.3.1 Sociological studies in neonatal care	37
2.4 Biopolitics, health and power.....	39
Problems posed:	40
Technologies used:.....	40
2.5 Conclusions	41
Chapter 3 Methodological Approaches.....	43
3.1 Introduction	43
3.2 Methodological approach: philosophical assumptions about the social world	44
3.2.1 Ontology.....	44

3.2.2	Epistemology	46
3.3	Critical Realism: an integrating approach	48
3.4	Research design	59
3.4.1	The study main aim and research questions: an evolving process	59
3.4.2	Research questions	62
3.4.3	Case study as research strategy	62
3.4.4	Description of research sites	66
3.4.5	Doing ethnography	67
3.5	Fieldwork in Mexico at a glance	69
3.6	Ethical procedures	71
3.7	Methods of data collection	72
3.7.1	Survey to staff	73
3.7.2	Interviews	76
3.7.3	Participant observations	79
3.7.4	Observing babies	80
3.7.5	Other sources of data	82
3.8	Data analysis	82
3.8.1	Reflexivity	86
3.9	Conclusions	86
Chapter 4	An analysis of the social order in the baby unit through hygiene practices	87
4.1	Four planes of being	88
4.2	Plane 1: material relations with nature	88
4.2.1	Hygiene and the governance of parents	92
4.2.2	Governance of women’s bodies and breast milk	101

4.3	Plane two: interpersonal relations between ‘impure’ service users and ‘pure’ members of the staff	108
4.3.1	Parents’ need to protect	108
4.3.2	The moral order in the unit	110
4.4	Plane 3: social structures and relations of power in the neonatal unit	116
4.4.1	Power relations at the empirical and actual level.....	118
4.4.2	Beyond the empirical and the actual	126
4.5	Plane four: inner being	129
4.5.1	Parenting in the unit through the discourses and practices of medicine ..	129
4.5.2	Flourishing	131
4.6	Conclusions	132
Chapter 5	Dignity in the neonatal unit	135
5.1	Introduction	135
5.2	Development of dignity as a principle.....	136
5.2.1	The beginning of a person.....	140
5.3	Thinking about dignity in the real world.....	141
5.4	Plane one: material relations with nature	142
5.4.1	Real bodies, real pain	143
5.4.2	No time and no place to rest.....	151
5.5	Plane two: interpersonal relations	154
5.5.1	Fragmented communication.....	155
5.5.2	Private matters in a public arena	160
5.6	Plane 3: Social structures	161
5.6.1	Bad mothers	161
5.6.2	Dignity, nurses and professional status.....	163

5.7	Plane 4: Inner being	165
5.7.1	Detached carers	166
5.7.2	Reasons over emotions.....	166
5.7.3	The emergence of the human person in the NICU.....	168
5.8	Conclusions	170
Chapter 6	Well-being	174
6.1	Introduction	174
6.2	1M – Well-being and non-identity	177
6.2.1	Well-being in Philosophy.....	177
6.3	Children’s well-being	179
6.4	Well-being at the beginning of life.....	180
6.5	A more realist view of well-being?	182
6.6	2E Negativity	183
6.6.1	Physical: the NICU environment	184
6.6.2	Biological: baby time, NICU time	184
6.6.3	Psychological: the becoming of a mother in the neonatal unit	190
6.6.4	Psycho-social: uncertainties	196
6.6.5	Cultural: on being a father.....	202
6.6.6	Normative: lack of evidence based guidelines.....	204
6.7	3L Totality	208
6.7.1	Insecurity and violence	209
6.7.2	Corruption and the system of favours	211
6.7.3	Poverty	213
6.7.4	Historical conceptions of children: doomed to fail	214
6.8	4D Flourishing – Transformative praxis	215

6.8.1	Education through shared knowledge	216
6.8.2	Creativity.....	217
6.8.3	Inter- and multi-disciplinarity, the way forward	218
6.9	Conclusions	220
Chapter 7	Conclusions	225
7.1	Why are preterm babies cared for as they are in Mexican hospitals? A discussion of findings.....	227
7.2	Reconciling dualisms: a critical realist perspective.....	232
7.3	A possible way forward.....	235
7.3.1	Nurses as agents of change	235
7.3.2	Enhanced communication at all levels	237
7.3.3	Normative procedures	239
7.4	Conclusion.....	241
References	242	
Appendices	271	

Tables and illustrations:

Table 1 Summary of evolution of social medicine	40
Table 2 Accessing research sites.....	65
Table 3 Fieldwork at a glance	70
Table 4 Members of research team	73
Table 5 Survey participants.....	75
Table 6 Survey response rate	75
Table 7 Interviewing staff.....	77
Table 8 Interviewing parents.....	79
Table 9 Characteristics of babies	82
Table 10 Example of first stage of analysis	84
Table 11 Second stage of analysis through DREIC	85
Table 12 Visiting time for parents in the NICU.....	93
Table 13 Highest transient noise	185
Figure 1 Als's Synactive Theory of Development: subsystem interaction	32
Figure 2 Bhaskar's four planes of social being	54
Figure 3 Bhaskar's and Danermark's seven-level laminated system.....	55
Figure 4 Bhaskar's MELD scheme.....	58
Figure 5 Path that a mother followed when coming to see baby in cot 3	98
Figure 6 Path followed by nurse and two doctors when caring for babies in the NICU	113
Figure 7 Priest's path when anointing oil on babies.....	124
Figure 8 Fragmented communication	159
Figure 9 concrete universal ↔ singular	234
Figure 10 Enhanced communication through multi-disciplinary work	239

Chapter 1 Introduction

This thesis presents a sociological study that looks at the intersection between biography and history, an attempt to bring the ‘private problems to public issues’ (Mills 2000 [1959]), in two Mexican neonatal intensive care units (NICU) through ethnographically informed field work over 10 months. The hospitals, each of them a case, were situated in two different cities in Mexico: Mercedes Duron Hospital (MDH) in Puebla City and Juan Dautt Hospital (JDH) in Estado de Mexico (pseudonyms). In an evolving process that included going back and forth to the literature, discussion with my supervisor and reflections on my past experience, the main aim of the project was defined as: to understand why preterm babies in Mexican hospitals are cared for as they are.

Through this introduction I present my motivations to undertake this study and briefly explain how I came to define the aim of the project. I found it imperative to then present an overview of the Mexican context: politics, economy, the welfare system and some current problems, such as violence and corruption that affect Mexicans, especially women and children. I give special attention to the history of the Mexican healthcare system and the creation of *Seguro Popular* (National Health Insurance) in 2004, which opened access to basic healthcare services to a segment of the population (mainly the poor ones), many of them participants in this research. Violence and corruption have attracted international media coverage about Mexico. It might seem irrelevant for an investigation about ill babies and their families to dedicate a space to such topics, and yet I argue, these social problems directly and indirectly affect babies, their families and the staff that care for them. I hope this will become more evident in subsequent chapters.

I conclude this chapter by presenting a structure of the thesis.

1.1 My motivations

I have worked with children of different ages and with their families for over fifteen years as a preschool teacher, special educational needs consultant, certified infant

massage instructor, researcher and advocate. Through my work as a special educational needs consultant and infant massage instructor I began to be interested in strategies that promoted parent-infant interactions as a means to ‘empower’ parents when they faced adverse circumstances, such as having a child with disabilities. For my Master’s degree dissertation in Pedagogy, I adapted a programme to teach infant massage to parents of preterm infants in the neonatal unit at City Hospital (a pseudonym). Although my views about *parenting*, *empowerment*, *child development* and *bonding* have changed dramatically since then, this work marked my professional life in many different ways.

It is common practice in hospitals in Mexico, both in the public and private sector, to restrict parents’ ‘visiting’ time in intensive and intermediate care due to concerns about infection control. Parents are allowed in the unit for very short periods of time (as little as half an hour a day).

Unlike many other units in the country, parents in City Hospital were allowed to be with their children for approximately eight hours during day time in the intermediate care unit; yet, as in many hospitals in the country, they were considered and treated like visitors. Because of poor staffing in the unit, babies were left to cry for long periods. Dummies were used in order to ‘calm’ babies down; so as to keep them on, dummies were stuck with tape to babies’ cheeks. I constantly wondered whether that helped or distressed babies even more. Nurses would refer to babies as ‘my baby’ and get angry if the parents re-positioned or tucked their babies differently than how they had been told. It was difficult for me to understand that these amazing, loving and caring doctors and nurses (most of them women), whom I learned to admire for their passion for helping others, caused the distress to babies and parents. City Hospital is not part of this research for reasons that will be explained in Chapter 3, but my experience there certainly influenced my interests in investigating and understanding why babies are cared for as they are.

I moved to the United Kingdom in 2010, and had the opportunity to work as research assistant in the NICU at St. Mary’s Hospital in London. The research was to validate a scale for evaluating the non-pharmacological strategies to manage painful and stressful

procedures (Warren et al. 2016). St. Mary's Hospital is also a NIDCAP Centre. NIDCAP stands for Neonatal Individualized Assessment Developmental Care Programme and it is a comprehensive approach to care for preterm and fragile babies. It is based on identifying babies' strengths and sensitivities through a detailed observation tool and on creating an individual care plan, working with NICU staff and parents. Working with parents and supporting them to become the best carers inside and outside the unit is one key component of this programme.

I returned to Mexico in 2011 and started to talk to health professionals about what I considered a more *humane* approach to caring for babies and their families. People seemed to be open to these ideas, however the conclusion was always the same: this would not work in Mexico. Public hospitals are understaffed and overcrowded, there are no economic resources but more importantly (the disadvantaged) patients and (in this case) their parents are ignorant and therefore a 'risk' to their fragile children. So, it seemed, there was no alternative.

Evidence about 'best practices' that promote family integration and enhanced developmental outcomes in neonatal care are extensive (see Chapter 2). I argue, there is an enormous gap between such guidelines and current practices in Mexican hospitals; this will be described throughout the thesis. I decided then to embark on a study to understand how care for babies in Mexican hospitals might begin to incorporate guidelines that encourage healthcare professionals to adapt care based on a view of babies as members of a family; as sentient beings; as people with rights and as persons able to communicate with others, in other words, baby-led care.

Initially, I considered designing an action research project for the present study, so as to implement 'baby-led' care strategies. Baby-led care means to adapt daily care to meet the individual needs of each patient based on critical, self-aware reflection and multi-disciplinary team work (that includes parents and babies). However, most of healthcare professionals' concerns (described above) referred to more structural problems: healthcare system organisation, economy, culture and others. After an initial review of the literature I realised there was a need to look at *deeper* possible causes that have an

impact on how the Mexican healthcare system is organised and how discourses around risk, health and children are produced and reproduced. Critical realism (CR) provided a philosophical framework for such an enterprise.

I also wanted babies to be at the centre of the study and the thesis and to hear their voices. Childhood studies seemed to be an adequate sociological approach to, borrowing the expression from James and Prout (2015), study them in their own right.

The following section describes the context of the study. It begins by considering the evolution of the Mexican political system, my objective is to present a background to understand how the Mexican healthcare system works. It also describes some current problems, which Mexican people face, and it especially considers how these shape the lives of women and children.

Some reports presented in this section have been taken from on-line news reports, this is with the intention to bring some academic debates into context. On-line news reports and material of limited availability will be presented in foot notes, so as to differentiate them from academic references.

1.2 Context of the study

A patriarchal political system that contrasts with the current neoliberal agenda, very unequal distribution of resources, entrenched corruption, gender and ethnicity biases, among other factors, intersect and give shape to the current welfare system in Mexico. Inadequate public policies (Castillo Fernandez & Arzate Salgado 2016) meet with crime and violence that have become ‘normal’ part in the life of Mexicans, and ultimately affect the poorest of the poorest.

Even though Mexico is considered by the World Bank (WB) the second largest economy in Latin America¹, official figures estimate that almost half of the (approximately) 120

¹ <http://data.worldbank.org/country/mexico>

million people that inhabit the country live in poverty and almost 10% live in extreme poverty².

1.2.1 Neoliberal Mexico

Some authors have argued, the neoliberal turn that took place some three decades ago have contributed to inability from the Government to fight poverty (Laurell 2015; Castillo Fernandez & Arzate Salgado 2016; Weaver et al. 2012).

The early 1980s have been recognised as the beginning of the neoliberal era in Mexican politics. Weaver and colleagues (2012, pp.4–5) offer a helpful review of events. Due to a crisis in the oil sector, 1982 saw a great depression in Mexican economy. By 1983 the external debt represented approximately 63% of the GDP. Mexico's Federal Government was forced to adopt neoliberal policies as the result of international pressure; the International Monetary Fund (IMF) and the WB (among others) offered a bailout conditional on the implementation of a series of structural reforms. New policies, at the federal and local levels, were characterised by reduction in government spending, open markets and increased exports. The ultimate result was the reduction of programmes and subsidies, as well as a reduction in spending on health, education and welfare. This brought about unemployment and loss of services.

In the late 1980s, Mexico's President Carlos Salinas de Gortari consolidated a neoliberal agenda. In doing so he implemented a series of structural reforms, privatised publicly owned companies and negotiated the North American Free Trade Agreement (NAFTA) with Canada and the USA, liberalising the trade market and capital flows but not labour, which, as noted by Laurell (2015), was unfavourable to Mexico. Weaver and colleagues (2012, p.9) argue NAFTA greatly affected small producers, who were forced to abandon farming and left 'rural communities in search of wage work', and resulted in the 'Zapatista' armed rebellion movement, among other problems. Changes in agricultural policy benefited larger companies and producers, who were granted tax benefits and

² http://www.coneval.org.mx/Medicion/Documents/Pobreza%202014_CONEVAL_web.pdf

were able to replace indefinite contracts with more flexible forms of employment, leading to an increase in self-employment (Castillo Fernandez & Arzate Salgado 2016).

1995 brought another economic crisis, by this time jobs in the informal sector (*empleo informal*) had increased. In face of the need for a new rescue loan, the Mexican government under President Zedillo's mandate agreed to implement a new austerity programme, reducing government spending further (ibid).

To date, efforts by the Mexican government to decrease poverty have been described as flawed and social programmes as inadequate. Even advocates of the economic model recognise a structural failure that lead six out of 10 Mexicans to work in the informal sector (Ernesto & Córdova 2016).

People working in the informal sector, many of them participants in my study (domestic employees, peasants, informal sellers, among many others), are vulnerable because they do not benefit from any type of social security. Sociologists such as Castillo and Arzate (2016) suggest that the informal sector is in part the result of the insertion of the national economy into a global one, and the inefficiency of an economic agenda to create jobs. Politicians, such as Ernesto and Cordova (2016, pp.31–32) propose the informal sector is associated with:

low levels of educational attainment of the labour force; a mismatch between the skills demanded by the productive sector and workers' abilities; social security schemes that may reduce demand for workers in the formal sector; and a real or perceived mismatch between the costs and the benefits for a firm to operate in the formal sector (taxes and costly regulations over access to credit and government programs).

And economists such as Alcaraz and colleagues (2015, p.2), members of the *Banco de Mexico* (Bank of Mexico), suggest 'an important proportion of workers self-select into the informal sector'.

Castillo and Arzate (2016, p.101) note that social policy in Mexico 'is limited by the structural factors of the free market economic model' and it is further obstructed by the

‘persistence of certain political and social control tactics, bureaucracy, and paternalistic policies that tend to distort and complicate social program operations.’ Laurell (2015, p.247) contends corruption, influence trafficking and patronage, among other factors, have contributed to the maintenance of a political elite in spite of the ‘popular clamor for democracy’.

Corruption and patronage have historically characterised life in Mexico. From 1930’s to 1980’s the country’s Government was dominated by one political party; Institutional Revolutionary Party (PRI), which also held almost all elected positions. Selee (2011) contends patronage was characteristic of this period. Patronage, according to Selee, was a strategy devised by the Government in order to deliver services, enforce rules of law or respond to citizens’ demands by creating alliances with key participants at local levels who acted as ‘political intermediaries’. In the system of favours citizens are in need to appeal to these ‘political intermediaries’ for favours, resources or justice rather than trusting in their constitutional rights. Furthermore patronage contributed to the creation of alliances with leaders of drug cartels during this period. This in turn granted greater freedom of movements and relative peace (Dube & Garcia-Ponce 2013; Osorio 2013) thus promoting corruption. It has been documented that criminal organisations in Mexico would spend around \$500 million dollars a year in bribes (Morris 2012).

The new millennium brought a transition in Government. In 2006 the new political party in power, National Action Party (PAN), launched a military campaign against drug cartels. This war against drugs seems to have started a conflict of enormous consequences: according to official figures, by the end of 2010 there had been a little less than 35, 000 deaths related to this conflict in the country. Conversely journalists, academics and activists have gathered much higher numbers: between 45, 000 and 60, 000 (Morris 2012; Osorio 2013). The number of children who have lost their lives in relation to this conflict is unknown. It has been the latter groups, especially activists, who have demanded the Government to conduct appropriate investigations and recognise the magnitude of this problem.

Violence, corruption and political reforms have had an important impact on the Mexican economic system; the informal sector has shaped in many forms the welfare system in Mexico and healthcare organisation has been no exception in the neoliberal transformation; which will be reviewed in the following section.

1.2.2 The Mexican healthcare system: past and present

During colonial times in the sixteenth century, provision of health care in Mexico took a charitable dimension with great influence of the Catholic Church and the Spanish missionaries. After the Mexican Revolution (around 1920 and 1930) the state, through public health policies and with ideals of social justice and equality, aimed at protecting (some of) the people in most need (Castro 2001). The Ministry of Health and Welfare or *Secretaria de Salud y Asistencia Publica (SSA)* was established in 1943 (ibid.), now called *Secretaria de Salud* (Ministry of Health) to regulate Mexican health services. It provided social security for all those formal employers (either from private or public sector) and their families, and a very limited type of ‘assistance’ to the unemployed or people working in the informal sector. This means that, until 2004, when the National Health Reform took place, an estimated fifty million people did not have access to the most basic services of healthcare in Mexico (OCDE 2012).

An important reform to the Mexican Constitution took place in 1983, where it was stated that access to healthcare was a universal right (SEGOB 1983). Following recommendations from the World Bank in 1993 the state opened social security management to private investors (Castro 2003) and the costs in public health for the population in poverty were directed to the creation of a basic programme which included 12 activities among them: diarrhoea management at home, identifying alarm signals of acute respiratory infections, tuberculosis, hypertension and diabetes control, immunisation, family planning and pre and post-natal care. By the end of this period private insurance practices increased considerably (López-Arellano & Blanco-Gil 2001).

The total GDP expenditure on health in 2013 was 6.2% (3.2% for public expenditure and 3.0% for private expenditure), this situates Mexico below the average of 8.9% for OECD members (OECD 2016a).

Access to services

Public healthcare is provided by a number of institutions:

There is one type of shared responsibility between the state, private sector and private sector's workers through social security by Instituto Mexicano del Seguro Social (IMSS); state workers, their family and dependants have access to either ISSSTE, PEMEX, SEDENA or SEMAR, depending on their working relationship with the State. Between 2001 and 2006 a National Health Reform implemented *Seguro Popular* (Popular Health Insurance) to provide access for all to primary (yet limited) health care services (González-Pier et al. 2007)

Seguro Popular is a subsidised type of insurance. Families have to pre-pay a (controversial) fee (inversely proportional to their income) in order to access it, the 20% poorest families are exempt of payment.

Although official figures claim coverage of healthcare provision is almost universal (Frenk et al. 2006), independent studies refute this (Laurell 2007). Official figures do not recognise that many people have dual coverage in different policies. In the unequal provision of care, some people have more than one coverage whereas many others have none at all (Castro 2014).

A series of structural reforms in Mexico since the 1990s have been directed at transferring responsibility to citizens. For example, *Oportunidades* (Opportunities) is a welfare programme directed to 'empowering' women in deprived areas. Women receive financial support if they commit to assisting in workshops, doing community work and ensuring children's attendance at school and healthcare checks. This reveals a view by the State that only women are responsible for their children's health and education.

1.2.3 Women in Mexico

Gender differences in Mexico have always been high, although there have been actions in recent years directed to close those gaps. In 2005 for example, 10% of women versus 7% of men could not read or write (INEGI 2009). Today it is claimed that enrolment in primary school does not show differences in gender and there are more women enrolling in basic and higher education than men (OCDE 2012).

However numbers and conditions in employment are still uneven. It has been estimated that only 40% of women in working age are in paid employment and more than half of them work in the informal sector (INEGI 2009). This meant that, until 2004 when *Seguro Popular* was introduced, a significant number of women did not have access to the social care system or basic health care unless one of their parents or their husband had a formal job and therefore access to social security. The most usual informal job for women in Mexico is the domestic one or as informal sellers, both of them include long working hours and heavy physical work. Due to the lack of policies and flexibility to combine work with child rearing many women have no other option but to take these type of jobs (ibid.), which are underpaid and in many cases detrimental for their health. This adds to the fact that on average women spend four more hours per day than men caring for their own home and family (ibid. p.38), work that is not paid and in many cases not even recognised. Finally women who work in the informal sector are not entitled to any type of maternity leave, meaning they have to work as long as they can before the birth and come back to their activities as soon as possible after the birth. This also influences the number of children they decide to have or when to stop breastfeeding.

Women who work for the formal sector have, by law, twelve weeks of paid maternity leave. Paternity leave and unemployment benefits do not exist in Mexico. Hence, in spite of having better economic status, women in this sector also face difficulties when having to make decisions around maternity.

In the field of healthcare, *Seguro Popular* covers care in pregnancy, and during and after birth. This means, at least in theory, that all Mexican women should have access to these services either from the public or the private sector. However the latest report of the National Institute of Statistics and Geography in Mexico (2009) shows that one in four pregnant women do not receive any type of medical care before giving birth, even though the Mexican guidelines on health care suggest they should have at least five clinical antenatal appointments. Another important figure to mention is that around eight percent of women between 12 and 19 years old have been pregnant at some point (ibid. p.117). Hence teenage pregnancy is today considered a healthcare problem in Mexico.

INEGI (2009, p.113) also estimates that the rates of caesarean section have increased significantly (up to around 25%) in the last 20 years. This not only increases the risk of infection and death for women but also the national costs in healthcare. Additionally most births in 2007 were attended by doctors (around 80%) and only around 13% were attended by nurses or traditional *parteras* (birth assistants). Maternal mortality in Mexico in 2014 was estimated to be 39 deaths per 100, 000 births³.

Reproductive and sexual rights is a subject that has had special attention in Mexico in recent years, with a big and well positioned feminist movement on one side, fighting for women's right not only to decide over their own bodies, but also to demand that those who are taking decisions for them do not abuse their power (Lamas 2001). On the other hand the strong influence of the Catholic Church and the conservative political groups still resist discussing important subjects such as gay marriage or abortion. And in contrast, health institutions force the use of contraceptives through deception (Salinas-Beristain 2001) by, for example, performing surgical procedures to induce female sterilization after a C-section without women's informed consent, as documented by Castro and Erviti (2003). It is estimated that every year 33 out of 1000 women aged between 15 and 44 years old have an induced abortion in Mexico since 2006⁴. However these numbers only account for legal abortions in the country.

³ <http://www.omm.org.mx/index.php/indicadores-nacionales/boletines-de-mortalidad-materna/2013>

⁴ <https://www.gire.org.mx/nuestros-temas/aborto/cifras>

1.2.4 Children in Mexico

More than 40 million children in Mexico live in poverty, the majority of those living in extreme poverty are indigenous people, and chronic malnutrition affects approximately 1.5 million children younger than 5 years old (UNICEF México 2014). OCDE (2016b) figures show that the infant mortality rate in Mexico is still high (13 deaths per 1000 live births).

Invisible children

Insecurity and violence in Mexico hit children constantly, not only by suffering the collateral effects of the drug war or, in the case of girls, gender violence, but sadly child abduction is another common problem. Members of the National Foundation of Investigators of Stolen or Disappeared Children (*Fundación Nacional de Investigaciones de Niños Robados y Desaparecidos*) informed there are approximately 45,000 (known) cases of missing children in the last 18 months. It is believed some of these children are kidnapped for sex or organ trafficking.⁵ Members of society have urged the Government to create a special commission in order to investigate these crimes, without success so far.

Violence and poverty in Mexico also affect children who have to make the difficult decision to migrate to the U.S. in the search of a better future. In 2011, José Miguel Insulza, General Secretary for the *Organización de Estados Americanos* (OEA) declared that there were over 4,000 unaccompanied children, who tried to migrate from Mexico, Guatemala, Honduras and El Salvador to the United States⁶. By 2014, the number of unaccompanied children travelling to the U.S. had surpassed the 50, 000. Children who are caught by border authorities in the U.S. are kept in crowded detention centres in Texas⁷, repeatedly described as ‘inhuman’ places by activists.

⁵ <http://www.sinembargo.mx/28-06-2014/1039967>

⁶ <http://periodistas-es.com/migrantes-infantiles-son-una-arteria-abierta-en-america-central-38185>

⁷ <https://www.theguardian.com/world/2014/jul/09/us-immigration-undocumented-children-texas>

Violence or migration are not the central theme of this thesis and it will be difficult to give an accurate description of them without deepening in the subject. Still it is essential to understand how Mexican society values the children, especially the most disadvantaged ones, and how neglect and dangers share in shaping children's well-being and healthcare in Mexico, if we want to identify better (realistic) possible practices in caring for preterm babies in the country. On the same line of thought, it is important to understand the challenges that women face in becoming mothers. Having a child admitted to the NICU brings about economic and emotional hardship; it is not known how this experience impacts on the lives of people who already live under difficult circumstances. This will be discussed in further chapters.

1.3 Structure of the thesis

After having introduced my motivations to undertake this study and some background information in this introduction, the second chapter presents a review of the literature. It begins by briefly reviewing the history of neonatal care and describes how it is that family centred care has come to be considered best practice. It also describes programmes that have contributed to a conception of the newborn baby as a social person. More specifically, it describes the NIDCAP programme, which is based on the synactive theory of development and that has informed my observations of babies. It also draws on concepts from the new sociology of childhood which greatly value medical and psychological concepts (such as babies' neuro-development) but warns against reducing children to a biological level and critiques the view of children as adults in process. Some sociological studies about mothers and babies in the NICU are also reviewed. Finally, this chapter reviews some concepts of biopolitics, this is, the development of strategies of management of everyday human practice from which women and children have been a constant target.

The third chapter reviews the methodological framework that underpins this project: it describes different ontological and epistemological approaches that shape research and positions this study within the critical realist (CR) stand. CR concepts such as: *ontological realism, epistemic relativism and judgemental rationality, the transitive and*

intransitive, epistemic fallacy, open and closed systems, natural necessity and emergence are defined in this section. *Four planar social being* and *MELD* are two CR concepts that I used as a ‘lens’ to make sense of and organise the data. The study’s main aim, specific objectives and research questions are defined; case study as a research strategy is reviewed and so is critical ethnography, the method used to collect data. Subsequently, the chapter outlines access and sampling strategies, characteristics of research participants and the method used to analyse data collected through a survey, interviews, focus groups, participant observation, systematic measurement of noise levels (dB) and examination of documents. A brief discussion on ethical issues encountered through this research closes the chapter.

Results are presented through three overarching themes: hygiene, dignity and well-being in Chapters four, five and six respectively.

Chapter four presents an analysis of the social order in the NICU of JDH and MDH through hygiene practices and is organised through the concept of *four planar social being*. It considers embodied practices of hand-hygiene and extraction of breast milk, which I argue, are used as methods of surveillance and regulation of parents, and legitimate the practice of isolating babies. It also looks at inter-personal relationships in the baby unit and reveals attitudes and beliefs about moral hygiene, and considers ideas and beliefs that shape the social order in the unit. It explores relationships of power that arise from hidden but powerful forces at the level of wider social structures. Finally, it notes how parents make sense of their role in the NICU through medicalised discourses and practices, and it reviews some initial possibilities of flourishing in the NICU.

Chapter five makes a review of dignity in the neonatal unit and is organised in similar fashion as the previous chapter, through the lens of *four planar social being*. The chapter problematises the concept of dignity when babies and their families in these public hospitals seem to be viewed and treated as second class citizens and basic human needs are not considered. It also considers material working conditions and power relations that alienate healthcare workers and which affect the type of care babies receive.

Powerful but sometimes unobservable forces, such as gender or social class, and their

effect on healthcare provision are addressed. Children's rights are considered throughout this chapter as a 'practical guide' to enshrine concepts of dignity in the NICU.

Chapter six is about well-being in the neonatal unit. The chapter is organised through the CR concept of *MELD*. The first section, 1M, defines the concept of well-being. The second section, 2E, looks at absences or inconsistencies, which work to the detriment of well-being, at the levels of: the physical, biological, psychological, psycho-social, economic, cultural and normative. The next section, 3L, brings together the global into the local; it considers how violence, corruption, poverty and historical prejudices about children are linked to practices of caring for children in MDH and JDH. This is followed by 4D, which considers flourishing and possible paths to well-being.

Chapter seven presents the conclusions of this study. It begins by re-instating the aim and research questions of this project and considers how childhood studies and critical realism, as theoretical and philosophical frameworks respectively, informed and guided this study. This is followed by a summary of the two cases and a summary of results. The chapter then presents a proposal of practical solutions towards transformative change through: considering nurses as agents of change, enhanced communication at all levels and the development of normative (evidence based) procedures to guide practice in the NICU. The chapter closes by considering wider implications of this study and next steps for research.

Chapter 2 Preterm babies, women and health: a theoretical background

2.1 Introduction

Recognising that the literature review is an important stage of research, which might lead to better understanding the study's topic, a first step within this project was to define the objectives of the review of literature.

In order to arrive to these objectives I had to consider the advantages and limitations that different types of literature reviews provide. Systematic reviews are a common type of literature review for evaluating healthcare interventions, they 'adhere to a strict scientific design based on explicit, pre-specified and reproducible methods' (Norman & Griffiths 2014, p.1) which include a comprehensive assessment of the quality of empirical sources and, in itself, it is considered a research strategy (Gough et al. 2012). For reasons that are explained in the following chapter, I considered it important to include in my review of the literature both qualitative and quantitative studies, which incorporated books and long reports usually omitted from systematic reviews. Moreover, including theoretical as well as empirical papers was considered very relevant in order to provide a full picture of the ideas that have influenced the work presented in this thesis.

Integrative reviews allow combining empirical and theoretical sources, thus aiding a more comprehensive understanding of a given phenomenon (Whittemore & Knafli 2005). Scoping studies are characterised by the breadth of the review, and might be used to map the most relevant literature around a certain area, integrating studies with a variety of designs (Arksey & O'Malley 2005). I consider that the literature presented in this chapter falls into a 'scoping' type of review, given that breadth was prioritised over depth, so that different very relevant areas could be covered but it also takes characteristics from the integrative type of review, so that a variety of sources can be included.

As it has been stated, this research is about babies, their parents and carers in two Mexican NICU. My aim is to understand why preterm babies in Mexican hospitals are cared for as they are. Using a critical realist framework I wanted to consider and acknowledge babies' experiences of being in hospital. I also wanted to learn more about parents' and staff members' experiences and views, thus the use of ethnographic techniques.

I needed to identify a theoretical approach that allowed me to interpret babies' possible feelings of comfort or discomfort. Als's Synactive Theory of Development considers preterm babies as social actors, able to interact and communicate with others from birth. Als's theory has resulted in a specific form of caring for preterm babies in hospital known as NIDCAP. This theory informed and shaped my view of babies and also some of my decisions in the methods of observation. Description of Als's theory and NIDCAP follows a brief review of the history of neonatology.

Babies' experiences can hardly be conceived without considering them in the dyadic relationship with their mothers and more extensively in a relationship with both mother and father. The view of the role of parents in the baby unit has shifted gradually in NICUs in some countries from passive visitors to active carers. The end result has been the current 'family centred care' (FCC) promoted in many hospitals around the world; which I briefly review in this chapter.

A very important task was to situate children within a theoretical framework that allowed me to understand 1) how babies might contribute to different aspects of human life even if they are born very preterm or sick, 2) the impact of illness and hospitalisation on their lives and 3) how their experiences, and parents' experiences, are shaped by the context and culture of the hospital and in the wider context. The sociological study of childhood seemed to be a viable path in order to consider babies' participation not only in social interactions but also in other domains of human life such as the economic and political. This is described in the second section along with a review of some sociological studies that have looked at interactions in the baby unit.

Women's experiences as mothers also needed to be addressed. I consider these briefly in this chapter within notions of biopower and puericulture.

Further review of the literature took place as findings called for further exploration and new themes became apparent through the analysis of data, this is presented throughout the rest of the thesis.

Different strategies were used in order to identify the authors whose ideas and theories underpin this research, these involved: critical reading and discussion of texts considered 'key' in the field, many of them accessed through reading seminars I attended during the course of my studies; presenting preliminary ideas in conferences and seminars and benefiting from suggestions from people in the field; tracing references within relevant literature; and the search of specific topics in bibliographic databases, library catalogues and indexes.

Both theoretical and empirical papers informed this chapter. Selection of texts was based on a critical evaluation of the quality of empirical papers (data collection and analysis techniques), bibliometric measures and/or author's recognition (reputation) in the field.

2.2 Preterm babies and neonatal care

As medical knowledge and technology advance, so does the survival of babies born preterm. Not surprisingly, most babies cared for in NICUs are premature. Babies born before 37 weeks of gestation are defined as preterm (WHO 2014). Preterm birth is further divided in sub-categories according to gestational age: babies born at less than 28 weeks of gestation are considered extremely preterm, very preterm babies are born from 28 to less than 32 weeks of gestation and babies born from 32 to less than 37 weeks of gestation are considered moderate to late preterm. Neonatology is a relatively new sub-specialisation of medicine, thus understandings about care for very sick and preterm babies are also relatively new.

Most births during the 19th century occurred mostly at home and were attended by midwives. Consequently, physicians (who practiced mainly in wealthier homes) had little understanding of newborn diseases. Infant mortality and morbidity were alarmingly high (Cone 1983). In the later 20th Century, more women gave birth in hospital in the United States from 1950 and in the UK following the Peel Report in 1970 (Beech 2006), which led physicians to treat more babies. Neonatal care also developed in Britain through the National Health Service founded in 1948.

The incubator, a box with glass walls, was invented around 1880 by the French obstetrician Tarnier, probably inspired by previous work of other physicians (Cone 1983). By the early 1900s, live preterm babies were taken to world fairs for display. Incubators provided a sanitised and thermo-regulated environment, therefore they became the norm in caring for babies in neonatal units. Mothers were not allowed to care for babies since it was believed their germs could cause respiratory problems to newborns. By the 1950s it was discovered that respiratory problems were caused by immature functioning of the lungs, and later by cross-infection between babies by nurses and doctors, which was proved to be a serious problem and was tackled in innumerable reports⁸. However the practice of isolating babies continued and many other interventions with neonates at the time were experimental, such as withholding all food or fluids for several days in order to prevent fluid aspiration that could worsen respiratory problems in babies (Davis et al. 2003).

Neonatology, as a sub-specialisation of paediatric medicine, dates back to the 1960s. The term was coined by the American paediatrician Alexander Schaffer (Philip 2005). Since then, a great number of scientific discoveries have increased the survival of very preterm babies. To name a few: techniques for intravenous nutrition and tube feeding babies; respiratory support through oxygen and assisted ventilation for very immature babies and those with severe respiratory problems; and control of infection with the use of antibiotics. However, indiscriminate use of technological advances can increase

⁸ See for example the Matrons Board Report from a UK hospital
<https://www.nuh.nhs.uk/handlers/downloads.ashx?id=14211>

morbidity. For example, high concentrations of oxygen can cause blindness through inducing retinopathy of prematurity (ROP).

Neonatal care represents remarkable progress and has transformed the lives for countless babies who survive and flourish and that would once have died or been severely impaired. However, progress raises new questions about how far it is kind or wise either to try to rescue extremely premature babies, or to provide extremely complex expensive NICUs within very low budget national healthcare systems responsible for millions of extremely needy, disadvantaged children and adults.

2.2.1 New understanding of babies as persons

History of neonatal care is mainly of babies as passive recipients of care. Thanks to the innovative work of Brazelton, Als (1979), Stern (1977) and many others, babies started to be recognised as active participants able to communicate with others and thus contribute to their own care.

Through detailed observation of babies with their Neonatal Behavioral Assessment Scale (NBAS), Brazelton and colleagues (2011 [1973]) showed that babies born at term are able to communicate and engage in complex interactions through different identifiable behavioural states and adapt to the environment through facial and body 'language'. Understanding what these cues mean in terms of babies' strengths and vulnerabilities is important because it enables parents and carers to understand babies' different forms of meaningful interactions.

Als (1982; 1986; 1999) proposed that preterm babies are equally able to interact and communicate, although their cues and communication signs are more subtle and take place within a set of stratified subsystems.

Figure 1 represents my summary of the interaction of subsystems. The first and most basic of Als's systems is the physiological or autonomic subsystem in which breathing, heart rate, temperature and digestive movements are involved. This can be observed in

the pattern of breathing, colour changes, tremors or startles, visceral movements, hiccoughing, gagging, and others. A stable or balanced physiological subsystem lays the foundation for the second motor subsystem, which involves posture, muscle tone and movements. The organisation of this subsystem can be observed in the quality of the muscle tone and the fluidity of movements. Stability in the motor subsystem means that the baby can relax and more easily rest or interact (by looking around for example). The range of states (asleep, drowsy, awake, distressed, and crying) forms the third states subsystem. This can be observed in the transition from one state to the other (i.e. when the baby gets sleepy and looks drowsy). A balanced awake state brings the possibility to engage in social interactions and elicit cognitive information from the environment through the fourth attentional subsystem. This can be observed in a range of actions from short periods of interaction or brief glances to 'fussing'. Finally the regulatory subsystem involves the organisation in the other subsystems and it can be observed in the ability to maintain the balance among them. This is known as 'Synactive Theory of Development'.

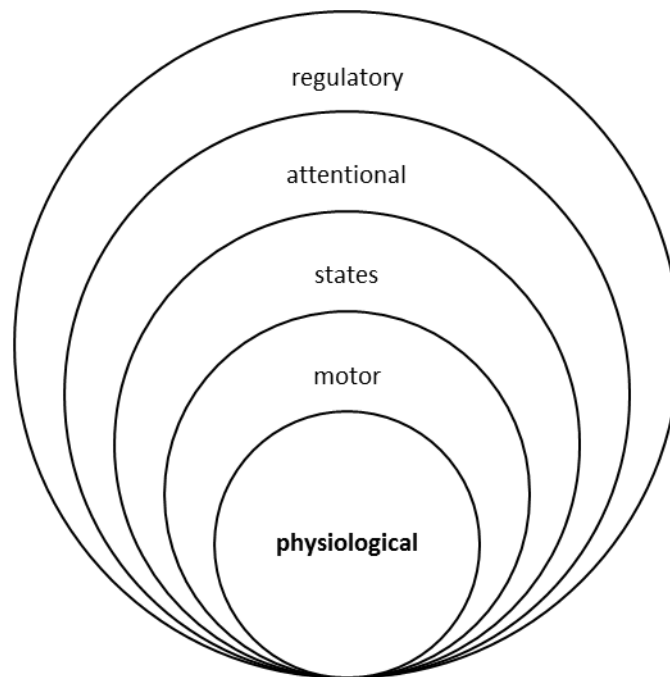


Figure 1 Als's Synactive Theory of Development: subsystem interaction

Furthermore, Als and colleagues (2004) propose that the environment, such as the NICU, and the quality of the relationship with carers have an important impact on the development of the baby's strengths or in exacerbating vulnerabilities.

This might be further explained by neuroscience, through which some researchers suggest very important neurodevelopmental processes take place in the second and third trimester of foetal development, these are: cell migration, cell differentiation, synapse formation, myelination and among others (Kolb & Gibb 2011). Questions have been raised as to how early preterm sensory experiences, especially those which are not ready to be exposed outside the warmth and muted sensations within the womb, could impact on this development (Lickliter 2011). Other authors have suggested that the quality of care (Coughlin et al. 2009), the quality of sleep (Graven & Browne 2008) and the quality of the first relationships (Weber et al. 2012; Schore 2005) could affect this developmental process.

From this point of view, the baby is not only seen within a biological dimension although a stable physiological subsystem (normally the main aim in intensive care) does give a foundation to the rest of subsystems. The implications of Als's theory of subsystems at a social level are that, when healthcare professionals fear (uneducated) parents might 'disorganise' very ill babies when they touch them or talk to them, consciously or not the professionals worry that this can alter the synchrony of subsystems leading to physiological instability. Understanding babies' abilities to organise their activity in this way shows how carers, including parents, can support babies through different activities that might be stressful.

The work of Brazelton and Als was both innovative and revolutionary because they helped change the view from studying babies' negative abnormalities to understanding babies' positive capacities, strengths and sensibilities. Although based on developmental psychology, this theory moves beyond the biological dimension and sees the baby interacting with other people and the social context.

NIDCAP

The Newborn Individualized Developmental Care Assessment Program (NIDCAP) is based on Als's theory. NIDCAP is an early intervention programme that focuses on babies' competence; that is, on 'the degree of smoothness and modulation, regulation, and differentiation of [the] five different subsystems of functioning that are behaviorally observable' (Westrup 2007, p.445). Repeated naturalistic observations of babies during and after caregiving episodes (60 to 80 minutes of observation in total) lead a trained observer to identifying babies' competence in interacting with the environment. The final outcome from these series of observations is an individualised plan to adapt cares and the immediate environment in order to meet each babies' needs (Als & McAnulty 2006). This individualised plan might involve recommendations such as protecting a baby from bright light by shielding the incubator, which might support baby's rest; positioning the baby in certain form that seems to be soothing or allowing the baby to suck from a dummy during a painful procedure. NIDCAP intervention calls for multi-disciplinary work, baby-led approach that facilitates parenting in the NICU (Lawhon & Hedlund 2008) and is considered to be respectful towards babies, parents and members of the NICU staff.

Although I did not use the NIDCAP protocol to observe babies in this study, my descriptions of babies' behaviour during observations were informed by my background knowledge as a NIDCAP student.

2.2.2 The parent-infant relationship mediated by the NICU experience

Alongside an increase in the awareness of newborn babies' competencies, questions started to be raised about the practices of separating babies from their parents in hospital. Klaus and colleagues (1970; 1972) argued that the immediate period after birth is crucial for mother and baby bonding and, if disrupted, later increased the risk of child abuse. A nation-wide campaign in the UK called for the recognition of parents to be allowed into the baby unit and to take into account babies' and parents' emotional needs (Alderson 1983).

With time, 'family centred care' (FCC) was accepted (in some countries) as best practice in caring for children in hospital. This means that babies are recognised as members of their family and parents are seen as important in babies' daily life in the NICU (Poppy Steering Group 2009; Raiskila et al. 2014; Institute for Patient- and Family-Centered Care 2012), however internationally the process of accepting parents as partners in care in the NICU has been difficult. The NICU environment might be stressful and alienating for parents and some may need support in, little by little, feeling able to care for their babies (Cleveland 2008) although many others want to do so from the start.

Examples of FCC programmes in the NICU are:

Creating Opportunities for Parent Empowerment (COPE) which is based on education of parents about preterm babies' behaviour and development (Melnyk et al. 2004). Benefits from this programme include reduced maternal anxiety (Mianaei et al. 2014) and reduced anxiety in children born preterm at 24 months of age (Oswalt et al. 2013).

Family Nurture Intervention (FNI) facilitates mother-infant 'nurturing activities' (such as guiding mothers to touch their sick baby) supported by a 'nurture specialist' (Welch et al. 2015), reported benefits for children who were born preterm are significant improvements in different neurodevelopmental areas at 18 months of age.

Family Integrated Care (FIC) where parents provide most of the care to babies in the NICU and parent to parent support is promoted (O'Brien et al. 2013). Reported benefits from this programme are: increased weight gain of babies, increased incidence of breastfeeding at discharge and decreased parental stress at discharge.

FCC is yet to be recognised in the neonatal care of babies in many countries, such as Mexico, and this seems to be ignored by world researchers who assume such approach of caring for babies is widely known internationally. And as identified by others (see for example Altimier 2015), even when FCC is the approach of care mother-infant separation in the neonatal period is still very much an accepted practice.

2.3 New understanding of children in sociology

In contrast to the important medical and psychological research about babies and children, the new sociology of childhood focuses on studying children, and less often babies, beyond the long tradition of depicting infants as immature and pre-social (Burman 2008; Bradley 1989; James & Prout 2015). Developmental psychology studies ‘universal stages’, mainly based on behaviour, which children go through in their journey to become ‘mature’, and Burman (2008, chap.1) argues development has been conceptualised as a unilineal process which follows direct steps in a hierarchical order. This is due to Darwinian ideas, followed by theories proposed by Piaget and Freud, which have greatly influenced the systematic study of children. Within this perspective, the biological aspect of children is studied without considering their material and relational dimensions. However, a number of scholars have challenged the practice of studying children in their becoming adults instead of as children in their own being. They call for a new paradigm that considers the position of children as a group within society, and that examines children as social agents who participate actively in the social world with others (Qvortrup et al. 2009; James & Prout 2015; Burman 2008; Alderson 2013; Alderson 2016).

James and Prout (2015) propose childhood is a variable that cannot be separated from other social variables such as race, ethnicity or social class. What is universal for children, the authors contend, is biological immaturity. Childhood, they argue, is a socially constructed concept. In their view, children’s lives should be studied in their own right, and not only with respect to how adults view them.

Mayall (2015; 1996) proposes childhood needs to be defined as a social status in inter-generational relation to adulthood. It is within those relationships, the author argues, that embodied relations should be studied, because adult-child relations are partly constructed through adult’s attention to infants’ physical bodies.

2.3.1 Sociological studies in neonatal care

Foretelling futures: dilemmas in neonatal neurology (Alderson et al. 2004) was an ethnographically informed study in order to understand how different kinds of knowledge and expertise (multi-disciplinary work) inform 'babies' all-round needs'. The study included interview to parents and staff, structured observation of babies (NBAS and NIDCAP), observation of interactions among babies, parents and staff members in the NICU of four hospitals in London (UK) during 18 months. Discussions with an advisory multi-disciplinary group (including parents) through six meetings added to the data. Themes that emerged from this study were: communication and information sharing, trust, discharging procedures and follow up care, uncertainty, parent-infant relationships in the NICU and the future of neonatal care. Insights about babies' rights (Alderson et al. 2005a; Alderson et al. 2005b) were an important development of this project.

Flacking et al (2006) studied experiences of women in becoming a mother and breastfeeding in seven neonatal units in Sweden. Their qualitative study involved interviews with 25 women. Among other results, the study underpins the importance of developing 'trustful bonds' and balanced power relations between mothers and clinical staff in the unit in order to enhance mothers' confidence that might lead to enhanced mother-infant interactions and the enjoyment of breastfeeding.

Fenwick and colleagues (2008) studied the development of mother identity within two special care units in Australia. Data were collected from interviews to mothers and staff and records from field notes. Their findings show the complex and intricate relationships between mothers and staff that arise when women have to 'negotiate' access to their sick babies and the factors that either facilitated or inhibited their 'journey' as mothers. These were: babies' well-being and progress, women's confidence in themselves and the relationship between nurse and mother.

Although mainly seen from an adult-centred perspective, sociological studies about mother-infant relationships in the baby unit bring an important insight into some

challenges women experience as mothers in medical encounters. For instance, in Flacking's study breastfeeding was encouraged because it benefited babies' development, however mothers' enjoyment of feeding was not considered by medical staff or by mothers themselves.

Mother-infant interactions have been studied through attachment theory (Bowlby 1969), which proposes, following Anna Freud and Melanie Klein, that the relationship of the mother and baby is crucial for future development. This idea of placing on the mother the sole responsibility for the future development of the child has been resisted and contested by feminists, such as Burman (2008), who criticise the exclusion of fathers and other carers and siblings, and the over-burdening of mothers, that works to maintain a sexist social-political order.

There has been a tendency in the Mexican State to portray women as the solely responsible carers for children. Smith-Oka's (2015) anthropological exploration of women's medical encounters while giving birth in a Mexican public hospital is a good example. Women in this study were educated in 'proper child-rearing' by clinicians and deemed responsible for adequately stimulating their babies in order to develop their 'best potential'. The previous chapter gave a brief example through the welfare programme *Oportunidades*. Indeed some criticisms have been that in aiming to 'empower' women by giving them some financial relief, the State has over-emphasized the responsibility and potential blaming of women in educating and caring for children in the household, without considering how men could also contribute (Molyneux 2006). Moreover, *Oportunidades* has been identified as an example of the Mexican neoliberal agenda, which aims to transfer financial and other responsibilities for the well-being of children, and blame for unsuccessful outcomes, from the state onto individual parents, especially mothers.

It seems important then to review some aspects of neoliberal governments in relation to women, children, health and neonatal care from a historical perspective.

2.4 Biopolitics, health and power

This section shows how current neoliberal states make use of technologies, such as hygiene in science, healthcare and the home, expert advice and compilation of risk statistics, to govern the day-to-day life of individuals. In this sense preterm babies might be seen as an ‘at risk’ population in need of surveillance through networks established in hospitals, clinics and through the family.

Nadesan (2011) examines the emergence of the biopolitical government of populations within the Western liberal state. Biopolitical strategies refer to the strategies of management of everyday human practices through technologies of power and knowledge that neoliberal states use to regulate society (Foucault et al. 2010). These strategies bring or even force individuals to internalise and adopt practices of ‘self-government’ in day-to-day routines and disciplines (Rose 1999).

Nadesan (2011, chap.4) traces health practices of western liberal regimes throughout history and which I have summarised in Table 1.

Twentieth century..... Eighteenth century	Form of social medicine:	Problems posed:	Technologies used:	Discipline Security (imposition and discipline quarantine) (statistical representation)
	State medicine Eighteenth century	Population in need of surveillance and intervention.	Statistical measures of fertility, health and productivity revealing problems that required state or private philanthropy intervention. Books targeting literate populations.	
	Urban medicine Eighteenth and nineteenth centuries.	Social body seen as sick. Surveillance and policing of the poor seen as a source of disease and contagion (illnesses in the physical environment) and a threat to national vitality.	Sanitary science.	
	Labour force medicine Nineteenth century	Surveillance and administration of the poor and the workers to maximise productive capacities.	Control of vaccination, organisation of records of epidemics and diseases, mandates to report dangerous illnesses, localization/intervention of unhealthy places.	
	Social surveillance Twentieth century	Aims at producing worthy citizens.	Understanding interpersonal norms of transmission and prevention of bacteria-transmitted diseases. Overseeing and engineering the overall health of populations.	

Table 1 Summary of evolution of social medicine

Through a gradual process which began in the eighteenth century sanitary sciences, domestic hygiene and medical hygiene became a product of ‘new’ disciplines through which biopolitical authorities sought to shape the practices of populations. Later, collections of risk factors were gathered through epidemiological data which encouraged surveillance of ‘at risk’ populations as a preventive measure. Risk at this point was considered not at an individual level but at the level of population. Parents, doctors and teachers were part of surveillance networks of children, especially of those at risk (Nadesan 2011).

Early in the twentieth century the family was governed less by overt political power than in the name of moral principles and by professional expertise. In Mexico these moral principles were promoted by the *science of puericulture* (Stern 1999) or child development which emerged from the eugenic movements in Mexico and many countries around 1920. Women were deemed by the state as the most appropriate to nurture children through educating girls and women in aspects of hygiene, nutrition, and health. These practices still prevail, not only in programmes like *Oportunidades* but in hospitals through ‘talks’ as seen above (Smith-Oka 2015) and in schools (Gómez 2012). Concerns about hygiene that underlie power and control will be examined in Chapter 4.

2.5 Conclusions

Pre-term or premature babies carry in their very name a stigma of immaturity and of being out-of-place. In addition, studies that portray them as an at-risk population, and developmental theories that consider them in the process of becoming mature, discourage consideration of them in their own being, as sentient human beings and persons.

The ‘children’s needs’ discourse (Woodhead 2015) that is sometimes used to justify the implementation of projects (sometimes with hidden agendas, such as *Oportunidades*) add to a representation of children as vulnerable and in need of protection and women as solely responsible to fulfil those needs. This prevents us from considering how babies and young children take part in their own healthcare (Alderson et al. 2006).

Als's theory begins with considering babies' biological development but it moves forward to looking at preterm, ill term babies as active participants in the baby unit. I think it opens the door, alongside childhood studies, to see how babies and adults can co-construct alternatives in care which are more respectful of babies' bodies and feelings and complex needs.

The next chapter will show more on how childhood studies and Als's synactive theory have informed the methodological aspects of this research.

Chapter 3 Methodological Approaches

3.1 Introduction

The purpose of this chapter is to outline the philosophical framework (methodology) and research techniques (methods) followed for this research.

This study is underpinned by a critical realist perspective. Ontologically, it recognises an independent reality of events, while epistemologically it acknowledges that access to such reality might be partial and subject to error. The research has been ethnographically informed. Research design consisted of a mixed method approach, predominantly qualitative, with an embedded study of two cases: MDH and JDH; both located in Mexico.

The chapter is divided in eight sections. Section 3.2 begins by reviewing different ontological and epistemological positions that influence researchers' approach to the object of study. It describes two traditional paradigms in research: positivism and interpretivism. In this section I draw on strengths and weaknesses of both approaches and begin to explain why I chose not to adhere to either of them.

In section 3.3 I state my stand as researcher within the critical realist perspective: I explain how I believe CR integrates and surpasses empiricist and interpretivist approaches and I define some of the features that underpin this research philosophically.

The research design is outlined in section 3.4. It describes an evolving process from which the research questions emerged, the choice of case study as a research strategy and ethnography as the encompassing form of collecting data is justified. This section also portrays the two cases of study: JDH in Estado de Mexico (outskirts of Mexico City) and MDH in Puebla City (adjacent to Mexico City).

Section 3.5 gives a general view of the fieldwork time. Ethics procedures are described in section 3.6. Data collected are described in section 3.7. The mixed-method design,

predominantly qualitative, consisted of: a survey with staff in both hospitals (111 returned questionnaires); interviews with 34 staff members; interviews with 29 parents (20 mothers and 9 fathers) from which I had at least one follow up interview with 18 (16 mothers and two fathers), this included a focus group with fathers; observations of 29 babies during different episodes; participant observation were recorded in field notes; systematic measurement of noise levels (dB) and examination of documents.

Section 3.8 describes the process of analysing data. While keeping research questions in mind, an iterative process of reviewing data and literature led to creating several categories which were then condensed into three themes: hygiene, dignity and well-being. CR concepts of *four planar social being* and *MELD* were used to organise data.

3.2 Methodological approach: philosophical assumptions about the social world

In attempting to understand how the social world might be studied, a number of philosophical questions arise. It is inevitable then to define ontological and epistemological assumptions about the world (Ormston et al. 2014). Ontological assumptions have to do with the nature of the reality being investigated, epistemological assumptions are related to the knowledge and interpretation of phenomena.

This section will briefly review different approaches to these philosophical concepts.

3.2.1 Ontology

Ontology is concerned with the nature of what exists. The main ontological concern when doing research is whether there is a reality out there, independent of the researcher's possibility of accessing it, or whether reality is always context and perception specific. These two mutually exclusive ontological positions are known as realist and idealist (Blaikie 2007).

Realism considers that reality exists in the world independently of human conceptions or perceptions. Nonetheless how accurately human beings can access it is still a complex

matter. Variants of realism, summarised by Ormston and colleagues (2014, p.5) include the following.

Naive or shallow realism, in which reality can be observed directly; *cautious realism* acknowledges reality might not be accurately observed; *subtle realism* asserts that only through the human mind and socially constructed meanings can the external reality be accessed, *materialism*, a variation of realism, asserts that reality is formed by the independent physical structures and economic relations of a material world.

Another variant of realism is *depth realism* (Blaikie 2007) or *critical or transcendental realism* (Bhaskar 2008a) which contends that reality consists of three levels. The first, empirical, is accessible to humans through experience. The second level, actual, exists independently of humans' experience of it. Processes and mechanisms that have real effects take place in the third level of reality.

Idealism on the other hand contends that reality has no independent existence from our thoughts (Blaikie 2007) beliefs or understandings (Ormston et al. 2014), this is, 'the external world consists of representations that are creations of individual minds' (Blaikie 2007, p.16).

Blaikie (ibid) identifies categories that fall in two extremes. *Atheistic idealists* reject the existence of an external world while *perspective idealists* believe that the construction of reality responds to different forms of perceiving and interpreting the external world. Other variants identified by Ormston and colleagues (2014, p.5) include: *collective idealism* in which the context mediates the representations of the social world constructed by groups of individuals and *relativism* in which the social reality is formed by individual, rather than shared constructions.

In short, social reality from an idealist approach is formed by meanings and interpretations, either individual or shared, created and reproduced by human beings as social actors but without an independent reality (Bhaskar 2008a).

3.2.2 Epistemology

Epistemology refers to our knowledge of the world. Here I describe two traditional paradigms that have influenced researcher's approach to understanding phenomena.

Positivism

Positivism can be traced back to Francis Bacon (1561-1626) and later to the work of Auguste Comte (1798-1857), when they both referred to 'positive science' (Crotty 1998). Positive science refers to the method of arriving at knowledge through direct experience as opposed to speculation (although Bhaskar (2008a) argues, experience involves interpretation and speculation, which are mediated by reasoning).

'Rather than proceeding via some kind of abstract reasoning process, positive science proceeds by a study of the 'given' (in Latin *datum* or, in the plural *data*)' (Crotty 1998, p.20 original emphasis).

Concerned about the well-being and re-organisation of society, Comte embraced the scientific method; laws, he believed, could be scientifically established through observation, experiment and comparison both in the natural and social sciences (ibid). Within this view, facts can be verified through experience and need to be separated from values.

Ontologically, positivists believe there is a concrete reality that can be (epistemologically) measured, and, although its philosophical grounds have evolved (for example in post-positivism), 'it continues to form the paradigmatic basis for much health research today.' (Broom & Willis 2007, p.19).

As a researcher I recognise the value in positivism. Studies based on this approach have influenced and informed my study (see for example Carbajal et al. 1999; Bellieni & Johnston 2015; Holsti et al. 2008).

However, I also find some problems when adhering to this perspective. I will briefly mention these here although I will elaborate on them further throughout section 3.3. The complications I identify within a positivist paradigm are: the assumption of a constant reality (seen in the regularities from which laws develop) that can be abstracted from real life (as in randomised controlled trials) in which ‘objective’ facts are separated from values. Moreover, a positivist or more broadly an empiricist paradigm would only allow me to research phenomena that are accessible through sensory experience. This risks resulting in ‘shallow’ research that accounts only for superficial effects as identified but not analysed by the researcher.

Interpretivism

The interpretivist paradigm echoes ideas developed by, among others, Immanuel Kant (1724-1804) who argued for alternative forms to learn about the world, other than direct observation. Kant’s ‘transcendental idealism’ model goes beyond the empirical enquiry and realism. Understanding of social phenomena then is based on ‘interpretation’. Subsequently Wilhelm Dilthey (1833-1911) emphasised the importance of social and historical context in order to ‘understand’ people’s lived experiences. Expanding on Dilthey’s ideas, Max Weber (1864-1920) proposed ‘that the researcher must understand the meaning of social actions within the context of the material conditions in which people live’ (Ormston et al. 2014, p.12). Weber’s anti-positivist *Verstehen*, literally understands or stands in the actors’ position to see the world from their perspective and regard them not as objects but as subjects of research. Ontologically, interpretivists believe that social reality is the result of actors’ (epistemological) perceptions and interpretations; as such, it is not independent from the researcher’s understandings and it cannot be value free.

Interpretivism might be a better alternative to positivism when researching people’s lived experiences, which is partly what I intended to do with the current study. Once more, I have to acknowledge studies using this perspective that have been valuable for my work (see for example Sweet 2006; Spencer et al. 2015). During my research I listened to people and observed events, which I have interpreted. I have also observed

babies and given meaning to their actions (using my epistemological knowledge of baby behaviour). However, would it be fair for me to say that babies' physiological condition, pain or suffering in the NICU are only a construct of my mind as researcher?

As a summary, I draw on Henn and colleagues' (2009) overview of both paradigms:

The empiricist approach has been more related to the natural sciences, researchers in this field need to have control of identified variables and they focus on phenomena that can be observed and measured. The methods to collect information tend to be of quantitative nature such as experiments or surveys, and generalisability and reliability are main concerns. In contrast, the interpretivist approach has been more related to social sciences, researchers in this field seek to understand interpretations and meanings that people give to events and also some of the factors that underlie human behaviour. The methods to collect information are more of a qualitative nature such as observations or in-depth interviews, and validity is a main concern.

3.3 Critical Realism: an integrating approach

I see critical realism as an alternative when undertaking research, which combines some characteristics from empiricism and interpretivism. Moreover it moves beyond and helps us resolve some of the methodological problems I described in the section above. Some characteristics from critical realism that I find useful for this research project are the following.

1. It differentiates between being and knowing

Three principles are the basis of critical realism: *ontological realism*, *epistemic relativism* and *judgemental rationality* (Hartwig 2007, p.238; Bhaskar 2008a; Bhaskar 2008b).

Ontological realism refers to the assertion that there is a reality in the world independent of our knowledge or perception of it. This allows to overcome two problems posed by

both positivism and interpretivism: the former claims reality can only be accessed through empirical observations; the latter argues reality exists only through our interpretations and the meanings we adhere to our perceptions.

Critical realism overcomes these problems through the concept of the *transitive and intransitive* dimensions. *Intransitive* objects of knowledge are ‘the real things and structures, mechanisms and processes, events and possibilities of the world’ (Bhaskar 2008a, p.22). They exist independently of our awareness of them. Some of these objects can be identified by their *causal effects* (for example, magnetic forces). *Transitive* dimension refers to ‘antecedently established facts and theories, paradigms and models, methods and techniques of inquiry available to a particular scientific school or worker’ (ibid, p. 21).

Thus, in response to positivism, critical realism posits that intransitive objects of knowledge are real though not always accessible through our empirical observations. In response to interpretivism, it asserts that real events are more than our mental construction of them.

Epistemic relativism means that our knowledge of intransitive objects is constructed or interpreted depending on the theories and paradigms we adhere to, and it is also partially subject to scientific discovery. Therefore it is temporal, changeable and subject to error.

Judgemental rationality within applied research refers to the choice of methods and theories that inform all aspects of study. I believe it also refers to the understanding that I, as researcher, need to maintain a reflexive attitude about how my own set of values and beliefs have an impact on the process of data collection and interpretation of events.

This allows me to begin to address my question in the previous section: would it be fair for me to say that babies’ physiological condition, pain or suffering in the NICU are only a construct of my mind as researcher?

Babies' responses to different events in the NICU might reveal some of their feelings. As a researcher I might or might not be able to see and record their reactions. My interpretations of those reactions will be based on my previous knowledge about babies' behaviour and also by my personal beliefs (values) about babies as people (epistemological relativism). My interpretations will also be influenced by the techniques I have chosen to do my observations (judgemental rationality). This means my interpretation will always be partial and subject to error, let alone because babies cannot use words to describe their experiences. However, neither my capacity nor incapacity to record babies' responses, my knowledge about behaviour, my values nor my research techniques make those experiences more or less real (ontological reality).

Another form to explain it is through the concept of the *epistemic fallacy*, a common mistake in research. Positivists commit this when they treat data contained in statistics or graphs (interpretation and thoughts) as a mirroring image of the lived reality of research participants. Interpretivists, since Descartes, fall into the fallacy when they think being can only exist through our thinking.

2. Critical realism allows for the possibility of naturalism

The positivist tradition has been more related to research in the natural sciences. As mentioned above laws are generated through the identification of regularities (constant conjunction of events). In contrast, the interpretivist tradition tends to be connected to investigating about social relations.

Randomised controlled trials tend to be regarded as the highest standard of evidence of an intervention. They are very popular methods in medicine and they have certainly been useful to advance our knowledge about babies' clinical condition and the success of an intervention (see for example Mörelius et al. 2015). Variables need to be controlled in order to undertake these type of experiments. In other words, scientists need to create *closed conditions* in order to suppress some mechanisms and activate others. This might become problematic in places such as an intensive care unit, where

controlling for variables such as ‘timing’ of the intervention (some patients being sick for longer than others) is difficult (Vincent 2010).

The case of ‘developmental care’ in neonatology stands out; baby-led developmental care involves a collection of practices (such as light and noise modulation, baby positioning, prolonged periods of rest, and many others) that minimises stress in the NICU. However, research in closed systems tends to analyse a single intervention and therefore developmental care as a collection of individual practices has not been researched through thorough trials. This is exemplified in Cochrane Review by Symington and Pinelli (2006, p.2) where the authors conclude that: ‘because of the inclusion of multiple interventions in most studies, the determination of the effect of any single intervention is difficult’, although limited, there is evidence of benefit of developmental care overall and ‘no major harmful effects reported’, therefore more evidence is needed. Developmental care practices represent more gentle and humane care for treating babies and randomised controlled trials are expensive and take time. The case might be raised to question how much more evidence is needed to change practices that cause distress when a safe alternative is presented.

Critical realism argues there can be unity though not uniformity in the methods of the natural and the social sciences (Bhaskar 1998), however in social inquiry events cannot be isolated in *closed systems* (like experiments in a laboratory) in order to identify causal laws. Instead, the social world takes place in *open systems* where different causal (but sometimes unperceivable) mechanisms compete.

Initially, the main aim of my research was to understand under what circumstances baby-led practices could be implemented in Mexican NICUs. One possibility was to make an experiment: design a set of interventions to prove a hypothesis and analyse what happened when implemented (positivist and empirical approach). However, through the review of literature, and also from my previous experience, I concluded it was important to understand first what people (health professionals and parents) thought about this, to address their fears, concerns and different constraints. A second option then was to address peoples’ perceptions (interpretative approach). But then, I thought,

constraints could be the result of events at the level of structures such as socio-economic, cultural, and others that I did not understand at the time.

In other words, I needed to identify the *mechanisms*, at the level of structures, which resulted in certain forms of organisation in the healthcare system in Mexico that cause babies to be cared for in certain forms and not others.

The methodological way through in critical realism is *retroduction* which allows to infer the underlying causes of events at the empirical level, this is what Bhaskar (2008b) means by the Eureka moment of discovery.

Analysis at the level of structures needs deeper insights. Critical realism opens the path because:

3. It argues for depth in reality

For a critical realist not only is ontology real, it is also *stratified*. Bhaskar (2008a) proposes three different levels to look at reality:

- a) The *empirical*, in which events can be ‘experienced’ through our senses. In my study this would refer to babies’ responses; for example a subtle change in the colour of a baby’s skin.
- b) The *actual*, refers to the event as it happens, that I might only be able to experience partially. For the baby this event happened in a specific moment, under specific circumstances that I as observer might not be able to access in its entirety.
- c) The *real*, (but in many cases not available through our senses) mechanisms that cause events to happen. The change of colour in the skin might have been caused by a drop in the levels of oxygen in the baby’s blood (at a biological level).

Events that occur at the third and deepest level c) are real because of their causal effects (seen at empirical level) which entails movement and change (Bhaskar 2008b).

The examples I provided are simple (for the sake of being clear) and refer to a physical dimension. However the levels of the empirical, actual and real are true for events in the natural and social world.

The *retroductive* process entails responding to the question: what would the world need to be like for this to happen? This is known as *natural necessity*.

Emergence

Stratification in the world can also be explained through the concept of *emergence* (Bhaskar 2008a, p.113) in which ‘some substance, entity, property or system ... is dependant for its existence upon some other substance, entity, property or system’ (Hartwig 2007, p.166). For example, a baby’s consciousness emerges from the brain which emerges from the body but cannot be reduced back into it, although all three levels constantly interact; the higher level (consciousness) cannot be reduced back to the lower ones (brain and body) nor can it be explained or predicted by them.

Four planar social being

So far I have explained that reality as a critical realist concept has depth and is stratified. I would now like to add that it is also differentiated. This can be exemplified with the concept of *four planar social being* which works as a *laminated* system.

Bhaskar (2008b) asserts social events take place in four different dimensions, which are represented in figure 2.

On **plane one** of *material relations with nature* are all transactions that we, as embodied organisms, have with the material world. **Plane two** of *interpersonal interactions* is concerned with individual and group interactions. **Plane three** of the *social structures* refers to agency/structure relations. **Plane four** of *inner being* looks at the stratified personality, subjective agency and the possibilities of flourishing.

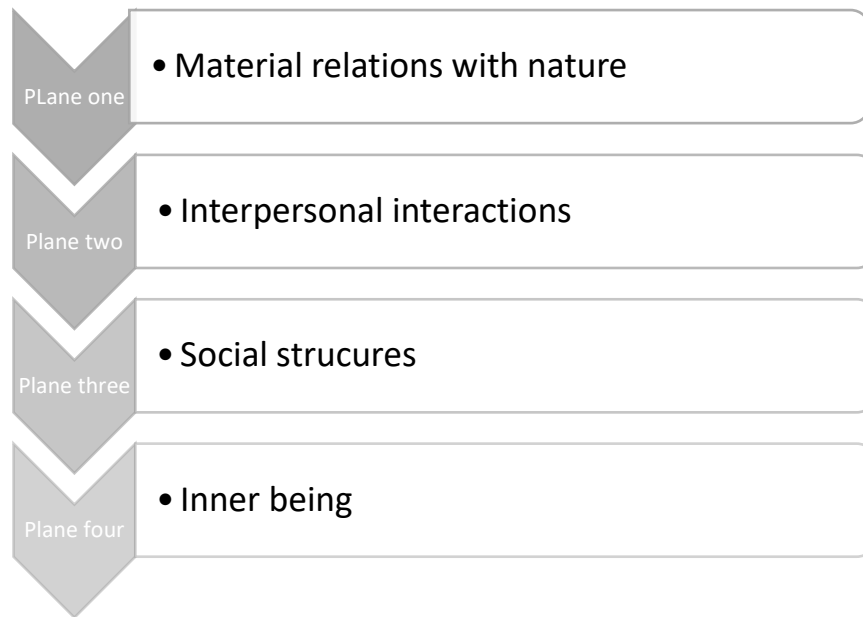


Figure 2 Bhaskar's four planes of social being

Four planar social being helped me to organise data in Chapters four (of moral and physical hygiene) and five (of dignity), this is because I was interested in exploring the concepts of hygiene and dignity within different aspects of being in the NICU.

Bhaskar uses different forms of laminated systems. For example, Bhaskar and Danermark (2006) looked at the physical, biological, psychological, psychosocial, socio-economic, cultural and normative levels in order to research disability. This is represented in Figure 3.

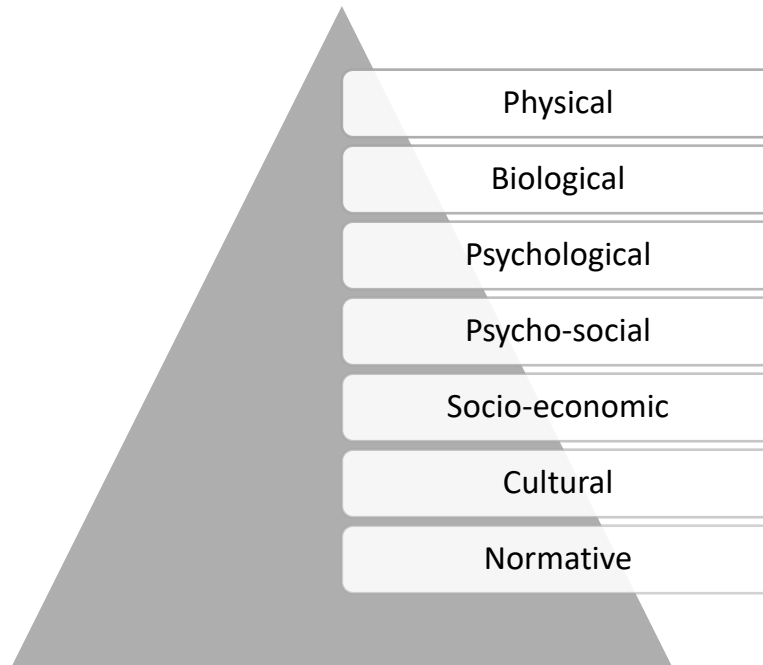


Figure 3 Bhaskar's and Danermark's seven-level laminated system

I used this laminated system to look at absences in caring for babies at MDH and JDH at different levels from the physical to the normative. This laminated system was embedded in the MELD scheme that I explain below.

There is one more feature that I recognise critical realism might contribute to my work which I review next.

1. Critical realism argues for transformational change

So far I have described concepts of basic critical realism. In a further move, the four moments of dialectical critical realism (DCR) known by the acronym MELD represent a process towards the resolution of inconsistencies and contradictions that lead to transformational change (Bhaskar 2008b).

MELD

In a first basic step we need to define the object of study (ontology) as differentiated (transitive and intransitive), independent of our knowledge but at the same time recognising that ontology encompasses knowledge. It involves identifying and differentiating the empirical (sensed events), actual (events) and real (causal mechanisms). As such, it involves the concepts of stratification and emergence (Bhaskar 2008b, p.237).

1M (Moment)

This first moment (1M) is compatible with ethnographic and especially anthropological research, in which the observer maintains a reflexive attitude in order not to impose her own views and preconceived ideas but makes an effort to apprehend and understand what is being observed. IM also considers underlying possibly hidden causes of observed events.

2E (Edge)

The next move in the MELD scheme is negativity at the second edge = 2E. Negativity can be better understood in the concept of absence. For Bhaskar absence is the key to change because '[v]oids are necessary for motion, and motion necessary for causality and hence change over time (transformation)' (2008b, p.239). Absence is the 'pulse of freedom', what moves agents to want to absent their ills, lacks, constrains, oppression.

2E seeks to resolve the problem of *ontological monovalence* (the idea that reality can only be seen in the positive/present), because this leads to *actualism* (Norrie 2010), the idea that there cannot be change in the world. For Bhaskar, absence is a process of change and not only of differentiation since it involves *becoming* (future possibilities) and *begoing* (past absences), therefore it is bounded in space and time.

Absence is a very important concept for my research. Absence has causal effects, for example, in how healthcare services are organised from an adult-centric perspective and might give rise to oppressive power₂ master-slave relations. But absences is not always

negative and they are necessary in the world; the aim of medical treatments, for example, is to absent illness; which leads to well-being (in health at least).

3L (Level)

The next level in MELD is 3L = totality, which sees ‘the parts’ in ‘the whole’. The objective of this third moment is to see how those parts are interconnected. However Bhaskar also recognises there are moments in the process of investigation when ‘it is essential to disconnect, separate, distinguish and divide’ (2008b, p.270). Totality, therefore also includes *differentiation* and *diversity of unity*. Whereas 2E can involve active intervention, 3L like 1M can involve stepping back to observe, this time possibly to see a larger view of action at 2E.

Totalities, according to Bhaskar (2008b) are partial: they are formed by internal relations but also by external ones. Characteristics of totalities are the interactions of shared universal properties of an entity with each unique identity-in-difference identified in the *concrete* ↔ *universal singular*.

In a totality the whole is formed by component parts which interact with each other (and therefore impact each other), in interacting with each other they also impact the whole but at the same time the whole impacts (causally determines) them. This is what Bhaskar calls *holistic causality*.

In the case of this study we could think that each one of the research sites is a totality. Each one of those totalities have external interactions with other totalities (other hospitals, the healthcare system, political and national and international socio-economic structures). The *concrete* ↔ *universal singular* is seen in all the people (universal) that interact with each other (as unique or singular). Those interactions have an impact on each other and on the hospital as a whole, but the hospital as structure also causally determines each individual.

The third moment of totality

‘encompasses such categories and themes as reflexivity, emergence, constellationality, holistic causality, internal relationality and intra-activity, but also detotalization, alienation, split and split-off, illicit fusion and fission.’ (Bhaskar 2008b, p.392)

4D (Dimension)

Finally, the fourth dimension = 4D is known as *transformative praxis*. This is another active moment when real change, freedom, flourishing and transcendence occur through creative power¹. Scientific discovery, for example, takes place when absences are absented through intentional agency (Bhaskar 2008b; Norrie 2010)

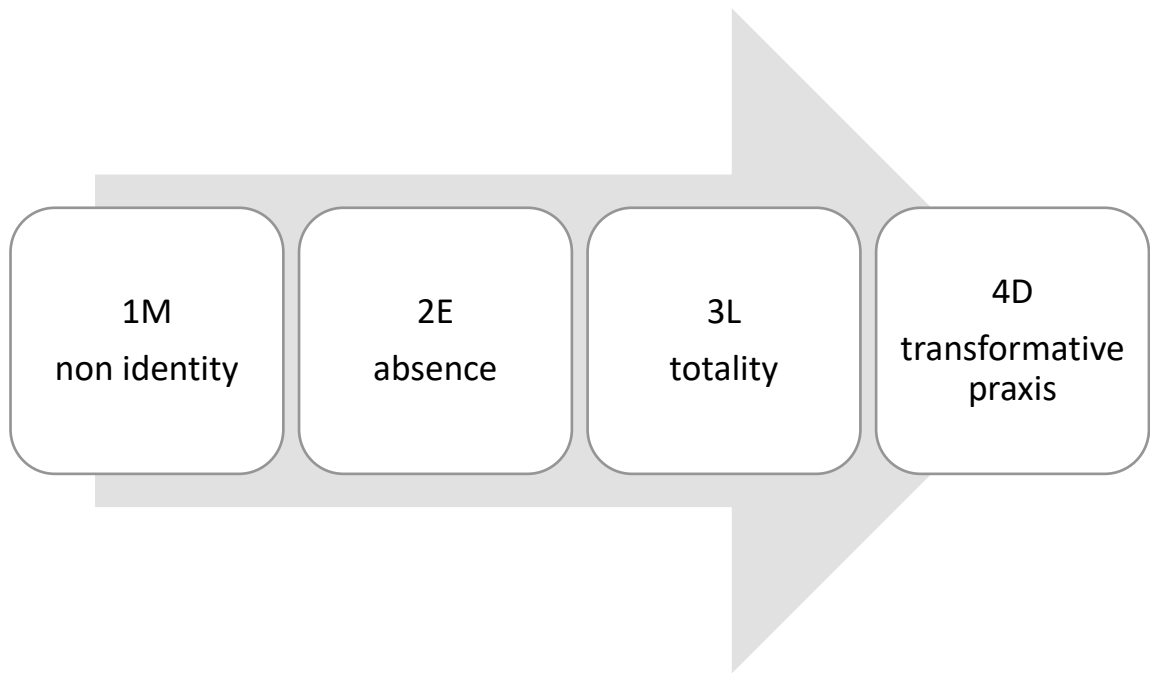


Figure 4 Bhaskar's MELD scheme

One specific objective in this research project is to identify possibilities of change towards baby-led care, that is, **the mechanisms that need to be put in place** so that the being of babies in hospital is recognised and can be kept at the centre of neonatal care. I argue, this would allow neonatal units to work in *unity-in-difference*, where it is

recognised that each individual (baby, parent and staff member) is unique and has needs but the well-being of the whole is paramount.

I used MELD as a 'lens' to look at data in Chapter six. Chapter six is about well-being, which I consider to be an evolving process in human life.

Concepts of critical realism will be explained further in my analysis chapters, where I hope I can show how I have applied them. All CR terms will be distinguished with italics throughout the rest of the thesis.

3.4 Research design

After having reviewed the different ontological and epistemological assumptions and situated this study within the critical realist perspective I proceed to describe the design of the study.

3.4.1 The study main aim and research questions: an evolving process

In the introductory chapter of this thesis I presented the overall aim of this research project: **to understand why preterm babies in Mexican hospitals are cared for as they are.**

Specific objectives:

- To examine beliefs and perceptions about babies' strengths and sensitivities in the NICU.
- To examine beliefs, perceptions and current practices of parents' participation in the NICU.
- To explore how hospital organisation, local healthcare policies and the socio-economic context impact on current practices of caring for babies in Mexico.
- To identify possibilities of change towards baby-led type of care.

The research was initially influenced by my experience as a volunteer in a neonatal unit in Mexico (in City Hospital) and by ideas about developmental care (Ohlinger et al. 2003) and family centred care (Shields et al. 2006) that I learned in St. Mary's hospital London, where I was research assistant in a project to validate a scale that evaluated strategies to reduce pain and stress in the NICU (Warren et al. 2016).

Aita and Snider (2003) identify three attributes of developmental care: *reciprocal interaction* between the baby and carers, *individualisation of care* (adapted to each baby) and an *evolving process* of care that is informed by assessment and evaluation of babies' developmental needs. Although a focus on reciprocal interaction places the baby at a social level (like Als's theory), the emphasis on 'babies' developmental needs' risks a reduction of the baby at an embodied biological level. So called developmental needs (readiness to suck or attempts to sleep for example) might be identified by a trained observer in babies' responses. Nonetheless the observer's epistemological stand will influence interpretation and give meaning (in this case developmental need) to babies' actions. For this reason I find it to be a restrictive concept.

I find the term family centred care equally problematic. It encompasses communication, shared information and support to parents, among many other components. These are extremely important because the baby is indeed a member of a family and needs to be recognised as such at all times. But then again, it is not the family who needs to be placed at the centre of care; it is the baby and the highest standard of care (which includes the family) that need to remain central through all processes in the NICU.

The term 'baby-led practices' as I am using it here encompasses developmental and family centred care but moves beyond them. This thesis is baby-led to the extent that I tried to keep babies from the two research sites at the centre (in many cases I had to do this through drawing on parents' and staff members' descriptions of babies) and through integrating concepts of rights and dignity. I argue, a critical realist stand point allows me to assert that babies' feelings and experiences of being in hospital are real but cannot be directly accessed.

These ideas shaped three of my specific objectives, which evolved from a FCC and DC perspective to a baby-led care perspective:

- To examine beliefs and perceptions about babies' strengths and sensitivities in the NICU.
- To examine beliefs, perceptions and current practices of parents' participation in the NICU.
- To identify possibilities of change towards baby-led type of care.

Ideas, perceptions and beliefs influence our actions (Mannheim 1936). They are real in so far they have *causal effects*. In critical realism *causation* means the generation of effects. They are like hidden forces such as magnetism, unseen but real and powerful.

Understanding the underlying assumptions and ideas about babies and about parents in the intensive care unit might allow identification of *absences* and *contradictions* in practice that, if *absented* (or removed), might lead to change.

To advance the argument, both childhood studies and CR made clear that different structures needed to be considered in order to understand how these impact on the organisation of the healthcare Mexican system. For example, in looking at inter-generational relations between children and adults Mayall (2000, p.248) observes that 'how children live their childhoods looks heavily structured by what adults want of childhood' and she goes on to note that, in the schooling system, 'children's days are largely controlled by adult agendas'. I find a similarity in the healthcare system, where the children's 'bests interests' are sometimes used as rhetoric to protect adults' interests. Using a laminated system, such as four planar social being (explained above), the relationships between structures (such as healthcare system) and agents (doctors, parents and babies) become clearer.

The transformational model of social activity (TMSA) in critical realism is useful in order to look at these agency/structure dynamics. CR sees society as a necessary condition of human activity. That is, people do not invent society or the structures within

it but over time they do reproduce and transform them in their day-to-day activities (Bhaskar 2008b).

As shown in the introductory chapter, the Mexican political and socio-economic context includes structural reforms that can be situated within neoliberal policies, besides continual upheaval and threats to services for disadvantaged Mexicans.

One more specific objective was added to this research as my understanding of CR evolved:

- To explore how hospital organisation, local healthcare policies and the socio-economic context impact on current practices of caring for babies in Mexico.

3.4.2 Research questions

The research questions that followed from specific objectives are:

1. What are the beliefs and perceptions about babies in the intensive care unit and how do these impact on healthcare practices in the research sites?
2. What are the beliefs and perceptions about parents in the intensive care unit and how do these impact on healthcare organisation in the research sites?
3. How do wider socio-economic structures impact on healthcare organisation in Mexican hospitals? And, how does this organisation affect staff, parents and babies?
4. Under what circumstances can baby-led practices be implemented in Mexican hospitals?

3.4.3 Case study as research strategy

The main aim of this study is to understand why babies in Mexican NICUs are cared for as they are, this implies an in-depth exploration of the phenomena. A case study design seems to be adequate for such exploration (Yin 2009). Some elements of case study approach that make it a suitable strategy to be used for this research are:

- a) An explanatory case study helps identify real but unseen structures, identify patterns and develop explanations (ibid).
- b) It focuses on the phenomena in the real context (Robson & McCartan 2016)

In relation to element a) critical realism proposes that underlying mechanisms that produce phenomena might be accessed through *retroduction*.

Real context (element b above) is seen in critical realist terms as activity that takes place in *open systems* within the *structure/agency* and *TMSA* interactions.

An in depth exploration allows me to grasp the uniqueness of each case and, at the same time, to identify mechanisms at deeper levels of reality that could help make more generalizable theories or explanations.

The ‘progressive’ nature of case studies (Stake 1995) allowed for an evolving process that lead to the final research questions.

Defining the cases

Gillham (2000, p.1) defines a case as:

‘a unit of human activity embedded in real world; which can only be studied or understood in a context; which exists in the here and now; that merges in with its context so that precise boundaries are difficult to draw.’

Initially I planned to undertake this study in three Mexican hospitals (each of them a case), my intention was to maximise opportunities to learn from each case in their uniqueness (Stake 1995). However, I only got access to two of them (JDH and MDH) at the time that my field work was planned to begin. I now explain the reasons for having chosen them.

When babies are very sick, it might be difficult for nurses or doctors to see how they can safely incorporate baby-led practices. How accessible a hospital is (in terms of its

location and availability of public transport), adequacy of facilities and availability of economic resources also influence practice. I wanted to compare sites that provided different level of neonatal care, with different type of facilities and in different geographical locations. In short, I looked for hospitals that allowed me to look at contrasts (Stake 2003).

I identified hospitals in Mexico that might be suitable cases. I contacted three hospitals in Mexico City which provided subspecialised (level III) neonatal care (City Hospital described in the introduction was included), with the hope that at least one of them would accept invitation. I also contacted one general hospital (level II) in the outskirts of Mexico City and one tertiary level (sub-specialised care) hospital outside Mexico City.

Flyvbjerg (2006, p.229) points at the ‘strategic selection of cases’ that might lead to ‘clarify the deeper causes behind a given problem and its consequences’; this cases might not be the ‘typical’ or most representative, atypical or extreme cases might prove richer in information. The level II hospital I approached (JDH) was located in a very problematic area in the periphery of Mexico City (probably an ‘extreme case’). The tertiary level hospital outside Mexico City (MDH) served a very wide area; service users came from remote villages, and experienced different problematics than the people living in or close to Mexico City. Finally, the level III hospitals in Mexico City attended the most critical cases and had a very good reputation as teaching hospitals, a good opportunity to see ‘leading neonatal care’.

Accessing the sites

Access to the sites took much longer than envisaged and proved to be a very bureaucratic process, especially in the hospitals located in Mexico City. Initially, invitation letters were sent to the Research Committee in each hospital via a personal contact, either a doctor or a nurse (all Mexican hospitals require to have an internal investigator who submits the protocol for revision). This took place by the end of my first year of PhD studies, while I was still in London, except for the hospital outside

Mexico City (MDH) because I had not been able to make contact via email. The following table describes the process of accessing sites:

Hospital	Research protocol submitted by:	Outcome
In Mexico City level III	Nurse	Declined after six months: a nurse was not considered to have the level of knowledge required to be the internal investigator for this research project.
In Mexico City level III	Nurse	An invitation to re-submit protocol was sent after 18 months (fieldwork was already finished by this time) due to re-organisation of Research Committee.
In Mexico City level III	Nurse	No reply. (This was City Hospital, management had changed, there appeared to be no interest in following up previous project)
In Estado de Mexico	Doctor (paediatrician)	Protocol accepted, process took around five months.
In Puebla City level III	Doctor (neonatologist)	Accepted. (This hospital was approached when I arrived to Mexico, protocol accepted within weeks)

Table 2 Accessing research sites

By the time my fieldwork began I decided not to continue trying to access a third hospital but rather to focus on the hospitals I had secured. This study of cases is considered *instrumental* given that the hospitals ‘play a supportive role’ in order to access the human interactions that take place within the neonatal unit (Stake 2003, pp.137–138).

Estado de Mexico and Puebla, where JDH and MDH are located respectively, are contiguous states in the Mexican Republic, commuting from one site to the other took approximately two hours and a half. Since my family lives in Puebla, I decided to have my residency there and I visited MDH twice or three times a week. I commuted to Mexico City once every week or every two weeks and spent one day at JDH. Appendix 1 shows some excerpts from field notes on the insecurity when travelling to JDH and the decision to visit every two weeks.

I now briefly describe the context of both sites, a more detailed description of each neonatal unit is provided in the following chapter.

3.4.4 Description of research sites

Juan Dautt Hospital (JDH)

JDH is a secondary level unit (a general hospital that provides specialised care) from the *Instituto de Salud del Estado de México*⁹ - ISEM (Health Institute from Estado de Mexico); it belongs to *Nezahualcoyotl* Delegation.

The NICU in JDH has a capacity for 8 babies and the intermediate (or special care) unit a capacity for 12 babies. When needed, extra spaces for babies are improvised in the surgery recovery area. Approximately, 47 nurses and 7 doctors are in charge of patients from the two units, covering six shifts. The most common cause for newborns admission is prematurity. In 2013 there were 4844 babies born at JDH. I was not able to access mortality rates from this hospital given that managers refused to reveal them.

This hospital not only serves families from *Ciudad Nezahualcoyotl* but also from other nearby communities. Estado de Mexico is the most populated area in the country, in

⁹ Estado de Mexico is one of the 31 estates which, along with Distrito Federal (also known as Mexico City), form the Mexican Republic. It is in the central area of the country and it surrounds Mexico City.

2010 with over 15 million, from which over 7 million are women. The fertility rate in the area is 2.3 children per woman on average (INEGI, 2010).

Mercedes Duron Hospital (MDH)

MDH is a tertiary (sub-speciality) level referral hospital, administered by *Secretaria de Salud del Estado de Puebla* (Health Ministry of Puebla State)¹⁰. It is a maternity unit that serves women and children from the different rural and urban regions within the state. Over 5 million people lived in Puebla in 2010, from which approximately 27% were women aged between 15 and 29 years old who, on average, had 2.5 children (INEGI 2010). People who came to this hospital travelled for up to five hours. Being a referral unit, the obstetric demand is large and complex; the main cause of babies' admission is prematurity.

Neonatal care is divided into three main areas: intensive care (17 beds), intermediate care (50 beds) and growth & development (15 beds). Because of high demand it is common that more cots for babies are improvised in recovery areas. Approximately 42 nurses and 8 doctors care for babies in the NICU only (in six different shifts), although managers recognise there should be at least 54 nurses in order to cover for absences. The ratio baby:nurse in the NICU is 2:1 and sometimes 3:1 only if there are no absences of personnel. In 2013 there were 6240 babies born in the hospital from which 1189 were admitted into the neonatal unit. Unofficially, I was told mortality rate in the hospital is one in four babies.

3.4.5 Doing ethnography

Through this research project I wanted to understand why preterm babies are cared for as they are in Mexican hospitals. I decided that understanding people's views and perceptions and the influence of wider structures (context) would be a first step in order to achieve this objective. The best form to understand the context was through observing

¹⁰ Puebla is in the centre of the Mexican Republic and is considered the fourth most densely inhabited state in the country.

events in the neonatal unit and other spaces in the hospitals. In order to address views and perceptions I needed to ask questions to people directly and then contrast the information collected against different forms of actions and interactions. An ethnographic approach seemed adequate because ethnography can be defined as:

‘a research process based on fieldwork using a variety of mainly (but not exclusively) qualitative research techniques but including engagement in the lives of those being studied over an extended period of time’ (Davies 2008, p.5).

Studies that have been done in the NICU using ethnography informed my choices (Anspach 1993; Alderson et al. 2004; Skene 2010).

Critical ethnography

Hammersley (1992, p.44) identifies two positions in ethnographic research that adhere either to a naïve realist or to a social constructionist paradigm. The former aims at discovering and representing ‘faithfully the true nature of social phenomena’, the latter poses that ‘people *construct* the social world, both through their interpretations of it and through the actions based on those interpretations’ (emphasis on original).

Both positions are problematic. A researcher who claims to have direct access to ‘faithful truth’ would not be taken seriously in today’s scientific world. I agree with Hammersley when he contends this position is in direct contradiction to one of the main aims of ethnography: to understand rather than to judge others’ perspectives. However, the second position from a social constructivist stand implies that a representation of the phenomena in question is not possible, the only possible outcome is a representation of the researcher’s construction; a version that has no more or less value than others’ versions of the problem.

Hammersley’s proposed alternatives to these positions are (ibid Chapter 3):

- a) There are phenomena that exist in our world even if we cannot access them directly;
- b) Our claims of such phenomena might be accurate or inaccurate, in this sense, our knowledge of them is relative;
- c) We have to assess claims based on plausibility, credibility and evidence provided.

Hammersley identifies this position with subtle realism, however these proposed alternatives are in line with the three principles of critical realism: a) *ontological realism*, b) *epistemological relativism* and c) *judgemental rationality* explained above.

Davies (2008) makes a call to maintaining a reflexive attitude when undertaking ethnographic research; to recognise it as a ‘political’ act given that the researcher has an interest in studying certain communities or selecting sites. Critical ethnography entails constant reflection of the links between underlying structures and events observed but also of the researcher’s Self as shaping and being shaped by the different events she encounters.

3.5 Fieldwork in Mexico at a glance

Table 3 provides a general view of fieldwork time in Mexico from June 2013 to April 2014.

June 2013	July-August 2013	September 2013	November 2013 – April 2014
<p>Finalising access to sites</p> <p>Forming a research team in each site and presenting the project to staff and parents.</p>	<p>Preliminary participant observations in the NICU.</p> <p>Five pilot interviews</p>	<p>Preliminary participant observations in the NICU.</p> <p>Administered survey: 111 questionnaires returned in total.</p>	<p>Analysis from surveys.</p> <p>Participant observation recorded in field notes.</p> <p>Interviews with 34 staff members.</p> <p>Interviews with 24 parents, from which I had at least one follow up interview with 18.</p> <p>Focus group with 3 fathers.</p> <p>Observations of 29 babies during different episodes of care.</p> <p>Systematic measurement of noise levels (dB) and examination of documents.</p> <p>Attended doctors' meetings, continuing education workshops in-site.</p>

Table 3 Fieldwork at a glance

3.6 Ethical procedures

Planning

This research project adhered to ethics guidelines provided by the British Sociological Association. Ethics approval was obtained from the (former) Faculty of Children & Learning in the Institute of Education (appendix 2) and from the ethics committee in both hospitals.

A thorough consideration of possibly troubling dilemmas was carried out before the fieldwork period, this included (but was not exclusive of): respect for intimacy in parent-infant interactions during observations, avoiding over-emphasising possible harm of separating parents and babies so as not to raise anxieties, avoiding raising high expectations when telling people about the hoped for benefits of this project.

I was aware that asking parents to talk about the difficult aspects of having a baby in intensive care could be distressing, I had an enormous responsibility in taking care of every stage of the interview, from preparation to closure (see for example Price & Nicholl 2013).

During fieldwork

The project was presented to all staff in the NICU of both research sites and leaflets (appendix 3) were handed in to parents at different times during fieldwork; this is because relevant aspects of the day-to-day practice in the units could have been recorded during participant observations and people needed to be made aware of that.

Information sheets and consent forms for parents (appendix 3, 4) and staff (appendix 5, 6) were carefully worded. All participants in interviews and focus groups received information about the project in advance, were given time to consider participating and were informed they could withdraw at any point in the research. Consent was obtained

from all participants either to be interviewed or for their baby to be observed, all of them received a copy of their signed consent form.

Data were carefully kept in a secure place. All names (hospitals, participants and babies) have been anonymised using pseudonyms. Confidentiality was considered paramount. I tried to be careful not to discuss subjects raised in the interviews with anyone else in the units. My role was not to corroborate that interviewees were reporting ‘the truth’ but to hear their experiences and learn from them. In some cases, this implied that it was difficult to contrast views of specific events (for example a discussion with a doctor reported by a parent).

I also took measures in order to protect my physical integrity as researcher, especially when I travelled to Mexico City. It was agreed with one of the doctors that I would let her know via text message when I was on my way to hospital and when I had returned safely back home.

3.7 Methods of data collection

A meeting was held in each research site to present the project to medical and administrative managers. Each site then appointed a small group of people who would assist with different aspects of the research, become key informants and act as ‘advisory committee’. The following table shows members of research team:

JDH	MDH
One paediatrician (acted as internal researcher)	One neonatologists (acted as internal researcher)
Two nurses (helped administer survey and took sound (dB) measurements)	Three neonatologists (helped administer survey)
	One (male) psychologist (lead focus group with fathers)

	Two nurses (took sound (dB) measurements)
Became key informants and act as ‘advisory committee’	

Table 4 Members of research team

3.7.1 Survey to staff

Surveys have been generally used for the study of beliefs, attitudes and values (Robson & McCartan 2016) and can help reach a wider amount of respondents. My intention was to begin to understand how staff perceived babies, parents, their own role and the environment in relation to the social life of the neonatal unit. Thus, I chose to administer a questionnaire as a preparatory phase which could help me plan further the data collection and semi-structured interviews to staff members.

Another reason for administering a survey is that I knew healthcare professionals from intensive care units tend to be extremely busy. I thought it would be useful to prepare a questionnaire as an initial exploration and do follow up interviews with a smaller group.

I also thought, if successful, this survey could be part of a wider study of Mexican NICUs in the future, because of this, it was decided that the administration of this survey in JDH and MDH would be a pilot.

Contents of the survey

The questionnaire (appendix 7) addressed five main areas:

- a. Perception about the different forms in which parents can participate in caring for their baby in the NICU.
- b. Perception about babies’ strengths and sensitivities.
- c. Perception of health professional’s role in supporting parents and facilitating parent-infant relationships in the NICU.

- d. Perception about the appropriateness of the physical environment and infrastructure in the unit.
- e. Space for change and improvements.

The questionnaire was originally written in English and shared with two healthcare professionals with experience on FCC programmes. Corrections were made following suggestions. It was then translated into Spanish by myself and shared with five healthcare professionals (two doctors and three nurses) to make sure the translation conveyed the same meaning as in English. Some semantic aspects were addressed. Subsequently it was shared with three mothers whose babies had been in hospital and who, at the time, advocated for FCC in Mexico. They had no further comments.

Confidentiality and anonymity of results were considered at all times during the survey process. I discussed with both advisory teams different options to administering them. We agreed it would be best if members of the team handed the questionnaires in person to the rest of the staff, many of them did not know me yet. The other reason for doing it was to make sure to cover all different shifts. This was especially the case of JDH because I only commuted to Mexico City once or twice a week.

Questionnaires were handed in closed envelopes by members of the advisory team to doctors and nurses from NICU and intermediate care areas from all shifts available on the week that the survey was administered.

All envelopes were stamped 'confidential'. Sealed envelopes were collected by two doctors in MDH using a black plastic bag and handed to me. In JDH sealed envelopes were collected in a cardboard mailbox located outside intermediate care room. Two nurses were in charge of emptying the box every day during a week and handing in the sealed envelopes to me. Table 5 shows the number of participants in the survey and table 6 described the response rate in each research site.

	Nurses	Doctors	Other
JDH	24	2	2
MDH	52	28	3

Table 5 Survey participants

	No. of questionnaires handed out	No. of questionnaires handed back	Response rate
JD	57	28	49%
MD	90	83	92%

Table 6 Survey response rate

Response rate for these self-completion questionnaires in MDH was excellent where in JDH it was not acceptable (Bryman 2012, chap.10). One factor that could have influenced the response was that envelopes were collected in person by a figure of authority in MDH.

SPSS software version 20 was used in order to do a descriptive analysis for measures of frequency and central tendency. Open questions were qualitatively analysed searching for recurring themes and subsequently grouping them into categories (Braun & Clarke 2006).

Not surprisingly, the survey raised more questions than answers that needed to be followed up with observations and further face-to-face interviews (Gillham 2007).

Extracts from my initial conclusions were:

New questions arose from these results for example: all the participants in this survey agreed that fragile babies need very gentle care, however many procedures in this unit could be considered as aggressive (at least for the researcher), also most of the respondents believe that babies respond if we talk to them, however during observations I have noticed very few staff members talk to the babies when they approach them, contrary to what parents do during visiting hours. Most of the participants also agree that

they find it easy to read babies' cues, but during observations I have noticed staff members tend not to look at the baby or not to watch or listen to the baby's cues because they have to finish a procedure. So this makes me think that many answers to this survey have a component of social desirability, where people tend to give the correct answer more than the real one. During conversations with the team members about survey results they mentioned 'it looks like you are talking about people from a different unit'. Hence these results need to be complemented with interviews to participants and more observations (extract from conclusions of survey in JDH).

It seems that NICU staff from MDH consider parents presence in the NICU as helpful for the recovery and well-being of babies and therefore recognise them as important members. However, there also seems to be a number of barriers that prevent them from integrating them into the daily care of the children such as: lack of personnel, lack of resources and deficient infrastructure, ideas about parents being very demanding and judgemental, and feelings of not having support from managers, among others. There seem to be some contradictions between survey results compared to observations and informal conversations in the unit; these will need to be addressed carefully in the following months (extract from conclusions of survey in MDH).

The contrast between survey responses and my preliminary observations in the NICU was apparent. In this regard I think the survey opened many questions that little by little became to be answered during fieldwork time, this made me aware that I would have to be very attentive to actions and not only to words around.

Final report of surveys can be found in appendix 8 (MDH) and appendix 9 (JDH).

3.7.2 Interviews

Interviewing might seem like an obvious choice of data collection technique in order to learn about other people's points of view and perceptions. In the case of this study, the choice for interviewing participants was also made on the grounds that the topics to discuss would most likely be sensitive. In line with recommendations (Liamputtong Rice & Ezzy 1999) I tried to be an empathic listener while maintaining an engaging two-way conversation with participants.

Interviewing healthcare professionals

Interviewing doctors, nurses and other healthcare professionals proved to be harder than I had envisaged. Nurses from MDH did not leave the unit at all during their shift and nurses in JDH had half an hour break. Doctors had more flexible break time but were normally called (due to lack of personnel, sometimes there was only one doctor in charge of the units) and the interviews were constantly interrupted. Four interviews took place in an office (with a doctor, two managers, one social worker). The rest of the interviews (9 doctors, 15 nurses, 4 psychologists, one dietician, and one social worker) took place in hallways, in the lactation room, outside the NICU or in the NICU.

Initially interviews with healthcare staff aimed at clarifying some of the results in the survey that appeared to be in contradiction with observations in the NICU, as the project progressed the interviews became honest conversations about day-to-day events and difficulties staffed faced. All interviews began with asking them to talk about their work in the NICU. A guide was prepared (appendix 10) in order to make sure objectives were kept in mind, however I tried not to be directive and allowed spontaneous issues to be discussed when they arose.

	Doctors	Nurses	Psychologist	Manager	Dietician	Social Worker
JDH	3	7	1	--	--	--
MDH	7	8	3	2	1	2

Table 7 Interviewing staff

Interviewing parents

As part of the research design I planned to contrast views of parents whose babies had been discharged with those of parents whose babies were still in the unit. I decided to interview parents whose babies had been discharged as a pilot. For this, I developed a

series of themes that I wanted to investigate and formulated questions and prompts to guide the interview (appendix 11). However, this was just a guide and I aimed at being flexible, allowing parents to guide the course of the interview and having a conversational style, not presenting myself as an expert (Graham & Oakley 1981). All interviews started by asking parents to tell me their story.

Invitations for pilot interviews were made by one doctor from JDH during follow up consultations. A total of four mothers and one father were interviewed in an office as part of the pilot. Not having invited parents myself proved challenging in regard to breaking the ice and forming rapport (Price & Nicholl 2013), which I felt was reflected in my having to guide the interview and ask questions. This was a challenge I identified to overcome for the rest of interviews. No changes were made to the questions and therefore I included these interviews as part of the data for my study.

The rest of the interviews took place in the remaining months of fieldwork. By the time I started to interview parents again I was already an insider in the units. I had been there as an observer, I felt comfortable moving around the hospitals, I knew most of the staff and I think they trusted me, and I had informally talked with most parents to present myself and the study.

Interviews took place either in an office, outside hospital (esplanade) or outside the NICU. I targeted specific people I felt important to talk to. For example, parents who I knew were also physicians or mothers who lived far away. However, the sampling was also opportunistic, sometimes parents were 'just waiting' outside hospital and that was a good opportunity to talk to them. In many occasions it was mothers who approached me to tell me their stories because they knew I had interviewed another mother.

A total of 29 parents were interviewed once. These sessions lasted between 20 and 60 minutes; 23 interviews were recorded using an electronic device. In six interviews I took notes either because parents did not feel comfortable being recorded (four) or because the place was very noisy (two outside hospital). I had the opportunity to meet with 18

parents (2 fathers and 16 mothers) for follow up interviews and observations in the unit; these parents became key informants.

	JDH	MDH
Total of interviews	11	18
Affiliated through <i>Seguro Popular</i>	6	12

Table 8 Interviewing parents

Focus group with fathers

Fathers in general tended to speak less during the interviews and were less available to talk: some of them worked and only came during lesser periods of time or waited outside hospital. I thought a group interview could provide a space where they felt able to discuss sensitive topics among peers. By that time I knew a male psychologist (Julio) in MDH who had experience and was very keen on leading a fathers groups, so I asked for his help.

Together we designed phases of the focus group (Finch et al. 2014) and decided he would facilitate the discussion (using the same interview guide appendix 9) while I discretely took notes. I also recorded the discussion with an electronic device. I invited five fathers, of whom three accepted; we identified a suitable room and I brought refreshments so as to ease the environment; Julio (the psychologist) explained (again) the purpose of the meeting and invited participants to introduce themselves and their babies to the group; Julio facilitated the discussion and drew it to a conclusion when no more topics arose.

3.7.3 Participant observations

I spent most of my time (two or three times per week in MDH, once or twice a week in JDH) inside the NICU, talking to people, and observing procedures and interactions. Staff were friendly but ‘defensive’ at the beginning.

During the initial phase of observations I did not bring any device to record events since I did not want to make people feel that I was grading or judging them. Instead I spent a long time introducing myself to people in all shifts (MDH) and in the morning and afternoon shift (JDH), explaining about the project and answering their questions. I used to leave the unit from time to time during the day to make notes discreetly.

The initial phase of observations was important in order to understand what aspects I wanted to focus on (McNaughton Nicholls et al. 2014), to learn different times in which events happened (babies' routine care, parents' visiting time, shifts changes) and allowed me to develop a guide for observing babies in different moments.

I was also invited to attend monthly reunions of chiefs of departments and doctors' meetings in MDH; teaching sessions for mothers in the lactation room in both hospitals, and other continuing education courses for doctors and nurses in MDH.

Sitting outside hospital in the esplanade was a fantastic opportunity to talk to parents, especially mothers who spent great part of their day there. This allowed me to gain their trust, some of them invited me to come to the lactation room to talk to other mothers and some invited me to the *Posada* (a shelter for women) where some of them stayed at night.

I kept a diary for each unit and discreetly took notes during the day, which I have also included in my analysis.

3.7.4 Observing babies

'Listening' to babies was a very important aspect of this research. My previous experience of (two years) observing clinical procedures and recording babies' reactions, and one year undergoing NIDCAP training in St. Mary's Hospital in London were fundamental for my observations. For this project I decided not to use any specific scale but to reflect on some aspects of babies' care.

I repeatedly observed a total of 29 babies during different times of the day and different interventions such as routine care (nappy change, blood pressure recording, taking the temperature, bedding changes and fluids aspiration), blood samples, enteral feeding, eye check and interactions with parents during visiting time. Appendix 12 shows my guide to observing babies which included: behavioural state before, during and after medical, nursing or parental interventions (from sleeping to calming to crying) (Brazelton & Nugent 2011), different behavioural responses during intervention (Als & McAnulty 2006), baby's positioning (Warren & Bond 2010), approaching the baby, types of medical or nursing interaction and attempts to make baby feel comfortable (Warren et al. 2016).

As part of the observation I recorded noise levels in the NICUs at both hospitals by placing a simple sound level meter (with a range of 35dB up to 130dB) close to the baby, although I also took measures from other sources of noise such as radio, typewriter, sink.

The sound level meter integrates all different sounds that take place within a given moment and gives a measure of central tendency (Philbin & Gray 2002). In other words, the measurements I took are only representative of that brief moment (transient noise). Because of this no generalisations or average can be taken from them.

I also considered layout of units (appendix 13 shows an example) and in the NICU I in MDH I was able to measure the square footage of space for each baby (actual baby bed area and parent space associated) by putting tape on the floor around every bed space, which reveals overlapping of baby spaces with other babies or walkways (appendix 14).

Finally, I consistently recorded movements of different people around NICU (see Figure 6 and 7 for example).

Male	Female	GA < 28 weeks	GA 28 to < 32	GA 32 to < 37	Other condition
18	11	8	9	9	3

Table 9 Characteristics of babies

3.7.5 Other sources of data

Both hospitals had started the process to become ‘Baby Friendly’ a recognition given by UNICEF to hospitals that promote breastfeeding. I reviewed the ‘Baby Friendly’ implementation guidelines.

During my fieldwork time I was invited to present my work in different hospitals (public and private) in different cities in Mexico and other Latin American countries; this allowed me to gain a broader picture about healthcare organisation and to compare and contrast types of care.

3.8 Data analysis

The iterative process of data analysis began alongside data collection. For example, survey results were analysed during the ‘preliminary’ or ‘exploratory’ phase of the project. Preliminary NICU observations were added to the analysis and, together, informed the next steps of the project.

During fieldwork time, I constantly reviewed records from field notes. These included not only actual observations of what happened inside and outside the neonatal units in both research sites, but also my own reflections about other possible sources and steps for data collection, which I constantly shared with my supervisor. This for example led me to the decision that I needed to map movements of people in the neonatal units and their connection to hand washing.

During my time in Mexico I also followed the news and included events that took place in the economic, political and social environment within my field notes.

Upon my return to the UK, I began the formal process of data analysis which involved: going through the data several times, generating initial codes, searching for patterns to make themes and subthemes, and finally using two critical realist concepts: four planar social being and MELD, which enhanced the analysis and helped to organise the report. I also returned to the literature at different stages. The process of analysis is explained in more detail below.

Transcriptions of interviews, observation of babies, field notes, measurements of noise, maps with movements of people in the units and results from the survey were reviewed several times, so as to ‘immerse’ myself in the data.

Early on, I made notes manually at the margin of printed pages (transcripts of interviews, maps, results of survey, noise measurements, Baby Friendly guidelines) and research diaries (observation of babies and field notes), and began to ‘label’ excerpts, thus generating initial codes. I used markers with different colours to collate codes and these created initial categories. Mind maps were powerful visual aids that allowed me to re-define categories and look for patterns that generated sub-themes and subsequently broader themes (Braun & Clarke 2006; Bryman 2012).

When necessary I carried out further literature reviews, which allowed me to make sense of emerging themes and took me to identify three overarching themes: hygiene, dignity and well-being.

Table 10 shows an example of the first stage of coding:

Codes	Categories	Theme	Broader theme
'unavoidable' pain, physiological signs of pain, signs of comfort/discomfort, painful procedures, suffering pain relief techniques (or lack), empathy (or lack), comforting techniques (or lack), compassionate care, torture in care, routine procedures, left to cry recovering from clinical procedures, enduring physical hardship, overcoming pain, being there, not seeing child,	Baby's pain Attitudes towards baby's pain Mother's pain Making sacrifices	Healing through suffering	Dignity

Table 10 Example of first stage of analysis

A second stage of analysis comprised the DREIC scheme (Bhaskar 2010) which stands for: D) description of events, R) retrodution (**finding possible mechanisms or structures that explain phenomena**), E) elimination of competing explanations, I) identification of causally efficacious mechanisms and C) iterative correction. This entailed continually returning to the data and to the literature to look for new theories that provided 'good enough' explanations or models.

In this second stage I used two 'lenses', which helped to develop a coding index (Smith & Firth 2011): *four planar social being* for the themes of hygiene and dignity, and the four stages of the acronym *MELD* (explained earlier in this chapter) for well-being. This involved re-thinking and re-organising categories and sub-themes. An example of the re-organisation of categories and sub-themes can be seen in Table 11.

Plane 1. Material relations with nature				
Codes	Categories	Sub-theme	Underlying mechanisms	Overarching theme
Unavoidable physical pain, physiological signs of pain, signs of comfort/discomfort, painful procedures, suffering Compassionate care, torture in care, suffering, not being heard/seen. Recovering from clinical procedures, enduring physical hardship, overcoming pain, being there, not seeing child,	Babies' pain and comfort management Attitudes towards babies' pain Mothers' physical and emotional pain	Real bodies real pain	Darwinian ideas (development) Mind/body dichotomy Catholic ideas of salvation through suffering Ideas about 'the good mother' Gendered violence	Dignity

Table 11 Second stage of analysis through DREIC

The critical realist concept of *four planar social being* enhanced the analysis because it allowed me to compare and contrast the data with different aspects of what it means to be human: embodied experiences, interpersonal relations, structure-agency interactions and self-awareness.

The well-being theme was analysed through the *MELD* process. At 1M I tried to define the object of study: what it means to be well in this context; at 2E I looked for absences within a broader laminated system of seven scales; at 3L I went back to the whole thesis from introduction as well as to the different categories that comprised well-being and the absences and I looked for connections at deeper levels; finally at 4D I looked at possibilities of transformational change.

The example above in table 11 shows how the DREIC scheme and use of laminated systems contributed to a richer analysis of data through *retroduction*.

3.8.1 Reflexivity

Reflexivity can be described as ‘turning back on oneself, a process of self-reference’ (Davies 2008, p.4) and it entails considering ‘the ways in which the products of research are affected by the personnel and process of doing research’.

I kept a personal diary in order to reflect on the different roles I enacted during my fieldwork in MD and JDH. During ten months I tried to be a ‘neutral’ observer, however I was also a user of public services, a woman who wanted to be a mother, an advocate for babies, and, inevitably, a friend with many participants with whom I spent many hours and to whom I feel grateful.

3.9 Conclusions

Through this chapter I aimed to show the philosophical framework and practical aspects that have informed all stages of the research project. It works as a preamble for the following chapters where I present and discuss the results of the study. I have tried to implement standards of care and respect for all research participants: babies, parents and staff members, and the very precious data they provided, through the methods and stages described above. I hope this is reflected in the rest of this thesis.

Chapter 4 An analysis of the social order in the baby unit through hygiene practices

Due to the nature of their fragile immune system, but also because of the numerous NICU procedures carried out, preterm babies are prone to contract hospital acquired infections. These infections pose an important risk in morbidity and mortality rates. Hygiene, and especially hand-hygiene, plays a vital role in the prevention of hospital acquired infections. Data collected from both study sites are analysed in this chapter using the critical realist concept of *four planar social being*, introduced in Chapter 3, with the overarching theme of physical and moral hygiene.

The first section of this chapter reviews embodied practices in the neonatal units such as hygiene and breastfeeding. Through excerpts from my records I contend that discursive practices and strict rules are directed at parents in the form of technologies of surveillance and control. These practices are consistent with biotechnologies used by neoliberal states reviewed in Chapter 2.

In the second section I consider tensions that arise in the relations between members of the staff and parents, when the latter challenge inconsistent practices and struggle to protect their babies' biological body from infection. I also reflect on attitudes that reveal how a moral order is conceived in a hierarchical system such as the hospital. In order to attempt to understand the duality of purity and impurity, both in the physical and moral domain, I review conceptions of dirt and disgust from two contrasting fields. An evolutionary perspective emphasises disgust as the universal force that drives human beings to avoid disease. A socio-cultural approach focuses on context and culture as mediators of hygiene practices and beliefs. I also review an alternative position that seeks to integrate these two perspectives through the notion of contamination appraisals.

In the third section I draw on Foucault's notion of power (1982) and I use his framework to begin to localise power relations in hospital. I also review Bhaskar's account of power (2008b) and I use the concept of *natural necessity*, from a critical realist perspective, to

advance the analysis. I argue that Bhaskar's perspective of power opens a path towards human flourishing in the neonatal units.

The fourth section analyses how parents make meaning of their time in the neonatal unit when they adhere to or challenge medicalised discourses. This section also looks at alternatives on how parents might be able to contribute to their baby's care.

4.1 Four planes of being

Social life, in Bhaskar's view, can be seen through four dialectical and interdependent planes that constitute human nature (2008b, p.153). As outlined in Chapter 3, these are:

- Plane 1: material relations with nature as embodied beings
- Plane 2: inter-personal interactions among people
- Plane 3: social structures (agency/structures relations)
- Plane 4: inner being (intra subjectivity)

4.2 Plane 1: material relations with nature

In order to 'set the scene', this section begins with field notes describing the material conditions on both sites.

Juan Dautt Hospital

JDH is a secondary care regional hospital mainly for local families, in a very busy area of Mexico City. There are few local buses and 'peceros' (van-style vehicles), taxis and service users' vehicles and little hospital parking space for service users. Here, in one of the most dangerous areas in the city, assaults with fire arms are common on the public transport and murders of young women are a serious problem.

As in most public hospitals, a line-up of street-food stalls surrounds the front entrance, which is guarded by a police officer. The pavement outside the hospital serves as a waiting room, some people sit, or even lay down out there. Some others queue at the gate. A visitor's badge is provided in exchange for an official identification, which is kept by the police officer at

the entrance. In order to get access, people need to prove they have a doctor's appointment or that a family member has been admitted. Only one visitor per hospital bed is allowed in.

A series of hallways lead to the neonatal unit at the back of the building, on the first floor. Lack of signalling made it difficult for me to find the way into the unit for the first time. Another security guard makes sure all visitors carry their badge. When babies are discharged, parents need to have clearance from the police officer, who makes sure the baby belongs to them.

Entrance to the baby unit is decorated by 'Disneyland' characters. Three doors lead to intensive care room (NICU), intermediate care room and paediatrics ward.

Parents' visiting hours are displayed on the NICU door. A small entry hall gives way to the intensive care room. A screen on the right hand separates the lactation room from the hall. The lactation room consists of a small space with around five plastic chairs, one electric pump and a small refrigerator. Two nurses' dressing rooms are located on the left-hand side.

A second door divides the NICU from the hallway. Right outside the glass door is a sink and a small table. A signpost explains the international guidelines of hand washing. Hats, masks and gowns are available next to the sink. Another small room, surrounded by glass windows, is used as the doctors' office. The windows allows doctors to overlook the neonatal unit.

Intensive care consists of a large rectangular room. Eight open cots, four on each side, stand out from two opposite walls. Cots are separated from each other by fabric curtains. A large window at the back of the room lets sunlight in. No blinds or curtains filter natural light from the windows due to infection control (it is not clear why curtains in the window pose a risk and curtains between the cots do not). This makes the room very bright during the day. Ten overhead panels, some of them above incubators, add illumination to the room. Cartoon characters decorate the floor.

A working space with desks, shelves and high stools for nurses are located at the centre of the room within a circular structure. Pop-music from the radio is normally on, coming from overhead speakers at the back of the room. The sounds of equipment alarms, footsteps, people talking loudly and the writing machine from the doctor's office are part of the day-to-day environment in the room. Up to 23 people: doctors, nurses, other healthcare professionals, parents and babies are in the room at the busiest time. The highest transient noise in the room, according to my measurements, was 85.5 dB during the day.

Babies in this room normally lay naked, except for their nappy, on their back, in open or closed incubators. Some babies have rolls made of sheets

around their body (which is known as nest to imitate the enclosing uterus). An array of medical equipment such as a monitor, ventilator, infusion pumps and small tables surround the incubators.

A small piece of paper stuck on the front of the incubator reveals the baby's sex, date of birth, date of admission, condition and treating doctor. There are no chairs for parents to sit when they visit, but mothers who are breastfeeding are allowed to pull a chair from the lactation room.

Mercedes Duron Hospital

MDH, part of a compound of hospitals in Puebla City, is a tertiary referral gynaeco-obstetric hospital in what it used to be the outskirts of the city. Families come from within the city or from different towns over a wide region.

Buses and 'peceros' pass the hospital. As in every Mexican city, the streets are unsafe, especially at night, but in general the atmosphere does not feel threatening. There is no parking space for service users although 'franeleros' (people who earn their living by looking after cars parked in the streets) are around during the day; this does not guarantee that cars are safe.

As with most Mexican public hospitals, street-food stalls line-up alongside the metal fence at the front of the hospital. A small cubicle with two or three safety guards stand at the entrance of the compound. Visitors are asked to write their names on a notebook at the guards' cubicle, but no identification is required. At certain times of the day big queues are made in order to have access to the notebook (the purpose of the notebook is not clear to me since they do not corroborate people's names. Not everyone is asked to register on the notebook, only service users. I have never been asked to sign, I do not wear a uniform or a hospital ID, but probably the guards think I am a member of staff).

A large esplanade with cement benches gives way to the main entrance. Another officer guards the doors to the hospital and provides 'visitors' badges. A third officer guards the entrance to the neonatal care area at the back of the building on the first floor.

The NICU in this hospital is split into two separate rooms. NICU I on the right-hand side consists of a long, rectangular room with 12 open cots along the four white walls. A long table at the centre of the room is used as the working area for nurses and doctors. Nurses tend to sit at the far back of the table and doctors closer to the door. Many chairs surround the table, these are rarely used for parents to sit on.

Two small windows at the upper end of the back wall let sun-light in and 12 overhead panels illuminate the room. There is no ventilation or air extraction system, and the area gets extremely hot, especially at busy times. The background noise of medical equipment such as ventilators and monitors can be constantly heard. The sound of music from the radio, a type writer, people talking or laughing, telephones ringing, a baby crying and loud footsteps, among others, sometimes add to the already noisy room. At the busiest time 30 people: doctors, nurses, other health professionals, parents and babies are present in the room. My measurements showed that the highest transient noise in the room during the day was 84.5 dB.

NICU II is a small room with five open cots that stand out from one wall. A desk for doctors and nurses to sit and work is located in one corner. There is no natural light in the room. Although smaller and apparently quieter, noise recordings tend to be louder in this small room. The highest transient noise registered on was 90.7 dB. At the busiest time 14 people were in the room.

Babies' sex, date of birth, date of admission, condition and treating doctor are shown on a paper stuck at the front of each cot. Additionally, parents are encouraged to bring a hand-made paper with their baby's name. They are also allowed to leave religious stamps on the cot.

Babies in both units are kept undressed except for the nappy. They normally lay on their back, sometimes in nests made up with rolled sheets and sometimes on flat surfaces.

Extremely preterm babies are among those cared for in a NICU. Their tiny bodies are subject to necessary and unavoidable invasive procedures such as intubation, endotracheal suction, insertion of catheters and intravenous cannula, lumbar puncture, tube feeding, and many others. Along with these invasive procedures, an immature immune system, exposure to antibiotics and constant contact with healthcare workers make babies prone to acquiring hospital-related infections (Cipolla et al. 2011). These infections, also known as nosocomial, threaten patients' life, increase the length of hospitalisation and, as a result, the costs in medical care (Sydnor & Perl 2011). Additionally, it is well known that fighting an infection undermines neurological development (Newburg & Walker 2007), therefore it contributes not only to mortality but also to morbidity rates in the units.

The most recommended, simple, cost-effective measure to prevent cross-infection in the NICU is hand-washing (Cipolla et al. 2011; Pessoa-Silva et al. 2007; Allegranzi & Pittet

2009; WHO 2009; Feasey & Molyneux 2011; Sydnor & Perl 2011). Other preventive measures include early enteral feeding with human milk, minimising the use of invasive devices, following safety guidelines during invasive procedures, limiting unnecessary empiric broad-spectrum antibiotics (Cipolla et al. 2011), constant watchful of hospital epidemiology and outbreak investigations, implementation of evidence-based control policies and procedures, education, training and support for healthcare professionals, proper cleaning and sterilisation of medical instruments, materials and facilities and prevention programmes that respond to local needs (Sydnor & Perl 2011).

The following section focuses on embodied practices of (hand) hygiene and provision of breast milk. While hand hygiene seems to be a logical form of preventing infection cross-contamination in the unit, the promotion of early enteral feeding with human milk might need to be explained further.

Breast milk contains immunologic components (Field 2006) that help babies fight infection in hospital, even those born very early and with low weight (Hylander et al. 1998; Goldman 2007). Breastfeeding plays an important role in preventing infections. The ‘enteromammary pathway’ (Newburg & Walker 2007), could provide an explanation for this: epithelial receptors in mother’s breasts detect pathogens (bacteria and virus) from the baby, and produce the anti-pathogens which are transported back through breast milk, thus protecting her infant’s immune system.

4.2.1 Hygiene and the governance of parents

Both MD and JDH had maternity units. This means that most of the babies admitted to the NICU had been born in these hospitals. However, given that MD was a sub-speciality hospital, sometimes babies from other hospitals were transferred to this unit.

The physical conditions described above resulted in parents having to spend great part of the day outside the hospital, either in the esplanade (MDH) or in the street (JDH), except for the (few) mothers that were allocated a bed in the women’s *Posada* (MDH) due to a lack of physical space for them to remain. Parents were only allowed into the NICU

twice a day. If a baby had been born after the last ‘visiting’ period (table 12), parents had to wait until the next day to see their baby.

Restricting visiting hours for parents in Mexican NICUs is thought to be one strategy to prevent infections in neonatal care. This seems to respond to the longstanding belief that outside service users bring disease and infection into the unit.

Table 12 shows visiting hours in the intensive care unit in both research sites:

JDH	MDH
Reports to parents within the unit at 13.00 hours.	Reports to parents included in the morning visiting time.
Mothers’ visiting time at 15.00 to 16.00 hours.	Morning visit at 11.30 to 12.00 hours.
Fathers’ visiting time at 16.00 to 17.00 hours.	Afternoon visit at 18.00 to 18.30 hours.
Breastfeeding mothers allowed to come in every three hours.	Only one person allowed to come in at a time.

Table 12 Visiting time for parents in the NICU

Staff members tended to be very busy before visiting time, given that babies needed to ‘be ready’ for when the parents arrived. Routine procedures such as head-to-toe cleaning, suctioning or changing nappy and bedding were performed prior to parents’ morning/midday visit.

The ritual for hand-hygiene before visiting babies was very similar in both units. Parents used to come to the hall outside the units ten to fifteen minutes before it was visiting time. They were understandably anxious to see their babies, visiting hours were short and they did not want to waste a minute. The process of washing hands and getting ready to come into the unit took some time. Additionally, lack of resources, such as gowns, sometimes caused visiting time to be significantly reduced.

Moni was born 8 weeks early at JDH. After Moni had been in the NICU for almost two months, her mother Lupita told me:

You have to arrive early and be one of the first to wash hands because sometimes there are too few gowns, so [if they run out of gowns] you have to wait until they bring more and you are left with five minutes instead of half an hour to visit your baby. (IP11)

Visiting time in JDH was supposed to be an hour long, but Lupita above refers to it as half an hour. It was common that nurses delayed parents' access to the unit by making them wait outside. In MDH visiting hours had been reduced from one to half an hour. A doctor told me:

It used to be an hour but they turned it into half an hour, I don't know why. (IS1)

Nurses felt that parents were judgemental and demanding on how their babies were treated, and therefore they did not like to feel observed doing procedures or routine care. I told the Chief of Nurses in JDH that I was planning to interview a group of parents before visiting time and she replied:

Great, and hopefully you can hold them until five to twelve so that they don't arrive here earlier than that to their visit. (Field notes)

Other staff members I talked to, such as nurses, doctors and the social worker, confirmed this view. Katy, a social worker said:

Mothers pay more attention to what happens to other babies than to theirs, and that produces friction in their relationship with nurses. (IS6)

With time, I became very intrigued about this apparent need of the nurses to 'protect' themselves from being observed, as exemplified by Nurse Melina's view:

People who have 'Seguro Popular' (Popular Healthcare Insurance, SP from now on) have access to three [telephone] lines to make complaints, to me it feels like harassment. (IS14)

Leslie was born at MDH at 38 weeks of gestation. During birth, she suffered from asphyxia and had to be admitted into the NICU. Leslie had been in intensive care for seven days when I met her father Rodolfo, who was also a doctor. When I asked whether he thought parents were judgemental of staff in the units he said:

Yes, I have seen this happening. Many ladies are with their babies but they are also looking at what happens to other babies [and they say] 'they pricked him' [or] 'did you see the big needle they put in?' and these procedures have to be done, but since they are not involved in this field they think it hurts the baby and the parents get scared. (IP13)

For this father, it seemed to be fine to observe what happened to other babies when he did it in his capacity as a doctor. When I asked how it was for him when he visited his baby, he answered:

Sometimes some [other baby's] alarm goes off and I turn to look, just in case the baby is having a [cardiac] arrest and they haven't even noticed, but when I see everything is fine I return to my baby. Or I also look around when I have doubts about how to move my baby, so I look around to see how others are doing it and then I do it myself.

Chapter 5 will show how communication was fragmented and information was kept from parents, which indeed caused great anxiety around what happened in the unit when they were not present. The levels of noise in these units were very high, partly because monitor alarms tended to go off constantly, which greatly worried parents.

Before coming into the NICU for the 'morning visit', parents from MDH had to take the register of assistance *pasar lista* with the social worker. For this, they queued as the social workers called their names and informed them if they had outstanding administrative procedures to be completed, afterwards they were allowed in.

In both hospitals, parents were asked to leave their belongings in a pigeon hole outside the unit, then they formed a queue in front of the sink, located outside the units, and started their ritual.

Parents seemed to be very cautious about hand-washing. Steps for this process commonly involved: bringing sleeves up to the middle of the arm; turning the tap on, sometimes using the elbow, as if their hands did not deserve to touch anything from within the room; they put soap on their hands and, some of them, followed the seven-step guide to washing hands¹¹ (from the posters on the wall). If the partner was available (in MDH), it was normally the mother who washed her hands first and the father would open and close the sink tap for them, as well as lowering the level to get some paper towels. However, if only one person came (as in JDH), he or she would close the tap using the elbow, lower the level by him/herself and afterwards clean the level again with extra paper towels.

Not only were parents careful about this process, they also expected the rest of the people to be the same. They normally learned how to properly wash their hands by observing other parents.

Pedro was one of the tiniest babies in the NICU of MDH. He was born unexpectedly at 27 weeks of gestation. During those first days his mother Ana told me:

I wish there was a person in charge of teaching parents how to do it [wash their hands]. The other day I saw a father who did not wash his hands properly and I wanted to tell him something, but I don't want to have problems you see? (IP12)

Once the process of hand-washing was finished, parents would make another queue at the entrance of the intensive care unit. If parents arrived early (quarter to the hour) and staff members had not finished routine care, they would close the door to the unit.

¹¹ Rub palms together, rub the back of both hands, interlace fingers and rub hands together, interlock fingers and rub the back of fingers, rub thumb in a rotating manner followed by the area between index finger and thumb, rub finger tips on palm, rub wrists in a rotating manner, all of these on both hands.

Parents then would start whispering, wondering if this was due to an emergency or worse, one of the babies dying (it was common for staff to close the door if either of this happened). The first person in the queue normally tried to see through the slit of the door and informed the rest of the (very anxious) people what the situation was, which was especially irritating for staff members. Nurse Claudia said:

They just want to see what we are doing and if they tell the rest [of the parents] this makes everybody anxious, because they not always understand what we do in here, especially if a baby is crying or if it is an invasive procedure. (IS23)

When it was time for parents to come in, or after staff members had finished with routine care, one of the nurses would come out and hand out gowns, hats and masks. Only one person per baby was allowed in at a time. In MDH it was common for the mother to come in first and spend most of the time in the unit. If the partner was available, he would help the mother put on all these items. This prevented her from touching anything after having her hands cleaned. The father would wait outside. As the door opened, parents would come in and spread antiseptic gel on their hands (nobody else was expected to follow this step), before approaching their baby's bed.

In JDH mothers came in one by one. They opened the door, placing the gown between their hand and the door handle, and asked for permission to come in.

Once parents were with their baby, they tended to stay only in that area and it was highly improbable that they would have contact with any other baby, material or surface in the room. Figure 5 shows the path that a mother usually followed when visiting her baby (from the door on the left to cot 3 and back) in one intensive care room. The dots

represent the surfaces that she had contact with:

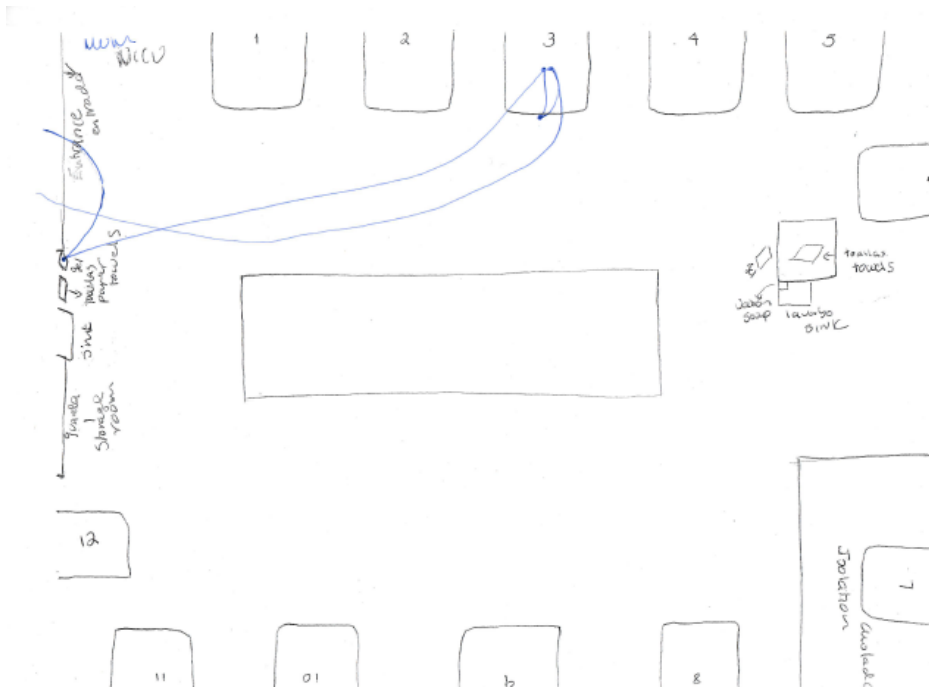


Figure 5 Path that a mother followed when coming to see baby in cot 3

In contradiction with discourses about hygiene, visitors' toilets lacked soap, hand towels, toilet paper and sometimes even water. One mother, Julia, mentioned:

I can't believe it, all mums in the unit are menstruating; we just had a baby! But there are no clean facilities for us to go or for fathers to have a shower. If they have been here for a long time they are smelly. (IP15)

I was invited to attend a meeting where three male senior managers, medical and administrative, met with architects in order to discuss plans to build a new NICU in MDH. When discussing location of the toilets for parents one of the managers thought it would be better to have them outside the NICU building, because of hygienic reasons. I raised the point that some mothers were recovering from surgical procedures, he replied:

Well, they would only have to walk for like one block [to get to the nearest toilets]. (Field notes)

MDH was indeed a very big hospital. The plans for the unit did include toilets for staff members within the building. The manager explained unlike parents, healthcare professionals were able to keep clean facilities. As a Mexican I know, toilets are a powerful sign of social class. Medium or higher class people avoid sharing toilets with the 'lower' classes.

I interviewed a senior manager in the administrative area, Mr. Diaz, almost at the end of my field work period. Infection rates in MDH seemed to be alarming. Almost all babies whose parents I interviewed had been infected, at least once, at some point through their time in hospital. I asked what measures were being taken in infection control within the unit, apart from restricting patients' visiting hours. He mentioned:

[...]we have two fundamental goals[...]the first one is [...]reduction of nosocomial infections through hand-hygiene, concretely hand-hygiene and the other one is prevention and control of infections basically it is through these two processes that we work on hand-hygiene. Today people [staff] wash their hands, badly but they wash their hands, in the past they didn't [...] (IS3)

Mr. Diaz claimed these (vague) plans included education for healthcare workers on hand washing, but nobody else in this hospital seemed to know about this strategy. When discussing how difficult it was to bring staff to follow hand-hygiene guidelines he mentioned:

There are many doctors from here who also work in (he names two well-known private hospitals) if you see them [working] here I don't need to tell you about it, you have seen them in action. Let's go to (one of the private hospitals) [...] and see if he [the doctor] washes his hands or how much his patients are exposed [to infection] and you will find a big discrepancy. In there he [sic] follows the guidelines [...] because the patient pays [...] it is a client [...] and he can be sued... and he can lose his licence, but not in here [...] I don't know how to say it, it is...it is unpunished.

This view makes each individual (doctor) accountable for not following basic procedures of hand-hygiene. It also reflects neoliberal practices where healthcare is most valued when it becomes a product sold to clients.

Mr. Diaz expressed frustration at the lack of resources needed to maintain high standards in the management of the hospital. This frustration was translated into the inevitable fate of babies in the unit:

...we have a demand [of service] that exceeds the supply in a relation of three to one [so] we have two [options], we either infect them or they die... they either come, get healed to get out infected of something, or they die. Then again it is quite a quandary for the people in charge of the service, for the chief of nurses, for the supervisor and even for the chief of neonatology.

A systematic review of studies on compliance with hand-hygiene guidelines in hospital care undertaken by Erasmus and colleagues (2010) shows that adherence to hand-washing is a universal challenge. This review included 35 studies from Europe, 50 from the USA and Canada, nine from Australia and two from Asia. While it is true that implementing this practice takes time and resources, the above extract suggests that there is a perception about patients from public hospitals have to pay the price of 'getting infected' if they want their lives to be saved, as if getting infected did not come with the risk of death.

The review shows that non-compliance with hand-hygiene seems to be greater among physicians and higher in intensive care units than other wards. Although it is not clear which type of health-care activities are more prone to spread microorganisms from the patient to health-care workers' hands, it has been proposed that even 'clean' activities such as lifting, taking blood pressure or temperature can cause contamination. Moreover, flakes of patients' skin also cause contamination in the immediate environment (WHO 2009).

'Transient' flora on the hands has a lesser interval of survival but is highly contagious, compared to 'resident' flora, with less pathogenic effects. The former is the cause of most type of nosocomial infections and antimicrobial resistance, thus decreased levels of contamination can be gained through enhanced hand-washing by healthcare workers (Pittet & Boyce 2001). It is much more likely that transient flora is spread in the unit by

healthcare workers' hands, because they touch different patients, equipment and surfaces in the unit.

So far, this section has shown how hand-hygiene of visitors and restricted visiting hours are promoted as an important preventive measure of infection in the units. It has also started to reveal how these practices are used as technologies of regulation of individuals. Finally, it has also briefly exemplified how new mothers' basic embodied needs are not considered in the services, which will be further discussed in later chapters.

In contrast to non-evidence based practices, such as restricting parents from being with their babies, it has been suggested that contact with parents, such as skin-to-skin holding, protects the baby's immune system (Conde-Agudelo et al. 2011) and components of breast milk reduce the risk of infection (Cipolla et al. 2011). But then again, the following section shows breastfeeding seems to be used as a means to control women's bodies.

4.2.2 Governance of women's bodies and breast milk

Breastfeeding is considered the 'gold standard' form of feeding babies (Eidelman & Schanier 2012). The Global Action Report on Preterm Births states that 'premature babies benefit from breast milk nutritionally, immunologically and developmentally' (March of Dimes et al. 2012, p.66). Other benefits have been suggested when breastfeeding preterm or ill babies, such as development of mother-infant attachment (Cross 2015).

MDH and JDH seek to be adhered to the 'Baby-Friendly Hospital Initiative'¹². As a result, many adjustments were being implemented and this did not come without challenges. This section will show how, in the name of breastfeeding, mothers were asked to follow tight schedules. This sometimes caused breast milk became objectified

¹² 'A maternity facility can be designated 'baby-friendly' when it does not accept free or low-cost breast milk substitutes, feeding bottles or teats, and has implemented 10 specific steps to support successful breastfeeding' (UNICEF n.d.).

and a fetish, while breastfeeding practice did not match official rhetoric. Moreover, there seemed to be a moral judgement of ‘the good mother’ (Marshall et al. 2007) who made great efforts and sacrifices in order to provide food as ‘love’ for her babies. Women ascribed to or resisted being accountable for the ‘well-being’ of their baby through the provision of breast milk.

Breastfeeding in the NICU is not always possible due to the gestational age and clinical condition of babies, therefore expressing milk was actively promoted in these hospitals. Mothers were required to go to the lactation room every three hours. The ritual when arriving to these rooms was similar to the one described above for visiting babies; women had to queue, leave their personal belongings, wash their hands, take off their top, put on a gown and then they came into the room.

Once inside the room, they learned about the multiple benefits of breastfeeding, they also learned about physical hygiene, how to massage their breasts and how to express and store their milk safely. By the end of their time in there, they were expected to have left some milk for their babies.

In MDH, mothers were ‘graded’ through a traffic light system. The nurse reviewed the amount of milk and marked a happy face with green colour if it met expectations (eight feeds covered for a 24-hour period), a serious face in yellow colour if the amount of milk was sufficient (three to four feeds in a 24-hour period) and a sad face in red if the amount of milk was not acceptable. I spent several days in the lactation room talking to women, many of them told me how much stress they felt, and sometimes sadness or guilt, with just the thought of not having enough milk for their babies. In many instances mothers were shamed or threatened for not bringing enough milk to feed their babies.

Luisito and his twin brother were born in MDH at 31 weeks of gestation. Luisito’s brother died a few days after the birth. Luisito had been in the NICU for over three months when I first met him. I asked his mother Sonia about her experience with breast milk extraction, she said:

There was a day in which I felt so desperate, because the nurse told me ‘if you don’t bring enough milk your baby won’t eat’. [On] that day my baby had caught [sic] a temperature and I was very worried [...] because what was he going to eat? (IP6)

Women were left with the ultimate responsibility of producing milk or the blame for failing to do so. Some mothers resisted having to be accountable for not providing enough milk and asked for it to be a shared responsibility. Ana, the mother of Pedro told me:

You are supposed to have a balanced diet and I mean there is a dining room in there (to which only staff had access) but all the mothers who are breastfeeding have to eat in the street with millions of kilos of contamination, grease, cholera and the like so, if there is a dining room why don’t they let us in? (IP12)

Sonia also said:

The nurse tells me ‘drink water, eat’...and I say we eat what we can because it is difficult, being here for so long, it is really burdensome and from where is one supposed to get the strength?(IP6)

In both hospitals, mothers who were already breastfeeding (more common in intermediate care) were allowed to come in every three hours and they got a chair. This caused great distress in mothers who, for different reasons, were not producing the desired amount of milk.

Yuridia spent over two months in hospital, some of that time in the NICU, due to her early birth. She had been discharged over a year prior to my interview with her mother Alexa, who told me about some problems she had in order to begin breastfeeding:

I had to stand up all the time [during the visits] even though I had a C-section, only the ones [mothers] who were breastfeeding got a chair (IP3).

It seemed that mothers were punished, along with their babies, for not being ‘good enough’ as a mother or as a woman.

Yet less support was provided for mothers to initiate breastfeeding than to mothers who expressed their milk; breast milk seemed to be considered the best nutrient for babies but the act of breastfeeding did not seem to be as important.

Rodrigo was born at term (40 weeks) in JDH. He was admitted into the NICU due to a condition called ‘craniosynostosis’ (a problem with the skull that causes abnormal growth). He was discharged after 20 days in hospital. At the time of the interview Rodrigo was two years old and had been back for a follow up consultation. His mother recalled some of the problems she experienced when initiating breastfeeding:

They said my nipple wasn't properly formed and they told me off because I didn't do the exercises [to form the nipple], but I didn't know [I had to do them]. Thank god my mother and grandmother helped me when we got home. (IP2)

I asked the nutritionist at MDH (IS9) to describe her service. She spent more than ten minutes talking in detail about the process through which women were educated, trained and supported to express their milk and store it safely in the lactation room. Her department did not have a member who supported women with breastfeeding at the baby unit. None of the units had a certified breastfeeding consultant on the staff.

Two mothers (Sonia and Julia) mentioned it was they who realised their babies, who had been transferred to intermediate care and were stable and were rooting for milk. They asked to initiate breastfeeding, to which the doctors said yes.

Through a phenomenological study in an Australian hospital, Sweet (2006) describes the objectification of breast milk that results from discursive practices about the benefits of breast milk for low birth weight preterm infants. The author proposes that breast milk becomes a precious object that needs to be measured and quantified, therefore directly breast feeding the babies might not be encouraged in hospital.

Because of the ‘Baby-friendly Initiative’¹³, a programme from UNICEF that promotes breastfeeding in hospitals, bottles and dummies were not used in any of these hospitals. Babies who were not yet breastfeeding drank milk from a syringe, mainly administered by nurses although some involved mothers in this process.

When talking about her feelings on feeding with the syringe Doris mentioned:

In two occasions they [the nurses] told me to feed her with the syringe, and they... well ... they fed her too quickly. Well they have more experience and they know best and maybe that’s why they do it so quickly, I used to do it more slowly because she kind of choked on it. (IP4)

Probably, nurses could not wait for the baby to feed at her own rhythm, they had other patients to care for and no mothers who helped. What Doris described, forcing milk into babies’ mouths, seemed to be a common practice in these hospitals.

Babies might find it difficult to transition between the teat of bottle and the breast, therefore syringes were used. While this seemed to be a logical practice, exceptions and individual circumstances were not taken into consideration.

Jason’s (single) mother died giving birth due to complications. His grandmother, Mrs Irma, remained as his main carer. Jason did not like to feed from the syringe and Mrs Irma had repeatedly asked whether she could bring a bottle. She told me:

I don’t understand why they insist on feeding him with a syringe, he will have to drink from a bottle anyway. (Field notes)

Routine common practices, which failed to consider individual needs, are discussed further in chapters 5 and 6.

A big poster on the front wall by the entrance of JDH showed an image of a happy, middle class, white-skinned woman breastfeeding a healthy, smiley, white-skinned baby.

¹³ http://www.unicef.org/nutrition/index_24806.html

The image contrasted with the physical characteristics of the population, mestizo or indigenous dark-skinned, served by the hospital. Women in this hospital also received a flyer from the government with the slogan 'to breastfeed is to love'. Breastfeeding seemed to be advertised as the ultimate goal in order to be a good mother with a contented, healthy child.

Then again, there was a type of double moral; visiting hours for women and men in JDH were split so that mothers could breastfeed during their visit without being observed by men. It was not clear to me whether this measure protected women from 'pervert' men or, if the action of 'showing' their breasts was considered immoral. In any case, this gave breastfeeding an impure connotation.

Breastfeeding practices and the 'regime' that came with them were sometimes challenged. Jazmin, whose baby Liz (born at 32 weeks of gestation) had been transferred to intermediate care, chose not to continue going to the lactation room:

I used to go there [to the lactation room] but I think they threw it [the milk] away because my baby was not eating yet, so I stopped and now I have no milk. (IP21)

Ana could not see the point in expressing her milk while Pedro (born very early) did not feed from it:

After a month and one week they told me that my baby was going to start with two [millilitres] and I was like oh no the milk! I went to the lactation room and nothing, not even a drop. (IP12)

Threats were used so as to bring mothers to comply, Ana continued:

But that is when the stress begins again because supposedly, if there is no breast milk they don't give you your baby [for discharge], I mean supposedly he has to drink breast milk.

Baby Evelyn was born at term in JDH. During her birth she suffered from asphyxia and spent 15 days in hospital. During this time her mother Doris was not allowed to feed her at the breast. After a few days:

I had chills and fever, the doctor [from JDH] told me it was because of a medicine I was taking... I went to see a private doctor and she said it was an infection and gave me treatment for eight days, in the end I lost all my milk. (IP5)

Heinemann and colleagues (2013) interviewed seven mothers and six fathers whose babies were at a level III NICU in a Swedish hospital. They showed how mothers experienced regular breast milk expression as a stressful factor. This in turn had a negative effect on the time they spent in close contact with their babies, such as skin-to-skin contact. It is noteworthy that women from this study could express milk inside the neonatal unit while they were with their babies.

Other mothers I interviewed thought breast milk was not only the best food for their babies but also helped the babies to recover. This was the case of Julia who had twin babies. Her baby girl Iris had already been discharged and stayed with Julia's mother along with her two-year old son. Cesar, Iris' twin, had been in hospital for over a month. Julia told me:

They [medical staff] do put a lot of pressure like 'the breast milk, the breast milk' and so but seeing that he was delicate I said 'yes' and now I am breastfeeding. (IP15)

Section 4.4.1 describes Julia's tight schedule in order to provide milk for both her babies. Even though it was tiring and she had not fully recovered her health, she mentioned feeling happy with being able to provide 'the best' for her babies.

Despite different strategies intended to regulate parents, and especially mothers' bodies, some women in this study showed how they are active in making decisions or challenging rules which they found contradictory. The next section will review how

interpersonal relations that take place in the neonatal unit are tense and seem to be mediated by ideas about ‘purity’ and social class.

4.3 Plane two: interpersonal relations between ‘impure’ service users and ‘pure’ members of the staff

As described above, one form of protecting babies’ biological bodies from infection in these hospitals was through strict rules for outside visitors. Yet, parents also felt they needed to protect their babies from other sources of infection within the unit, and felt anxious when they failed to do so. This in turn brought tensions in their relation with staff members. Strict rules for parents, and the use of gowns, masks and gloves, were also used as symbols of hierarchy as will be shown in this section.

4.3.1 Parents’ need to protect

The expected ratio of patient per nurse in the intensive care units was 2:1 or 3:1. However in intermediate care this increased disproportionately to 5:1. Adding to this, intermediate care units were much more crowded. Intermediate care units were perceived by parents as places where babies got constantly infected, probably they felt hygiene control was stricter in the NICU.

Managers in both hospitals were cautious about revealing official statistics of infection rates in intensive and intermediate care, therefore I did not have access to them.

Unofficially, I was told that the most common infections in one of the hospitals were: *E. Coli*, *Enterobacter*, *Klebsiella Pneumoniae* and *Staphylococcus Aerus*. The latter are related with procedures such as catheter insertion and fluids aspirations.

Far from being passive and compliant, parents spoke about and actively fought to protect their babies from getting infected. This was the case of Bety, Juanito’s mother.

Juanito was born 12 weeks early. When I met him he had already been transferred to intermediate care in MDH. His mother told me:

They have now transferred my son to intermediate care, but I get so stressed because many things are said about the intermediate unit, like there are many viruses and bacteria. For example there was a baby girl in intermediate [room number] four and she got Candida (a bacterial infection), so they took her back to intensive care into isolation, it was very serious. (IP16)

When Jazmin told me that her baby Liz had just been transferred from intensive to intermediate care, I got excited and said I supposed that was an important achievement for her and her baby, to which she replied:

I don't know, I feel intensive care is more hygienic, I mean it is clean here [in intermediate care] but it is not the same, there's too many people.... And I mean, yes it is an achievement for me also because I now can hold her in my arms and I feed her, but sometimes they don't respect, I mean my baby has an infection and other parents come and use the gown that I wore to hug my baby (this was common if no more gowns were available). Anyway yes I guess it is better because I can have my baby, I can hug her and hold her. (Field notes)

In their need to protect their babies from nosocomial infections, mothers sometimes had to fight doctors and nurses so as to have their voice heard. Julia told me how one of her twin babies developed diarrhoea while being in intermediate care unit:

My baby boy has diarrhoea since a week ago, when it started it wasn't diarrhoea as such but he started doing [poo] very frequently, so I told his nurse – I don't think this is normal – I mean when I came in he had a poo, which never happens, I asked the nurse whether she had changed his nappy and she said yes and that he had also done with his first feed, so I figured he had done twice already and with his third feed he did [a poo] again and then again so I told the nurse – this is diarrhoea – and I saw the colour in his poo was changing. The nurse said – don't worry this is normal and I said to myself – this is not normal, how can it be normal? (IP15)

But it was not until a few days after that tests were prescribed to know what was causing her baby's diarrhoea. Julia mentioned how frustrated she felt and wondered if it was due to doctors thinking that she is ignorant the reason why her views were not heard since the beginning.

Parents became very frustrated when they felt their babies were exposed to unnecessary risks. Another mother told me:

I don't like when the psychologist comes into the unit because she caresses all the babies without washing her hands (IP22)

Although parents were concerned and sometimes took action in order to protect their babies, the fourth plane in this chapter will show examples of how they also ascribed to ideas about them bringing disease from outside and posing risks to their babies. The following section shows how staff members failed to consider themselves as a source of infection.

4.3.2 The moral order in the unit

Many contradictions arise in how rules had to be strictly followed by outside visitors but inside members of the staff were allowed exceptions. Ironically, infection control measures seemed to be more relaxed inside the units.

Mobile phones, handbags and containers with food were not allowed into the intensive care units, this was another preventive measure of infection.

Nurses from JDH had a small room outside the unit where they changed their clothes and left their handbags, but it was very common that their personal belongings got stolen. Because of this, they brought valuables with them into the unit. In MDH, doctors and nurses brought their handbags into the unit and left them in a small storage room inside. As already mentioned, parents from both units were required to leave all their belongings outside with the same risk of having them stolen.

Staff members tended to have their mobile with them at all times and leave it on their working table. While Pedro was still in intensive care Ana, his mother, told me:

I don't say they shouldn't be on Facebook, it is one hundred percent valid, but sometimes because they are in the so called Facebook or sending 'Whatsapps' [sic] they are fooling around and you are like –my baby has

done [a poo], [and they say] I'll change him in a minute – and you are like [my baby] is all soiled and your will change him in a minute? (IP12)

When I asked the senior manager (Mr Diaz, IS3) about this, he confirmed mobiles were prohibited in the unit.

Lack of material and human resources were seen as a barrier in the prevention of infection. I asked one doctor in the NICU how many babies were infected that day, on that room, and she replied:

Ah (with a frustrated expression), it might be easier to say which babies are not infected. Most of our babies get infected due to lack of resources and space. (Field notes)

One of the nurses also commented:

We are supposed to perform some activities, such as suctioning, between two people to prevent infection, but that never happens, there are not enough staff. And for example doctors, they should insert catheters in pairs as well but it is almost impossible. (IS11)

Parents were immediately blamed when a baby was infected. When Pedro, Ana's baby, was transferred to intermediate care she told me:

I felt really bad, really ashamed. The other day I came in and my son had diarrhoea, so the nurse came and told me, in front of everybody, that I had to be more careful with my hygiene. I mean, I am extremely careful and it seems to me too coincidental that the baby next to Pedro also has diarrhoea, because I have never touched that baby in my life but she, she cares for both babies and their cots are too close together. (P12 from field notes)

Ana's example also shows how parents contested the belief that they are disease holders. Javi was born at 29 weeks of gestation and spent six weeks in hospital, with a subsequent re-admission. When describing the first time she saw her baby, his mother Lorena said:

When I tried to touch my baby the neonatologist approached and said it was not possible. I started crying and saying I needed to touch him, the doctor asked me to stop crying and to thank God that my baby was not dead, so I cried even more.... For me, touching my baby was like a necessity, an impulse. (IP1)

Doctors and nurses who made an effort to help parents approach their babies had to do it in secret. When I asked Lorena to describe one of the best moments she could remember from the NICU she told me:

When a doctor said 'I will give you permission to touch your baby, but if somebody comes you take your hands out immediately [from the incubator]'. He also let me take a picture, although that was prohibited, but for me that was my incentive, to see his picture.

My survey administered to staff members asked for their perceptions about the safety of parents participating in their babies' care. Results show that some staff members viewed parents as a source of infection due to lack of education or because of their ignorance:

Parents in the Mexican Republic, as well as the socioeconomic status our population belongs to and their low levels of study, make it difficult to inform and help them conduct themselves carefully in the NICU, which evidently increases the risk of infection. (Su32)

Parents must be well informed and need authentic support from medical staff; however our population lacks hygiene culture and commitment. There have been two cases in which parents have been asked for support and they ask why they should do the nurses' job. (Su87)

Moreover babies seemed to also be perceived by medical staff as 'disease holders' by nature. Lorena commented:

My baby was re-admitted after three days because he had some fever. We came to the hospital, a different one, and the doctor said he had to stay because he was an infected baby and I said infected how? How can you know that? But they didn't want to tell me, it was only that day he had fever but he still had to stay.... In the end they did not find any infection, he did not have an infection as such, we don't know what could have happened. (IP1)

Back in Vienna Austria, in 1847 Ignaz Philipp Semmelweis proposed that health-care workers in the maternal clinics were cross-infecting patients through their hands, that being the reason of high incidence in puerperal fever (Bencko 2006). After detailed observations and record keeping, he introduced the practice of hand-washing with chlorinated lime solution, reducing maternal mortality notably (Pittet & Boyce 2001). Despite providing evidence that cleansing hands with antiseptic substances, rather than plain soap and water, helped reduce hospital acquired infections, Semmelweis' ideas were rejected to the point that he had to leave the clinic. Barriers for the implementation of hand-hygiene in health-care settings have already been mentioned above.

It seems appropriate to review here a sociological analysis to this problem. Bencko (2006, p.4) thinks doctors might have fought Semmelweis' proposal because they considered their hands could not be dirty; medicine was seen as a 'divinely blessed' profession. Alderson (2013, p.5) suggests doctors might have found it difficult to accept being source of disease since they were 'respectable, professional, healing men' who considered themselves to be very different from the patients they attended.

In an attempt to explain further what happens in the NICU, I have looked at the concept of disgust from different perspectives.

Curtis (2007, p.660) defines hygiene as '*the set of behaviours that animals, including humans, use to avoid infection*'. Within this evolutionary perspective disease avoidance behaviour, as part of an adaptive system, helps animals escape disease by evading dirt, driven by disgust. Successful adaptation to the system then leads to survival. Curtis and colleagues (2007) propose that dirt, disgust, hygiene and disease have a biological link in evolutionary history. Nonetheless they recognise that disgust, hygiene behaviour and culture are interlinked as part of an adaptive system (Curtis et al. 2011) in which individual's responses to disgust vary according to personal learning experiences, local culture and ideas about purity and pollution (Curtis 2011).

In the field of cognitive and behavioural neuroscience, Chapman and Anderson (2012, p.63) suggest that disgust evolved from distaste, the latter understood as a

neurochemical response in the form of oral rejection of unpleasant tasting food, commonly bitter, through which toxin oral ingestion is avoided. The authors contend that distaste and disgust should not be taken as synonyms. Parasites causing infections are different from toxins and can go undetected, hence the mechanism for recognising and avoiding them is different; odour, tactile and visual cues tend to signal their presence and this is where disgust takes place. Furthermore human beings use their judgement to understand that contamination might take place when an infected object/organism makes contact with another object/organism, thus avoiding both.

Disgust is transferred into the social domain identified by Curtis (2011, p.3478) as a 'moral emotion' playing an important role in the 'politics of exclusion' such as social class, caste or xenophobia, among others, that needs to be better understood. Moreover, the author suggests that exclusion is in many instances (unfairly) justified by labelling certain groups as disease carriers, dirty, unhygienic or polluting.

The social anthropologist Mary Douglas (1966, p.55) asserts that ideas about dirt sit within a symbolic system. From this perspective, rituals of dirt avoidance go back to primitive cultures and religious ideas about purity and defilement, although at the present moment they are also very influenced by our recent knowledge in pathogenicity. Douglas proposes that a common, abstract factor for these ideas is the fact that dirt belongs to the order of a system, where 'dirt' means something is out of place. Ancient taboos about 'abominations' involved things that exist between two distinct categories (male or female but not transgender, lesbian or gay). Pollution behaviour, according to Douglas, is then a reaction against anything that contradicts valued categorisations.

Feder (2015) contends that a way forward to understanding the interplay of contamination appraisals, pollution beliefs and capacity for disgust might be to recognise the latter as universal, while the modes of expressions in responding to it are mediated by the sociocultural context. This could help to reconcile tensions between naturalistic and social scientific approaches in understanding the relationship between disgust, contamination, and culture-specific pollution beliefs from an inter- and multidisciplinary perspective.

I agree with Feder. An evolutionary perspective might help us understand how disgust, as a universal emotion, could be used to enhance our embodied practices of hygiene. However it does not explain why medical professionals, who understand disease transmissions through pathogens, fail to ‘use their judgement’ in order to avoid contamination and follow sanitation practices in health-care facilities. On the latter, Douglas’ ideas about the order of a system might be more helpful. For example, preterm babies could be seen as out of place in the neonatal unit when; they are not foetuses anymore but they are not seen as fully developed babies. As such, they might be seen as ‘disease’ holders who will inevitably pass on their diseases to others.

The second plane of human social being has shown tensions that arise in the neonatal unit within interpersonal relations. The next section reviews the interaction of human agents and structures.

4.4 Plane 3: social structures and relations of power in the neonatal unit

The third plane of social being ‘concerns general social relations and structures, which endure over time and cause and shape events’ (Alderson 2013, p.95). This section will look at the power relations that take place in that interaction between social relations and structures.

As a starting point, I will use Foucault’s ideas about power (Foucault 1982) in order to localise them within the neonatal units. I then turn to critical realism to deepen the analysis using Bhaskar’s concept of *natural necessity* (Bhaskar 2008b; Bhaskar 2008a; Bhaskar 1998).

As a summary, *natural necessity* (introduced in Chapter 3) looks at social events in three different levels. In the *empirical level* events are perceived through our senses; the *actual level* refers to events that occur whether we are aware of them or not, the *real level* refers to mechanisms, that are powerful but might not be visible, and which cause events to happen. In order to identify these mechanisms we need to use *retroduction* (Bhaskar 2008b, p.109) which refers to models of analogy.

In Michel Foucault's influential study of relations of power in institutions, power is not just a mere relationship between partners but a form in which certain actions modify each other. Moreover, power exists only when put into action, it is not a manifestation of consensus, nor is it a renunciation of freedom itself or a transference of rights and it is not always a repressive force (1982, p.788). In other words, Foucault contends that power is not possessed but exercised.

In order to analyse how power is exercised, he proposes it needs to be understood as the interaction of three different domains: capacities, relations of communication and power relationships. In a hospital for example, technical capacities might be put into action by trained healthcare professionals; information can be shared through doctors' rounds and meetings, nurses' hand-overs, interactions between healthcare professionals and parents; and relationships of power are accommodated in a distinct hierarchical organisation, which leads to a well-regulated system (Foucault 1982, p.787). Discipline is imposed when the technical capacities in operation, the relationship of communications and the relationship of power adjust to one another.

Specifically, Foucault provides a framework to analyse how power is exercised in institutions (1982, p.792) through looking at systems of differentiation, types of objectives, means of bringing power relations into being, forms of institutionalization and degrees of rationalization. These will be exemplified below through the analysis of data.

For Bhaskar, power can be seen in two different forms:

Positive power₁ is 'the transformative capacity intrinsic to the concept of agency as such' (2008b, p.153). This will be reviewed further in plane four of inner being in section 4.5.2.

Negative power₂ in contrast

is the capacity to get one's way against either the overt wishes and/or the real interests of others in virtue of structures of exploitation, domination, subjugation and control (Bhaskar 2008b, p.402)

This is seen as *master-slave* relations. In these relations each element is distinct but at the same time dependent on the other; '[a] person can only exist as a master or slave, a teacher or student, a father or son, in relation to the other' (Alderson 2013, p.111)

Power relations in this view take place within the relationship between human agents and structures.

For Bhaskar,

social structure is a necessary condition for, and a medium of, intentional agency, which is in turn necessary for the reproduction or transformation of social forms (2008b, p.154)

This is represented in the *transformational model of social activity* (TMSA), in which, Bhaskar argues

intentional causality would be impossible without material causes which pre-existed it; and [...] social material causes exist only in virtue of the embodied intentional agency which reproduces and/or transforms them (Bhaskar 2008b, p.155)

From a critical realist stand, structures precede human agency but do not determine it; on the contrary, human agency reproduces and transforms structures through praxis. It is within this interactive framework that society is constituted and social relations take place, mediated by space and time (Alderson 2013 chapter 5).

I now turn to the analysis of power in the research sites.

4.4.1 Power relations at the empirical and actual level

a) Systems of differentiation

Gowns, masks and hats in the intensive care unit appeared to be used, not only to prevent cross-contamination, but also to differentiate doctors (as scientific, high ranked professionals), nurses (as technical workers) and (lowly) service users.

Doctors could be identified by their white gown as they arrived or left the hospital, and also when they attended meetings, conferences, during their break or at after-discharge consultation. When they came into the unit, they wore a blue gown, like the parents. However, in MDH doctors wore the gown in a different and very distinctive way to the parents; the opening went to the front, crossed over (as it has been designed to be worn) and tied over the shoulders (although when they just came in briefly they did not always tie it, leaving their clothes exposed). They only wore hat, mask and gloves when performing a detailed procedure, such as inserting a catheter.

Nurses came in and left the hospital in their white uniform with blue vest or sweater, and some of them also wore their nursing cap. It was mandatory to wear this uniform for any activity outside the unit. As for coming into the unit, nurses were required to wear scrub-type uniform, hat and mask.

Parents had to wear blue gowns, in the case of MDH, the opening went to the back. They were also required to wear hat and mask for as long as they were inside the unit. When gowns were scarce, it was expected that parents would wear doctor's gowns, after doctors had finished their round, but never vice versa. This revealed, once more, a deep belief that doctors (unlike parents) were not a risk of contamination. Research showed long ago that masks and gowns do not affect infection rates, and parents do not wear them in UK NICUs (Forfar & McCabe 1958), indicating that their purpose might be social control and performance, rather than practical action to prevent infection. They may be counter-productive in offering an illusion of preventive action and diverting attention from more effective methods. 'They are hot, uncomfortable and expensive...and make another barriers between parents and babies' (Alderson 1983, p.45).

The use of the sinks was similar, they worked as a symbol of status. The parents' sink was located outside the unit and, during my time in both hospitals, I never saw one staff member using them. Staff members' sinks were located inside the units, in contrast with outside sinks, these had motion sensors to open and close the tap, as well as the towel dispensers.

There were also clear differences when it came to food. Doctors could take a longer break and eat their food in the dining room area in both hospitals. Nurses could have half an hour break (except for members of the Union in MDH, more of this below), and in JDH they would also go to the dining room.

Parents were not allowed to bring food into the hospital at all, let alone into the unit, so it was difficult to bring their own food. They used to buy it from the stalls located in the pavement outside both hospitals. Some doctors and nurses would also come out and get food or juice from the stalls.

a) The types of objective

The very special case of MDH gives evidence of how political interests conflict with staff members' and patients' best interest.

Nurses who belonged to the National Health Care Workers Union in MDH were offered the 'benefit' of giving up their half an hour break during their working hours and leaving work half an hour earlier. First of all, it seemed like a paradox; nurses obtained the benefit of leaving work half an hour earlier, nonetheless they had to resign to their right of having some rest and time to eat/drink during their working hours of seven and a half hours (according to managers they had chosen to eat/rest on the way back home). The latter of course did not happen, what nurses did instead was to sneak their food into the unit and have it in a small storage room. This was not unknown to managers.

Offering this benefit had the purpose of gaining Union members even though it affected babies in the unit.

I asked Mr Diaz, the senior manager, about it. He answered:

This is stipulated in working general conditions and are Unions' benefits that go back twenty to thirty years, it replicates arrangements approved in National Unions that also apply to Regional Unions and, through this, workers obtain a series of benefits, that, as it happens some people make responsible use of and some others are more prone to saying for example 'I am late so I won't go and I will take it as an economic day'. (IS3)

When Mr. Diaz refers to people 'making responsible use' of benefits, he implies the proper form to make use of it would be not to bring food into the unit at all and therefore not having access to food or rest during the working hours. I was still puzzled, so I continued to ask.

Interviewer:

Is that a right you can give up? Because I suppose that not eating during seven hours and a half... I mean it seems almost impossible to me that one can work properly without some food

Mr Diaz:

Talking about people's inertia in a political context, when we talk about a contractor you can tell that person you are not allowed to eat and because he/she is subject to a contract they can't eat, or they do it during their break, but if you tell this to a member of a Union they accuse you of harassment, they gather more people and organise a strike [...] This [right to eat during working hours] is not a renounceable right, it is an administrative right so it is up to the personnel to take it or not...

Mr. Diaz' evasive responses mirrored the speech of a politician. This did not come as a surprise. Many people with political aspirations in Mexico, as in many other countries, hold key positions in public institutions. This is in order to advance their political career, or alternatively they are strategically positioned by the people in power in those places.

The case of Union benefits exemplifies how ulterior interests cast a shadow over babies' well-being and, in this case 'safe' practices around food aspects of infection control become rhetoric.

b) The means of bringing power relations into being

Cesar was cared for in intermediate care. His mother Julia came in every three hours in order to breastfeed. Cesar's twin sister, Iris, had already been discharged. Julia described a typical day in hospital:

My baby daughter (Iris) wakes up at around 6.00 or 6.30. I [breast]feed her and I go back to bed to sleep a little longer and I get up at 7.00. I have an older two-year old, I leave him ready [...] and I make my way here [to hospital]. I normally arrive in a rush at 9.00, at the 9.00 [am] feed. I feed him from 9.00-10.00 and go to the lactation room. I leave milk for his night feed and I leave at around 10.30 [or] 11.00. At 11.00 I go to take the register, it finishes at around 11.30 and there isn't much time left so, well I eat something because I get very hungry and I go to see the baby [Cesar] at 12.00, from 12.00 to 1.00 [pm]. At 1.00 I eat something else and they are now allowing me to stay in the Posada (only mothers who come from outside the city are normally allowed in) during the day because of my health (she had recently been re-admitted to hospital due to high blood pressure) and because I am not sleeping at night (she breastfeeds Iris through the night). If I have time I rest a little and at 3.00 I go to see the baby again from 3.00 to 4.00 and I go to the lactation room again at 4.00 and I finish at 5.00. I eat and rest a little [although] sometimes it's not really possible, or I read something to get distracted. At 6.00 I come in again to see the baby. I go to the lactation room at 7.00 and leave at 8.00 to go home [...] I arrive home at around 9.00 and I feed the baby [Iris], it takes her like an hour to feed and I go to bed at 11.00 and wake up at 12.00 [am] to feed her again and then like that whenever she wakes me up [to feed]... (IP15)

Power relations in plane three (social structures) emerge from events and relations at planes one (material relations with nature) and two (interpersonal relationships). In this case, power₂ relations are brought into being when women's bodies are regulated through tight schedules and routine practices. Even though women were recovering from surgical procedures, as in Julia's case, or from natural birth, they were expected to 'be good mothers', through being available, following instructions and providing milk.

The lactation rooms in both hospitals served to 'educate' mothers. Section 4.2.2 has mentioned different strategies used to 'convince' women to attend these rooms every

three hours; from explaining the benefits of breast milk to aggressive comments such as their baby being left without food if they failed to provide it.

In section 4.2.2 I argued that women seemed to be made ultimately and solely accountable for providing milk for their babies and that was a powerful discourse which might be difficult to challenge. However, keeping mothers 'busy' in the lactation room (when they were not with their babies) might have also been used as a means to 'control' them. If women needed to spend part of their day in these rooms 'for the sake of the baby', it was difficult to challenge restrictive visiting hours. Moreover, staff members' fear that mothers gathered to talk about things that happened within the unit could also be 'contained' in the lactation room; there was always a member of staff in there (normally a nurse student).

b) Forms of institutionalisation

The forms of institutionalisation can be identified in hierarchical structures when the moral order in the neonatal unit also reflected religious practices. The Anointing of the Sick, also known as Extreme Unction, is one of the seven sacraments in Roman Catholic Church. This consists on a priest laying his hands on dying or gravely ill people and anointing blessed oil for the remission of the sins mainly, but also in order to provide spiritual strength and with the hope of healing.

During one of my observations I saw the priest, dressed in his black gown, coming into the intensive care unit. He did not wear a hospital gown as everybody else, nor did he wash his hands at any point. He approached each bed and anointed oil on every baby's forehead, saying a few prayers and making the sign of the Holy Cross (See Figure 7). Since it was not visiting time there were no parents in the unit and therefore consent to perform this act was not obtained.

According to Mr. Diaz, one in four babies died in MDH. That did not account for the babies who were denied admission into hospital when capacity was exceeded, or babies who died during birth or all babies who survived but would have profound impairments. Perhaps the priest provided a type of salvation that doctors could not offer. And then again, it seemed that the fact of being a priest provided a status of purity which needed no other cleansing process.

c) The degrees of rationalization

Sections 4.2.1 and 4.2.2 have shown how hygiene and breastfeeding are used as technologies, in the form of discursive practices, in order to implement power.

Taking the register in the morning (*pasar lista*), queuing, wearing ‘uniforms’ (in this case gown, mask and hat) or asking for permission to come into a room are common characteristics from schools, where pupils are being educated through discipline. When rules are not followed, there tend to be consequences. A common theme during interviews and informal conversations with parents in MDH was the importance of taking the register in the morning.

You see, they tell us that, supposedly, if we don't come, they report our baby to... the authorities or something like that (IP10 in field notes)

However, when she says ‘supposedly’, this mother implies that she is not completely sure that authorities will be indeed notified if she fails to take the register. This shows that parents might adhere to the rules, although they not always believe there will be consequences if they do otherwise.

I asked a social worker if they would actually report parents who fail to take the register and she said:

By law, after 72 hours [of not coming to see the baby] it is considered as abandonment [...] we ask them to report with us every day so as to verify that they are attentive to their baby and at the same time to inform them, I don't know, if [...] there is any situation that has come up when they were

absent [...] But by law we do have to report them after 72 hours...obviously, before reporting them [to the authorities] I double check in the unit because maybe they did not come to me but they go directly to the unit [...] (IS6)

The social worker also explained she was in communication with doctors. If a parent failed to visit a baby, doctors would tell her. 'Pasar la lista' every day could be seen as a technology of surveillance of parents.

Examples throughout this chapter have shown how parents and staff members question some of the practices in these units when they find them contradictory. These contradictory practices also exacerbated parents' feelings of anxiety and frustration. This first analysis provided a description of events that occur within the realm of power relations. The next section will explore underlying mechanisms that could explain why these events happen.

4.4.2 Beyond the empirical and the actual

Lack of resources, poor infrastructure, over-crowding and under-staffing were evident conditions in these hospitals and were a common theme in interviews, informal conversations and in the surveys administered to staff. Healthcare workers' frustration partly emerged from these lacks but seemed to be increased by the belief that parents were ignorant and unhygienic, ultimately unable to care for the babies they desperately tried to save. Illusions about (doctors') purity and (service users') impurity seem to belong to perceptions of the social order.

'The types of objectives' in the previous section explained why nurses, who are members of the Union in MDH, brought food into the unit. However, eating in the unit was not exclusive of this group. I talked with a nurse who did not belong to the union and she explained:

We have no cover during our break, if I leave the unit one of my colleagues will have to look after my babies [and theirs], and if something happens meanwhile I am to be blamed. (IS8)

This was corroborated by Mr Diaz, the senior manager, who explained under-staffing was a serious problem in the unit.

A flat analysis of the empirical and actual portrays 'irresponsible' and 'negligent' nursing staff who only care about their own well-being, because the Union advertises a 'benefit' in being able to leave early. In looking at hidden mechanisms within structures we can gain a better understanding of the situation. Leaving the unit for half an hour break was not a choice for nurses in MDH: they needed to change their clothes and go to the cafeteria in the adjacent building, this left them with little time to eat. Additionally, taking a break put babies at risk and increased the workload for the ones who stayed. If something happened to a baby while they were resting that could make them look negligent, whereas increasing the risk of infection by bringing their food in was less obvious and no direct blame could be made, babies got infected anyway.

Detrimental conditions in which the staff in these units had to work exemplify master-slave type of relations. Once a doctor told me she was in charge of the patients and, at the same time, she was undertaking administrative work: the chief of the unit was on holiday. On that day she and a resident were the only doctors in the unit with 12 patients.

Additionally, she said:

There are 10 babies waiting [in the recovery area] to be allocated a bed in intensive care and we only have four ventilators available. (IS7 from field notes)

She added:

I already told the directors that I will send all those families with complaints to them because I can't take anymore. (Field notes)

Political decisions affected not only babies and families in general but also staff members, as a manager explained:

When this hospital was built, it was designed to be a level I care hospital. If it was kept as such, this would be a first class unit. But, due to a political decision, it was turned into a [higher] level III and we just can't manage. (IS16)

The power of the church

The power of the Roman Catholic Church is evident through the example of the priest seen as the purest moral figure in the neonatal unit, who does not need to wash hands or wear a gown and who is allowed to anoint every baby using the same oil, defying every measure of prevention of nosocomial infection in the unit. The result being that not even scientific medical knowledge questioned the priest's authority in the baby unit, perhaps because of the sanctity he represents.

The Catholic Church in Mexico has also been very influential in matters of women's sexual and reproductive autonomy, intersecting with political issues in a secular state. Amuchastegui and colleagues (2010) analyse two historical moments in Mexican politics that were contested by the Catholic Church, in alliance with conservative factions in government and civil society: the inclusion of emergency contraception in public health services in year 2004 and the decriminalisation of abortion in Mexico City and its re-criminalisation in 17 states of the federation. The debates sustained at the time exemplify the need of different institutions to 'govern' and 'moralise' the sexual and reproductive freedom of the less rational groups: women and young people. Treating women like children or, in other words, infantilising them was common in these units.

Ideas about 'irresponsible, hypersexual and promiscuous (low-class) women' in these hospitals will be analysed in the following chapter. These views position women as accountable for 'filling up' hospitals with the ill-functioning and sometimes undesired or inconvenient products of their immoral behaviour. In 2014, when this study took place, reproductive rate in Mexico was 2.2 children per woman. However this might not be the representative number for the poorest women in the population.

The influence of colonialism

Old powerful, hierarchical and patriarchal historical structures, such as colonialism that continued for 500 years in Mexico, take on new forms and adapt to carry on in new ways. Middle class female doctors and other healthcare professionals, such as the social workers, seem to reproduce the colonialist/occupied dualism. Structural morality, the idea that moral goodness belongs to the former, pervades their interactions with the low-class service users.

4.5 Plane four: inner being

The fourth and last plane of social being is concerned with self-awareness and flourishing. This section will review how parents make sense of some of the discourses shown in previous sections and will begin to review possibilities for flourishing.

4.5.1 Parenting in the unit through the discourses and practices of medicine

Parents in the neonatal unit seemed to incorporate a view of themselves which was in line with ideas about their impurity. I interviewed two parents who were also health professionals. It was very interesting to note how, when talking about their ‘role’ as parents and not as doctors, they assumed themselves as impure.

Bety was a mother and a specialist doctor. When I asked her whether she thought she could participate in her baby’s daily care she told me:

As a mum I would love to spend hours with him, but as a doctor I tell you babies are highly susceptible to any type of illness; we come from the street, maybe we stepped on excrement, the dog, fluff, if we come in every now and then it will harm them. Babies’ skin is very sensitive, moreover if they are premature, so any little thing can infect them so, as a doctor, I tell you I believe it is fine. (IP16)

Within this medical discourse, Bety positions herself as a mother at the bottom of the hierarchical (moral) order in the unit. Something similar occurred with Rodolfo, who was a general practitioner. His baby girl had recently been admitted to the intensive care

unit, when I asked him whether he felt the visiting time was enough to be with his baby he answered:

No [it's not enough], I would like to spend more time with her but I understand she is in an area where we can't stay all the time because it represents contamination for them...but I feel relaxed because I know they are watching her, they are evaluating her and they are giving the attention she needs. (IP13)

When I asked him to explain me more about how parents can contaminate babies he said:

Yes, we come from the street, the air is blowing and all that is contamination, bacteria, the man next to me has sneezed and spread his bugs, his viruses and all that you bring it into the unit in your hair, your clothes, your shoes...

It was interesting to note how both parents felt the need to make a distinction between them being a doctor and them being a parent. Section 4.2.1 showed how Rodolfo also talked about this double identity when he suggested he only looked at other babies during visiting time from a doctor's point of view, but he observed other parents and learned from them from a parent stand.

Other parents also identified themselves as a risk. Guadalupe was born at 28 weeks of gestation. He had been critically ill in the last few days. His father Gerardo said:

The most important thing, as the doctor says, is hygiene and when he is very delicate not to touch him, or not to talk to him and try not to make it worse by moving him. (IP20)

When asked whether he had held his baby Juanjo, born at 27 weeks of gestation, Enrique said:

Yes but not for very long periods...because since they are very delicate they let us hold them to give us that joy and for them to know we love them. (IP19)

Leopoldo also commented about his baby Edwin, who was born four weeks early:

Mine is very delicate so I cannot come and hug him or change his nappy because only they [the doctors and nurses] know how to do it. (IP18)

Some parents understood medical staff had medical knowledge, but believed their knowledge as parents was also valuable. Julia identified her baby had diarrhoea (in section 4.3.1) because he was emptying his bowels more often, but the nurse contended 'it was normal', and Julia argued:

...I mean I am seeing it, I know him, I change his nappy, I know his poo and I know my other two children's poo and this colour is not normal, the smell is not normal and it is not normal that he is doing [a poo] after each feed. (IP15)

Gendered roles of mothers and fathers as depicted by parents and healthcare workers will be reviewed further.

4.5.2 Flourishing

Power₁ entails the possibility of change and brings about the capacity of emancipation and flourishing

such as our capacity to investigate, communicate, plan, construct moral and ethical systems, feel and care for others, and come to agreement based on judgemental rational argument directed at practices that transform our lived circumstances (Hartwig 2007, p.372).

Because of the nature of ethnographic research, I developed a relationship with staff members and parents in the unit, especially with parents whose babies stayed there for months. They often came to talk to me about things that concerned them, especially on topics we had previously discussed in interviews.

Ana, mother of Pedro, came to find me one day and said she wanted to contribute to helping other parents through my research. She told me she had recently met a father who could not read and write. If this was the case, Ana wondered how he would be able to learn about hand-hygiene from the posters. Therefore, she thought she would like to

volunteer in talking to other parents about hand-hygiene, even when her baby was discharged. Ana had previously told me she regretted not having finished her studies because she became pregnant with her first child very young. This, she thought, was an opportunity to do something meaningful, apart from being a mother.

I discussed this idea with another senior manager (SP25), who recalled a time in which they successfully involved a group of parents in order to implement changes in the unit. He thought having parents volunteering to help others was a feasible option.

Planes one, two and three in this chapter have shown beliefs in these units that ‘there is no alternative’ to fighting infection. *TINA compromises* (Bhaskar 2008b, p.362) stand for ‘there is no alternative’. These can be described as false necessities that become necessities in their own right when accepted (Norrie 2010). The question here would be, might detrimental hygiene practices, which are mediated by ideas of moral purity and impurity, contribute to the unacceptable infection rates in these units?

4.6 Conclusions

Psychological distress pervades parents’ time in the NICU. Extremely reduced time to be with their babies; grief, trauma and terror of losing their child; inability to advocate for the well-being of their own baby; not being able to care for their baby and yet being constantly blamed for whatever happened to babies. All these events exacerbate parents’ anxiety and created tensions in their relations with healthcare workers.

Theory/practice inconsistencies, according to Bhaskar (2008b), are contradictions between beliefs or rhetoric and practices. This chapter has started to show some of those inconsistencies between the ‘strict’ rules in the NICU and day-to-day events.

Parents were constantly warned about dangers such as lack of hand-washing, miss-use of gowns, mobile telephones and food inside the unit. All these posed a risk of infection to their babies. However, in practice, doctors and nurses had a more relaxed approach

towards these rules; a reality that might also be very distressing and frustrating for parents.

Theory/practice inconsistencies are counter-productive not only when they undermine therapy and healing but also when they increase infection, anxiety, stress, distress, uncertainty and fatigue.

Master-slave power relations emerge in a system where 'healthcare' professionals (such as social workers and nurses) who in theory should support parents (power₁) are expected to coerce parents into following rules and threaten them when they fail to adhere to norms (power₂)

The critical realist concept of *four planar social being* helped to identify hygiene-related discourses and practices, along with contradictions that arise from them in the two research sites.

The notion of 'biopolitical strategies' was introduced in Chapter 2. This refers to strategies of management of everyday human practices through technologies of power and knowledge that neoliberal states use to regulate society (Foucault et al. 2010; Nadesan 2011). Through the use of technologies of the self, neoliberal governments aim that individuals will internalise social norms and exert their own self-government. Practices that seem to be in line with such technologies and norms include: education of women, not only about breastfeeding but also self-hygiene, in lactation rooms; the 'physical sacrifices' they are required to do as a sign of love for their children; and the tacit assumption of parents not staff being ultimately responsible for preventing risk through hygiene and breast milk.

Additionally, the implication that people in private hospitals receive better care because they are clients who pay for services also reflects neoliberal thinking, whereas free health services for the poorest groups are like, in Bourdieu's (1999, p.182) comment, 'a state charity, which is destined, just as it was in the good old days of religious philanthropy, for the deserving poor'.

In these hospital, babies' fate seems to be to get infected if they want to be saved. The following chapter will show other 'unavoidable' or possibly avoidable harms babies are to endure in order for their lives to be saved.

Chapter 5 Dignity in the neonatal unit

5.1 Introduction

‘Dignity’ was chosen as the overarching theme of this chapter. Dignity is usually identified with adults, but as a concept it can help in understanding and even resolving many contradictions that take place in the neonatal unit when its crucial qualities are recognised as relevant to babies too. Dignity might also contribute to the recognition of the difficult task that doctors and nurses undertake when they are confronted with uncertainty at the beginning of life and the great suffering of their little patients and their families.

The worth of human life has been advocated by thinkers over the years through the concept of dignity. Yet, the literature review below shows it has also been contested as too vague and problematic to be useful, for example in bioethics. Historically, dignity has been accorded to rational powerful and elite people and denied to others, such as women and children.

Dignity might seem more of a topic for philosophers and bioethicists to address. But the concept is constantly transferred into practice in the busy NICUs when, for example, practitioners are confronted with ethical dilemmas at the beginning and end of life. This raises practical questions that need to be addressed such as: does dignity in neonatal care sometimes feel more of a burden than an entitlement? Can concepts of dignity help to inform attitudes and practices towards babies and their mothers? Or are concepts of dignity more likely to be used to discriminate against them?

I begin by briefly mentioning some notions of the soul. Dignity, as we generally use it today to denote the intrinsic value that every human being possess for the simple fact of being human, has its origins in ancient discussions about the soul and human spirituality.

Integral part of being human, different events that take place in the NICU of JDH and MDH, and that I connect to dignity, will be seen through the lens of four planar social being.

On plane one of material relations I describe the embodied experience of babies, who are cared for in the NICU. Especial attention is given to physical pain of babies as patients and mothers, whose body recovered from giving birth. I also draw on exhaustion experienced by babies, parents and staff, and how all these experiences affect the interrelated dignity of babies and adults.

Plane two of interpersonal relations looks at complex relationships of communication. It shows how power₂ relations can be established through withholding information from parents, which in turns provokes distrust that undermines respect for dignity. It also shows how private matters can easily become public in these hospitals.

Plane three of social structures looks at hidden but powerful forces such as gender, which shape the type of relations that are established in these institutions.

Plane four of inner being presents a critical realist account of the Self, in order to make an analysis of how ‘the other’ is perceived. It shows some splits and fragmentations of the inner self when humans are confronted with suffering and pain, or when consciously or unconsciously emotions are denied.

Children’s rights, and possible ways in which they enshrine dignity, are considered throughout the chapter in an attempt to begin a conversation around their implementation in the NICU. This will be followed in the next chapter of well-being.

5.2 Development of dignity as a principle

Ancient Greeks such as Plato or Aristotle pondered the concept of the soul. What gave human beings unique dignity, compared to other beings, in the eyes of these thinkers was the fact that humans are capable of spiritual activities (Andorno 2014). Yet in

ancient Greece not all human beings had the same worth, public distinction and recognition were only given to certain people (Reis Monteiro 2014) and slavery was normal part of life. Following the concept of spirituality, Roman Stoic philosophers seem to have coined the term dignity (*dignitas*) ‘to indicate the intrinsic and universal worthiness of human beings’ (Andorno 2014, p.2).

Ancient Greek and Christian philosophical concepts of spirituality and immortality of the soul constituted the base of the intrinsic moral worth. That these ideas are universal is illustrated for example by Chinese philosophy, which has also developed the concept of dignity based on Confucianism, ideas about a sense of justice and the capacity to become good, among others, make human beings unique. In Islamic tradition the Qur’an, the sacred text of Islam, describes features that assign dignity to all human beings such as intellect and freedom (*ibid*).

Eventually, ideas about the soul were transferred to secular domains. A very influential account of human dignity was developed by Immanuel Kant at the end of the eighteenth century, in which the ‘freedom to conceive and follow the moral law’ (*ibid* p. 2) is a key component that differentiates human beings from other beings.

Kant poses an argument to explicate his concept of dignity, in which persons ought to be ends in themselves and never means to other people’s ends. This is accomplished through morality:

Now morality is the condition under which alone a rational being can be an end in himself, since by this alone is it possible that he should be a legislating member in the kingdom of ends. Thus morality, and humanity as capable of it, is that which alone has dignity (Kant 1972, p.47)

Notably, Kant links morality and dignity to being rational. Kant’s concepts of active and passive citizens are useful in understanding how the philosopher distinguished rational men from ‘the rest’. Three attributes characterise citizens in Kantian thinking: freedom, equality and independence. Free (as human beings) and equal (as subjects) are characteristics of both active and passive citizens. However, ‘passive citizens’ (such as

women, children and servants) are auxiliaries of ‘active citizens’ from whom they receive orders and protection. The latter then are independent from the will of others and, as such, independent to be their own masters (Mendus 1987)

A critique of Kant’s work advanced by Mendus (and see Alderson 2013, pp.145–6) who proposes that in retaining hierarchies, which reserve respect for rational and independent men, Kant discriminates against women, children and employees. Perpetuating old hierarchies in modern systems results in social constructs, such as IQ measurements, that preserve the interests of the powerful.

The critical realist philosopher Christian Smith (2010, p.435) argues that human dignity, understood as ‘an inherent worth of immeasurable value that is deserving of certain morally appropriate responses’, is a real feature of human nature; this is, the concept is not simply a social construction of a group of people who legitimate it through their discourse. Human beings’ ontology, according to Smith is characterised by real dignity, which makes us worth of respect, justice and love.

What makes us recognise the dignity of all people is the fact that it is ‘ontologically real, analytically irreducible, and phenomenologically apparent’ (ibid, p. 443). It exists even when it is not recognised given that it is inherent to all people, even to those who deny it. The fact that it is sometimes violated means it was real on the first place, otherwise there would be nothing to violate.

Commitment to human dignity is reaffirmed in the ethics of biomedical research, an example of this is the *Universal Declaration on Bioethics and Human Rights* which recognises ‘that ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms’ (UNESCO 2005; United Nations 1989).

Andorno (2014) asserts that the weight given to dignity in contemporary biomedical research indicates that the promotion of respect for the inherent worth of human beings,

as well as the preservation of their identity and protection from possible harms, is a real concern. But then again, he argues dignity on its own is not enough in solving dilemmas that arise in research. To address those dilemmas, the author proposes human dignity, as an overarching principle has to be combined with human rights as a practical guide.

However, transferring philosophical concepts into practical aspects of life might raise further problems. For example, the bioethicist Macklin (2003) and the psychologist Pinker (2015) propose the term is too vague to be used in medical ethics.

This scepticism is based not least on the impression that the concept of human dignity possesses so little tangible content that it can be deployed to support or undermine any position whatsoever (Rothhaar 2010, p.251)

Macklin (2003) suggests the term needs to be defined if it is to be used in medical ethics and proposes that, as it is now, it means no more than respect for autonomy and for the wish of the living.

For Pinker (2015) the term is useless and detrimental to scientific research. His argument is based in the idea that the benefits of research in biomedics are superior to the ‘speculative’ harms and therefore ‘truly ethical bioethics should not bog down research in red tape, moratoria, or threats of prosecution based on nebulous but sweeping principles such as “dignity,” “sacredness,” or “social justice.”’. An alternative according to the author would be that unanticipated problems are dealt with as they arise.

Even though substantial advancements have been made to promote high levels of respect and care for every human being in healthcare research, it is evident that dignity is a complex concept, and different questions arise when we refer to preterm or sick babies.

If dignity is a characteristic inherent to every person, the very first question that needs to be answered, or at least attempted to be answered is: when does the ‘person’ begin? Philosophers and scientists have tried to elucidate the response to this question over the years and so far no agreement has been reached.

5.2.1 The beginning of a person

Christian philosophers consider that ‘no human being needs to earn the right to be treated with respect or dignity’ (Wyatt 1998, p.142). Being made in God’s image makes human beings unique, dignity is thus intrinsic to humanity. Moreover they propose life is sacred and infinitely valuable in its own right. All members of the human community: babies, adults, people with disabilities, men and women, we all have the same worth. For Christian philosophers, such as Wyatt, the life of the newborn baby, term or preterm, with or without disabilities, should be saved unless there is no hope for the long-term survival of the child, and only then treatment might be withdrawn.

Conversely, Kuhse and Singer (1985) propose that the person begins with the capacity of self-awareness and therefore newborn infants do not possess a right to life. The authors suggest that, at birth, the infant is no more than a physical organism who gradually becomes a person as self-awareness develops.

Similarly Harris (1985, pp.18–19) asserts that the person begins with the ability to value its own existence. In order to value one’s existence we need self-consciousness and ‘once this threshold is crossed, no individual is more of a person or more valuable than any other’. Thus, the moral difference between a person and a non-person is the capacity to value life and ‘language is the hallmark of self-consciousness’. This view undoubtedly leaves babies, and moreover preterm babies, in limbo.

In studying the emergence of consciousness in the newborn, Lagercrantz and Changeux (2010, p.201) provide a basic definition of consciousness as ‘awareness of the body, oneself, and the outside world’; a requisite for the newborn baby to be considered conscious is to be awake and aware of outside stimuli and not only to react by reflex. According to the authors, the moment of birth plays a crucial role in ‘awakening’ the baby, a process which ‘is enhanced by the release from endogenous analgesia, possibly caused by... placental “suppressors,” which *in utero* selectively inhibit neural activity of the fetus’ (ibid, p.205).

Debates on human dignity and the beginning of personhood raise many questions, especially for the seemingly least rational and powerful human beings, premature and sick babies.

Authors who deny personhood to newborn infants seem to commit the *epistemic fallacy*, when they imply that our lack of knowledge and understanding of babies' (rudimentary) capacities are reason enough to consider them pre-humans. Moreover, by denying human status to babies, they deny all possibilities to advance human dignity and enjoyment of human rights at the beginning of life.

The rest of this chapter connects concepts of dignity to everyday existence and experiences of the babies I observed and their families.

5.3 Thinking about dignity in the real world

I begin by telling Tere's story, with the hope that it can begin to illustrate the theoretical debates reviewed so far. On one sunny morning she...

...lay slightly on her left side in an open incubator. A thin flexible feeding tube passed through her mouth. A sensor attached to her right wrist, and two sensors attached to her chest, picked up her vital signs; these were shown on a small monitor standing opposite the incubator. A bright lamp stood on the right side of the cot and lit Tere's fragile body. In this unit they used lamps to keep babies warm. Tere wore a hat, striped with blue and pink, and a big disposable nappy that covered part of her tummy and chest. The nappy was also used to restrict movement in her arms, which were kept inside the nappy on her sides. A pink bracelet (ID) surrounded her right ankle, I couldn't see if her name was written on the bracelet; she kept her right leg resting on top of the left one and covered the name-tag. A 'nest', made with rolled sheets, surrounded her body. This was supposed to provide 'containment' but in this case it seemed to be wide and loose. Her nurse made some notes on a table on the right side of Tere's cot. I said 'I think it's a girl right? Is she very active?' 'It's a boy' she said, 'I am getting ready to clean him', 'I can see a pink bracelet...' I responded, 'oh yes' she said, 'I hadn't noticed, then the boy is the one on the next cot... I can't recall her name'. I turned back to see the little girl. She kept her eyes opened wide, made a crying noise and arched her back; her face turned red, followed by a pale colour. She arched her back again and made movements with her

mouth, as if she tried to spit, I felt she was really uncomfortable and wondered whether she would be in pain. (From field notes)

Later that day I learned this baby girl's name, which I have changed here to Tere. Her mother told me she was born very premature and had been in hospital during one month and twenty days. To date, Tere's facial expression is vivid in my mind. Brief accounts of my observations partially represent the real being of babies, families and staff in the neonatal unit. This intransitive, ontological dimension of being contrasts with the transitive and changeable accounts of dignity that I have reviewed above.

I cannot claim to know, or fully understand the feelings of babies whose stories I try to portray in this chapter. Although babies are unable to communicate through language, I believe sensitive, empathic and experienced observers are able to interpret their subtle signs. I am thankful to parents who allowed me to observe their babies and I recognise my personal views, experiences, wishes and fears might have also shaped the final outcome in my descriptions. Still, I feel babies deserve to have their voice heard and their feelings acknowledged. I hope I was able to accomplish that to an extent.

The rest of this chapter is organised through the four planes of being:

- Plane 1: material relations with nature as embodied beings
- Plane 2: inter-personal interactions among people
- Plane 3: social structures (agency/structures relations)
- Plane 4: inner being (intra subjectivity)

5.4 Plane one: material relations with nature

To recall, the first plane of social being is concerned with how we, as embodied organisms, interact with the material world. Montagu (1986) argues we do it on the first instance through our skin. The author describes the skin as the first of the organs, with

the sense of touch, to develop and a very important means of communicating with the world early in life. However, he contends its importance is undermined. Biologically, the skin also performs important functions in the newborn baby such as infection control, protection from water loss, irritants and light (eyelids), resilience to mechanical trauma and thermal regulation, among others (Visscher & Narendran 2014). Physically and sociologically speaking, the skin is also the barrier between the self and the world.

From sticking tape that adheres and is torn off in order to hold tubes, to breaking it with needles, the thin and fragile skin of very premature babies is constantly traumatised in the neonatal unit. In addition, babies in MDH and JDH usually lay naked and alone on a flat mattresses. The quiet, warm, moist, infection-free and containing environment of the womb is suddenly turned into a painful post-womb reality.

5.4.1 Real bodies, real pain

Babies' bodies

The use of analgesia, anaesthesia and non-pharmacological pain relief techniques in neonatal care is relatively recent. Public debate around the question of when a human being starts to feel pain is still ongoing; in 1996 the *New Scientist* published a note highlighting three main hypothesis: some researchers claimed foetuses were able to feel a form of pain from thirteen weeks of gestation (when the first connections between brain and spinal cord are set), some others argued awareness did not develop until around thirty weeks of gestation (when the nervous system is more mature) and some others proposed it was only at birth (when there is consciousness) (Concar 1996). Latest evidence indicates that the sensory receptors of painful stimuli are present throughout the skin at 20 weeks gestational age (Buonocore & Bellieni 2008, p.59). It has been proposed that preterm babies are extremely sensitive to pain. However, pain in neonatal care is underestimated and pain-relief techniques, whether pharmacological or not, are only occasionally provided (Roofthoof et al. 2014; Cruz et al. 2015).

Babies' neurochemical reactions to painful events (Slater et al. 2010) correspond to the *intransitive* domain of being. In this sense, pain is a real condition of humans, born term or preterm. The person's experience of pain is *transitive* (dependant on interpretation, bounded in space and time), however we do not know how babies interpret painful experiences. Our understanding of babies' pain is also *transitive*: it depends on scientific discovery (in order to measure reactions) and it is informed by our own past experiences of painful events.

The bioethicist Bellieni and colleagues (2003) think preterm babies not only feel pain, they also experience suffering. Many parents I talked with shared the same thought. When describing the first time she saw her baby, Sonia talked about her baby Luisito being in intensive care and with sorrow she said:

I would have never imagined that so much suffering existed in babies. (IP6)

Parents tried to empathise with their babies' feelings, Enrique commented about his baby Juanjo:

I think he suffers, I think, because when they transferred him to the NICU they transferred him because he had an infection in the stomach, and when one is a grown up and has an infection one suffers isn't it so? (IP19)

Another father, Leopoldo, also mentioned how painful it was for himself to see his baby Edwin suffering:

My baby has felt the pain, he has suffered too much, and on my side I also feel it, it hurts to see him like that. (IP18)

Cassel (1992, p.640), a Professor in public health, proposes that suffering might result from acute pain but is not confined to the physical domain. Moreover, it might be not only a result of a disease but of the course of treatment. In order to understand and attempt to alleviate it, the mind/body dichotomy needs to be resolved:

If the mind-body dichotomy results in assigning the body to medicine, and the person is not in that category, then the only remaining place for the person is in the category of mind. Where the mind is problematic (not identifiable in objective terms), its very reality diminishes for science, and so, too, does that of the person.

Not surprisingly, the idea of babies as people who might experience suffering is problematic.

Staff members, on the other hand, seemed more detached from pain, and failed to see how they could help babies during stressful or painful procedures:

Doctor Hector approached the cot where baby Paty lay on her back, performed the procedure quickly and went back to the desk, where he prepared the sample to be taken to the laboratory. Baby Paty was left crying and no one came back to check on her. (Field notes)

Later that day I asked this doctor (IS13) whether he had ever considered using or heard about ‘non-pharmacological’ pain relief. He looked at me and asked with surprise ‘for a blood test?’

The fundamental principle of medicine ‘first do no harm’ (*primum non nocere* in Latin) requires physicians (including students) to consider every possible harm that an intervention would cause and search for alternatives in order to minimise it. Making every effort to prevent pain and suffering in babies entails recognising them as people, worthy of respect and compassionate care. As with infection in the previous chapter, pain seemed to be considered an unavoidable and necessary harm in order to ‘help’ babies recover.

Bellieni and Buonocore (2008) propose that it is very difficult to establish a correlation between prolonged exposure to pain and its deleterious consequences in the short and the long term. Health providers would not be found liable for not providing pain relief. This leaves pain relief to clinicians’ ‘good will’. In plane four of this chapter I will review other possible explanations as to why preventing pain was not considered.

Cruz and colleagues (2015) argue that, the frailer babies are, the higher the number of painful procedures they undergo. In their systematic review, the authors also found that procedures, such as gastric tube insertion or suctioning, frequently involved multiple attempts. Multiple attempts to carry out a procedure are common in teaching hospitals (such as MDH), where junior doctors learn by practicing, often with several attempts, on each real patient.

On the other hand, it would not be safe to provide pharmacological pain-relief on every painful event in the NICU. The American Academy of Pediatrics (AAP) and the Canadian Pediatric Society (CPS) recommend the use of non-pharmacological pain relief strategies for 'minor' procedures such a heel prick (Batton et al. 2006).

Some non-pharmacological, evidence based, pain relief methods are:

- Breastfeeding or breast milk (Shah et al. 2012): Although more research is needed with preterm babies, performing painful procedures such as heel prick while breastfeeding seems to be highly effective in reducing pain. Not all babies are able to breastfeed in the NICU, alternatively, some drops of breast milk can be offered prior to the intervention.
- Sucrose/glucose (Axelin et al. 2009; Gerull et al. 2013): It is proposed that sweeteners help to increase the levels of endorphins in the body (Hall & Anand 2014). Although its use has been widely studied, there is still controversy in the dose and regularity of its use, especially with very preterm babies (Stevens et al. 2013). Sweeteners are normally offered two minutes before the intervention and can be combined with non-nutritive sucking from a dummy.
- Skin-to-skin contact (SSC) (Olsson et al. 2015; Johnston et al. 2014): Taking blood samples is a very common procedure in the NICU. This is done either by a sticking a needle in the heel (heel prick) or through accessing the vein (venepuncture). In either case, this can be performed while one of the parents hold the baby securely on their chest.

- Facilitated tucking (Axelin et al. 2009; Alinejad-Naeini et al. 2014): A parent or member of the staff usually holds the baby by her hands while the baby lays on a side in a flexed position to help to contain the startle reflex and to reassure.
- Non-nutritive sucking (Liaw et al. 2012) refers to providing babies with the opportunity to suck outside the feeding context, either from a dummy, their own fingers or a carer's finger.

These strategies are used in combination or individually. For example, Axelin and colleagues (2009) provided facilitated tucking and glucose during routine care episodes that included a skin-breaking procedure; Liaw and colleagues (2012) used non-nutritive sucking and facilitated tucking during heel-prick episodes and Olsson and colleagues (2015) provided oral glucose and SSC during blood sampling procedures.

Concern to respect babies' dignity and full humanity led Warren and colleagues (2016) to consider further support needed during painful episodes such as: modulated noise and light levels, having a second person to provide comfort, allowing the baby time to rest before and after the intervention and making sure the baby is left comfortable after the intervention. This is done in conjunction with some of the strategies described above. I was very fortunate to participate in Warren's study as research assistant. Because of this, I spent several hours observing babies and scoring pain using a scale. Probably, this made me sensitive towards babies' cues. For the present study I did not use a pain scale during my observations. As an ethnographer, I chose to observe and make notes in the end so as not to make people feel I was evaluating their work.

Pain in the NICU is hard to identify. Sometimes causal pain in very preterm or sick babies can only be seen in its effects such as changes in vital signs, skin colour, facial gestures or hands and legs movements (Holsti et al. 2008). It is also difficult to assess, staff members' need to be trained. But most importantly, pain, as an expression of babies' human awareness, need and dignity first has to be acknowledged if it is to be treated.

The highest attainable standard of health is considered in article 24 of the United Nations' *Convention on the Rights of the Child* (UNCRC) (1989), it also considers the abolishment of traditional practices prejudicial to the health of children. Although this usually means male and female circumcision, it can be more widely applied.

Baby Tere (at the beginning of this chapter) lay alone, on her back, naked, in a noisy room with a bright light shining directly on her face and her hands tied to the nappy, which might have made her feel very uncomfortable. As in Tere's case, it was common to see babies' hands tied inside the nappy. I wondered whether tying the hands helped to decrease the visible response of distress and made it more tolerable for staff to continue with procedures where they had to 'inflict' pain in order to save lives. It was also common that nurses placed the thermometer on babies' armpit and tied an arm into the nappy in order to hold it.

Brazelton and Als (1979) describe preterm babies' behaviour beyond reflex movement, for example, they describe forms in which babies are able to soothe themselves. One of these soothing mechanisms is by bringing their hands together or holding on to something. Very preterm or sick babies might not be able to do this by themselves, but a carer can help with strategies such as facilitated tucking with the hands near the baby's face, described above. Tying babies' hands into the nappy represents a type of power relationship, where the baby is left with no control over what happens to his or her body.

Article 12 from the UNCRC (1989) reads:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 13 also from the UNCRC (1989) makes reference to the freedom of expression, 'through any media of the child's choice' and this can include body language or crying.

Observing babies' body language and physiological reactions before, during and after painful procedures might help with understanding their subtle forms of communication when they experience pain. This is an alternative approach to 'listening' to their cues.

In these units, pain relief was only considered for major procedures. There was no protocol for the use of pain scales and pain relief techniques. Yet, healthcare professionals were aware of babies' discomfort. One senior doctor told me:

some of the things we do to babies in this hospital are very wrong, for example passing dried air into babies' lungs is like torture, I can't begin to imagine how that feels. (IS16)

Neonatal units are highly technological places and machinery needs to be kept in good order so that the best quality of care can be assured. One type of mechanical respiratory support for babies in the NICU is called High Flow Therapy. This consists of passing breathing gas in higher rates than the baby's inspiratory demands through a nasal cannula. The breathing gas is normally heated and humidified to make it tolerable. It was common in these units to hear that the equipment was not working correctly due to lack of maintenance or materials. This raises questions about the problems of exporting highly technological care developed in wealthier countries and adapting it to impoverished areas.

The UNCRC (1989) on its article 37 also asserts:

No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment...

Ironically, the (arguably) most vulnerable of all human beings are sometimes subject to the most aggressive treatments, that many would describe as torture, and this tends to be justified by the age/maturity or else the best interests arguments. Moreover, the reason for carrying out such procedures has to do with 'the intention to save lives' (article 6 of the same Convention). The *Convention on the Rights of the Child* is a comprehensive document. When articles 6 and 37 seem to be incompatible in certain cases, like this,

articles such as 24, which is about the highest standard of healthcare possible, might help reconcile them. Saving babies' lives can be accomplished through compassionate care.

Mothers' bodies

But then again, it was not only the babies' body which was in pain in the NICU. Mothers were usually recovering from a medical intervention. I talked to Karen, who came to see her baby Jose to the special care unit. As we walked together I saw how she pushed a (very heavy) door with her back (walking backwards), she told me:

...it's because of my wound [from the C-section], it hurts when I push the door. (IP17)

Despite being in recovery, mothers made an effort to stay close to their babies as long as they could. Ana told me about the time when she was discharged

...and in the next morning I was here already [outside the NICU] and I have not left since [except at nights]. (IP12)

Bety, another mother, also told me:

as soon as they gave me my clothes I forgot I had had a C-section, the only thing that mattered was to see my son. After a week I wasn't in pain anymore because the most important thing was to see my son. (IP16)

But it was not always possible for some women to be with their babies due to health difficulties, Julia said:

I came out of hospital and after two days I was brought back because the preeclampsia never stopped, so I only saw my [twin] babies once... for two weeks I stayed in hospital only knowing about my babies by the [medical] reports. (IP15)

However the situation of all these women whose bodies were recovering from a medical intervention appeared to be invisible. When I asked Julia what she thought could be improved for families she said:

there should be a place for us to rest because the ones [mothers] who are breastfeeding every three hours have to stay here all day, sitting on those hard things [cement benches] and if you lie down on them they tell you off, and when you just had an operation it hurts a lot, at least it hurts me a lot... when you are here you can't be in recovery, it hurts, I have pain in my hips, in my uterus, everywhere and it has already been a month and a half [since my babies were born].

I return here to critiques (introduced above by Alderson 2013; Mendus 1987) about the Kantian legacy on the rational and independent man; for it contributes to undermining attention to practical respect, physical and emotional well-being as part of honouring each person's dignity.

5.4.2 No time and no place to rest

MDH provided a shelter for women who came from outside the city. This place was commonly known as *Posada*. Karen (IP17), lived in a small town, four hours away from the hospital. She took me to visit the *Posada*, which she called her home:

It consisted of a one-storey structure that stood at about 500 metres at the back of the main building. A cluster of plastic chairs, standing in front of a small television, formed the sitting room. On the opposite wall a small freezer, a stove and a shelf made up the kitchen. A long table and some chairs in the middle of the big room provided a space for women to sit and eat. Two opposite rows of beds, divided by fake walls, made up 48 open dormitories in the next section. Karen took me to her 'room'. A blanket, a small bag with her belongings, a rolled towel, a book with prayers and a rosary rested on her bed. A communal shower and some toilets were available in the next room. (Field notes)

Karen considered herself a quiet person and liked to spend time alone in her room, praying for the fast recovery of her baby. However, she also thought it was lovely to feel the company of other women in the *Posada*, especially at night, when they talked about

their fears and worries and encouraged each other to be strong and have faith in that everything would be fine.

Karen also told me how grateful she was for being able to 'live' at the *Posada*. When her baby was born, he had to spend four days in A&E, waiting for a bed to become available in the neonatal unit. Although Karen had just been discharged after her caesarean, she spent some of those nights in the waiting area of A&E. Her partner worked 'away'¹⁴ and had not been able to come to meet them. She only got access to the *Posada* once her baby Jose was formally admitted into the baby unit.

Mothers from MDH who lived in the city, did not have access to the *Posada*. This meant they had to wait outside the hospital in-between visiting hours. Exceptions were made, as in Julia's case (P15). Given that she was not well, she was allowed into the *Posada* during the day. She told me many mothers went to the lactation room, even if they did not have any milk left, just to have a place to rest.

Although there were cement benches in the esplanade of MDH, another mother told me:

...the guards don't let us lie on them, they say it gives a bad image to the hospital. (IP27)

Image was indeed a worry for hospital managers in MDH. Before the *Posada* was built, parents used to camp in the esplanade. This represented a sanitary problem; there were no toilets available for them and they met their needs out there. But it also affected the image, since they camped right at the entrance.

A senior manager (IS25) told me how difficult it was to convince the parents to move away their tents after the *Posada* was built. Indeed the *Posada* represented a step forward for some of the women, but greatly affected the men.

¹⁴ Some fathers worked illegally in the USA and could not travel back home to see their families.

Nurse Gina explained her mixed feeling about it as:

The Posada is a step forward for a few mothers who can stay around but a massive step back for fathers and women from the city who were able to stay in tents. (IS34)

One father described his nights in the waiting room outside A&E:

...it is very cold, and the guards get annoyed because we stay there ...there are people like me who have been sleeping here for two months... I don't say to give them a bed but at least a shelter so that they can wait for their patients. (IP8)

Parents were asked not to leave if the baby's condition was considered too critical. They were also asked to be available in their mobile at all times, but charging the battery was prohibited within the building.

Furthermore, parents whose babies needed a blood transfusion were required to donate and find donors so as to replace the blood used. One father told me how frustrated he felt when he was told he could not be a donor if he had not had a good night's sleep, but at the same time they insisted he had to replace the blood used for his baby.

Nurse Luzma told me:

They [parents] come from far away and they have to stay around in case of a complication, if they go away they are told off (IS11)

JDH did not have a physical space for parents; mothers and fathers tended to wait on the pavement in the street during the day. All the people I talked to from this hospital went back home at night. This is because JDH was a level II unit, and it served local people, unlike MDH which was a referral level III hospital.

Respect for the dignity of staff

Lack of appropriate spaces to rest was not only a problem for parents. In Chapter four I described nurses' problems when leaving the baby unit. Nurses from JDH took half an hour break to go to the dining room, and organised themselves in order not to leave babies unattended. In MDH nurses basically did not leave the unit, they took their break and ate in a small room inside the unit.

Doctors in both hospitals had access to the dining room and longer break times. Still they constantly looked exhausted. One of them told me:

There are days in which I don't even have time to drink water, and (she laughs) when I talk to parents I fear I have halitosis (bad breath). (ISI)

Noteworthy, drinking water was not available in any of the units, people needed to buy bottled water in the cafeteria.

Doctors were very busy, especially if another colleague was on annual leave or sick, as there was no cover for them. Residents also tended to be extremely tired. On one occasion one of the residents fell asleep and failed to follow up on a very sick baby. As a punishment he was given three night shifts in a row. The incident escalated when he complained of a violation of his rights, and the doctor who had given the punishment was suspended from teaching. It was very common to see doctors and nurses with terrible colds going to work so as to have their working day paid, especially those who did not belong to the unions. This posed a real threat to very sick babies in the unit.

Degradation of the body and of human basic needs of comfort and relief pervaded life in the NICU in both hospitals; places presumably dedicated to scientific healing. Second class citizens, as they were seen, babies and mothers in these institutions endured pain and exhaustion and were cared for by exhausted members of the staff.

5.5 Plane two: interpersonal relations

The second plane of human social being is about interpersonal relations, in this case, the focus will be how information is shared in the doctor-parents relations.

The ethical principles of human research are encompassed in the *Declaration of Helsinki* (1964-2013) which can also be applied to medical treatment. Physicians are bound in the doctor-patient relationship to provide clear information to their patients or families. A comprehensive explanation when deciding about a course of action should include: what the intervention is, why it is necessary, the potential effects, the risks and benefits as well as possible alternatives.

5.5.1 Fragmented communication

Visiting time was the only opportunity that staff and parents had to talk, however establishing communication seemed to be hard. As soon as parents arrived, nurses and doctors retired to their working areas and started filling in notes, checking their mobiles or talking to each other. Understandably, this was one of the few moments they had to sit and rest.

In MDH, doctors gave parents information about their babies towards the end of visiting time, the report took no more than two minutes unless parents had further questions. In JDH mothers came specifically to hear the report outside the unit.

Teaching parents basic caring procedures was not considered in the NICU of either hospital, however some nurses did take time to teach parents how to feed or change the nappy if the baby's condition was not very critical.

In general, information exchange in these units took place during brief episodes and tended to be one-way: health professional to parents. This sometimes resulted in missing opportunities to explain to parents important information about their babies and to hear parents' doubts and concerns.

It was parents' visiting time in the NICU at MDH. As it happened, nurses sat on the table in the middle of the room and made notes while parents stood next to their babies. An alarm went off, it was baby Nuria's alarm, she had been born 33 weeks early and had been recently admitted into the unit. Her mother looked around concerned. The nurse walked past Nuria's mother, silenced the alarm, and returned to her desk. (Field notes)

It was very common to hear alarms going off in these units. Sometimes this happened when the sensors failed to pick up information from the baby. When this happened, nurses checked that everything was fine and silenced the alarm. With time, parents probably got used to hearing the alarms and ceased to worry when they sounded, but for Nuria's mother it did not seem to be the case. Still she did not ask the nurse about the event.

At some other times, babies were distressed and parents seemed to feel helpless when they did not understand the reason for it, or when they could not calm their babies:

Baby Rafa looked agitated while he lay on his back. He squeezed his eyes tight, brought his tongue out and cried. He tried to bring his right hand to his mouth, but he couldn't, he kept his left arm on a side. He brought his right hand to a side and then splayed the fingers of both hands a few times and stretched his feet. He kept crying. His father leaned forward, put one hand around Rafa's head and talked to him. Rafa's dad looked anxious... The nurse, who was sitting at a table on the right, said 'visiting time is over'. Rafa's father started to move away from the cot but he hesitated and moved back, the nurse said 'just leave him dad, he is agitated, leave him', his father left hesitantly and stood by the door for a brief moment, he then turned around and walked to the exit. The nurse continued with her desk work. (Field notes)

Baby Rafa's case not only exemplifies lack of communication with and support to parents, but also it shows how babies' communication efforts were not acknowledged by staff.

During interviews, parents conveyed how difficult it was to request information from staff members or to express their views freely. Dominga said:

They told me 'you know what mummy? You don't need to keep asking me if I already put this or that [medicine] to your baby, I have trained personnel here and they are in charge of giving your baby what he needs. (IP7)

Jasmin was worried about the side effect of oxygen on her baby's eyes, when she enquired about this the doctor answered:

if you want me to take it away I will, but your baby dies. (IP21)

Parents sometimes felt angry and frustrated when they were not informed about important events. Francisco, father of baby Ari who had just been admitted to the NICU told me:

They asked me to be around and reachable in case of a life and death situation, but when I arrived today I discovered my baby girl has some sensors on her chest and nobody has told me why. (IP28)

Bety, who was a doctor herself (though not in neonatology) told me:

Yes they do explain it to you but sometimes it would be good, maybe I don't know, that they explained it better, as a mum I would like them to explain it better. (IP16)

When we spoke, Bety constantly made remarks about her talking as a mother or as a doctor. In this case, I wondered what she meant by saying 'as a mum' as if she separated her being a (literate) doctor from an (ignorant) mother.

Another problem with communication was that parents sometimes found it difficult to understand what they were being told:

And then they speak in some terminology that you don't know, I mean the bilirubin, what is the bilirubin? I mean there was some terminology that I didn't know, I mean what was a CPAP? What is that thing they call ventilator? I mean now I am familiarised with the terminology... (IP12)

It seems that doctors felt challenged by parents who requested 'extra' information. At the same time, staff members complained about them being ignorant or in denial.

In conversations many doctors and nurses told me about parents' apparent denial of babies' deteriorating state by asking about more 'superficial' matters, such as the baby's weight gain, after they were told the very difficult news that their baby had a fatal condition. This behaviour confused and frustrated health professionals, and sometimes

made them conclude that parents were unable to understand scientific information. In contrast, some parents might have felt these minor queries were the only type of questions they were allowed to make; not only not challenging doctors by seeming to imply the care was not good enough if their baby was so ill, but reaffirming the professionals' expertise by asking for information about minor details.

Some parents with whom I talked were aware that their babies were very fragile, and the prognosis was uncertain, however they also expressed the need to be informed in an empathic, respectful fashion.

I mean there are different ways to say your baby hasn't got many possibilities but we will do everything in our power to help him get better. (IP7)

If the doctors were more, some not all, if they were more understanding with parents when they give us information. (IP6)

Nonetheless they also mentioned the need to know the honest truth. Julia told me:

I prefer to know things as they are and to be prepared, otherwise I wouldn't be able to cope. (IP15)

Trust is vital in healthcare settings. Parents seemed to be anxious and scared; they had to leave their precious babies in the hands of health professionals. When information was withheld from them, they became suspicious. This created tensions and misunderstandings. Power₂ relations seemed to pervade the processes of information (not) being shared in the units.

Figure 8 represents fragmented communication processes:

Babies (B) are at the centre of care. Doctors (D) and nurses (N) rely on the monitor (M) and clinical chart (CH) to interpret babies' condition, which doctors then scarcely communicate to parents. Nurses' exchange of information with parents is also minimal, more directed to guiding them through basic care routines. Nurses and doctors rarely

talk to babies themselves. The communication of health professionals and parents is done in one way, except for the social worker (SW) with whom parents tend to talk about administrative procedures. The social worker (SW), psychologist (Psy) and nutritionist (Nut) have a role in ‘educating parents’ and are seen as external to the unit. The dotted lines also show fragmented communication among healthcare professionals, who talk to each other only when necessary. Multidisciplinary team meetings were not held in these units, this means each healthcare worker took decisions about babies’ care without considering others’ views. Parents talk to babies and also interpret babies’ cues. They also try to take ‘hints’ from the environment to make sense of what goes on with their babies.

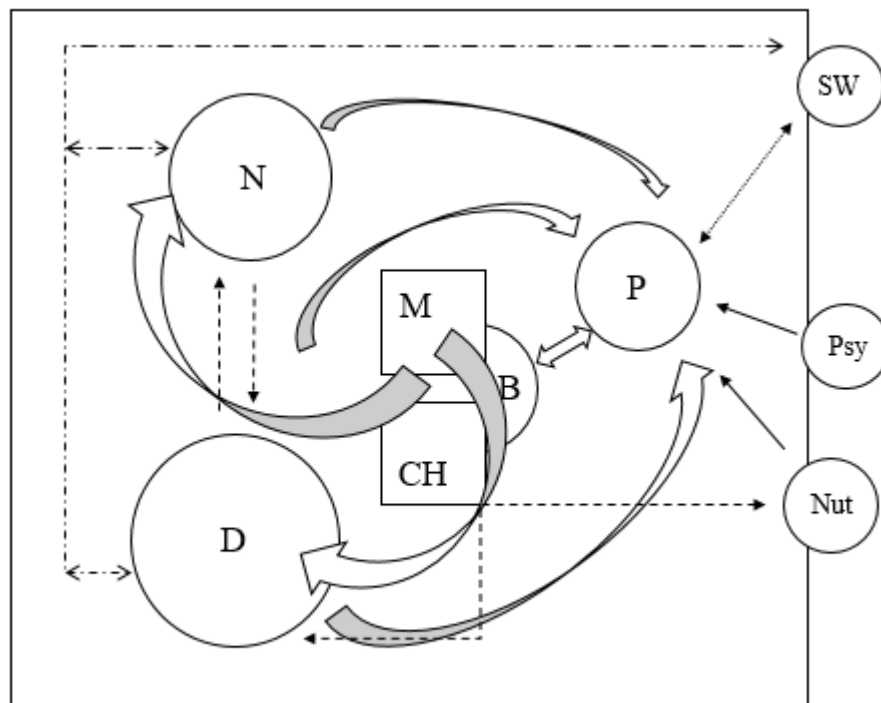


Figure 8 Fragmented communication

5.5.2 Private matters in a public arena

Intimate and powerful events took place in the NICU. Parents whispered their fears, hopes and dreams to their babies, they sang or prayed, they cried and held their baby for the first time. Unfortunately, in the face of death, some parents also said goodbye to their baby and all that their baby represented: their motherhood and parenthood, hope, joy, the idea of having a family and so on.

Disrespect for parents' dignity, for their feelings and status and privacy was shown by staff in several ways. In this public and crowded space it was difficult to maintain confidentiality, but moreover, this did not seem to be considered much by the staff, as if a public hospital entailed a public life.

Parents received the daily report from the doctors during visiting time. Some doctors provided this information at the side of the baby's bed, but it was also common to see parents being asked to come out and queue after their visiting time was over in order to receive the report. In one of my observations I witnessed how a couple were told there was no hope for their baby during one of these queues, in front of the rest of the parents. The couple stayed in the room, holding one another as they received sympathy looks from the rest of the parents. Everybody remained silent, heads looking down and sad faces left the room one by one. It was a sad and uncomfortable moment for everyone. Baby Sofia died soon after.

When a baby died, parents' visiting time tended to be cancelled and only the parents of the deceased were allowed in. Staff members continued their crucial activities in the unit and it was very rare to see any of them looking at or talking to the parents.

Making formal complaints was extremely difficult for parents. They feared their babies would 'face the consequences' if staff members found out. Ana (IP12) told me she went to see a senior manager to make a complaint about a nurse not being gentle with her baby. The nurse was called in that moment and the manager asked Ana to confront her. She said she felt embarrassed and in the end she regretted having done it. After all, it

was her baby's nurse and Ana had to see her very often. The event must have also been embarrassing for the nurse. Rather than solving a conflict, a new one was probably created.

Two-way interpersonal interactions and communication entail a perception of common humanity and equal dignity. Power₂ relations emerge when staff regard parents as 'inferior' in either worth as humans and dignity. Successful care in the baby's best interest entails valuing parents' personal knowledge of their own child along with healthcare professionals' knowledge.

The following section on wider structures on the third plane of social being might help continue to explain the uneven type of relations that started to be explored in the previous chapter of hygiene.

5.6 Plane 3: Social structures

So far, plane one of material relations with physical nature described experiences of pain and exhaustion in the neonatal unit. Plane two looked at how information is shared, or not, in the hospitals. In a way these represent the empirical and actual levels of reality, described as part of *natural necessity* in the previous chapter.

The third plane of social structures such as social status, gender, ethnicity, professionalism and subconscious values will begin to uncover some of the unseen mechanisms that influence the variety of events already described.

5.6.1 Bad mothers

...They should not have so many children, but it is the government's fault, because of the Seguro popular[...] they should threaten them, if they don't attend their [pre-natal] appointments they won't be admitted for their baby's birth in hospital, that way they would understand, and they should charge \$1000 pesos [the equivalent to £45 at the current exchange rate] per C-section and that way they would think it twice before having so many children... they don't realise their babies will have so many problems. (IS17)

Doctors, nurses (like the above speaker), social workers, psychologists and a dietician at some point revealed their view of low-class, dark-skinned (sometimes indigenous), women in these units: problematic, hyper-fertile, ignorant, filthy, unable to care for children whose contribution to society was ‘defective’ future citizens. This discourse, very commonly used by female (middle-class) doctors and (lower-class) nurses differentiated themselves (pure, moral, educated) from (impure, immoral, uneducated) service users.

These findings mirror the ones in Smith-Oka’s (2015) anthropological study of interactions between healthcare professionals and women during labour in a Mexican hospital. The author proposes that casual moral judgements result in verbal and physical micro-aggressions within women’s encounter with doctors. Judgements include: perceptions of suitability for good motherhood; ideas about modern motherhood; and a priori assumptions about the hypersexuality of low-income women. The author also proposes that exhaustion and frustration by overworked professionals contribute to exacerbate these practices.

Single mothers were particularly seen in JDH and MDH as problematic and in need of regulation. Doctors assumed they needed to take charge of women’s reproductive decisions by, for example, (deceitfully) inducing contraception.

Sol, a single mother whose baby Rodrigo was cared for in JDH, told me:

‘[After my baby’s natural birth] I was bleeding a lot and I found it very hard to sit, later I realised it was because they had inserted the IUD (intra-uterine device) [without consent] and it was sticking out’ (IP2)

Three single mothers, one in JDH Sol (IP2) and two in MDH Bety and Mrs Bertha’s daughter (IP16 and IP24) did not receive information about their babies in more than 24 hours. Only parents were allowed to visit babies, in these cases there was no father. Mothers received information when they were discharged (IP2 and IP16) or a grandparent got access after a couple of days and many red tape procedures (IP24).

Verbal and physical aggressions towards women in the context of obstetric care in Mexican hospitals have been described as ‘obstetric violence’ (Castro & Erviti 2003) and ‘micro-aggressions’ (Smith-Oka 2015). Events such as isolating women from family members for long periods after giving birth, separating mothers and babies, attaching guilt to mothers for the clinical condition of the baby, withholding information about the baby’s clinical condition and inducing fear, among others, seemed to be a continuation of those interactions in labour described by the aforementioned authors.

These events intensified mothers’ anxiety and left them feeling vulnerable:

[After my baby’s birth] they took me to the recovery area and it was horrible because all the women there had the babies with them, all of them! And millions of junior doctors came and asked where my baby was and I [said] I don’t know [and they said] why? And I said I don’t know [...] and you feel like a kicked dog (IP12)

The nurse told my daughter twice that it was her fault [that the baby was born with congenital malformations] that surely she took a medicine or didn’t take care of herself during pregnancy and the baby was born like that (IP24)

Policies that discriminated against single mothers increased moral judgements against women and resulted in normalised violence. Similarly, lack of economic resources and bias against social class promoted constant disrespect and symbolic violence against women.

5.6.2 Dignity, nurses and professional status

Stereotypes also affected nurses. Many of them fought to be recognised as professionals and not only as technicians or assistants.

During a cycle of conferences, I heard nurse Magdalena speaking about making change in the NICU. She started off by reminding the audience that Florence Nightingale described nursing as an art, the art of caring (Nightingale 1980 [1959]). Her speech was

filled with passion and was truly inspiring; her main argument: nurses were health professionals worthy of respect.

But in these hierarchical institutions, nurses' efforts to be recognised as professionals were resisted by doctors. For example, a specialist female doctor mentioned she had to constantly remind nurses that

I am the one in charge here and I won't discuss this because, frankly, we are not the same (IS22)

It seemed that the system accentuated the differences between doctors and nurses, but at the same time, diffused the individual being of nurses. This is accurately portrayed by Menzies description:

The nurses' uniforms are a symbol of an expected inner and behavioural uniformity; a nurse becomes a kind of agglomeration of nursing skills, without individuality; each is thus perfectly interchangeable with another of the same skill level. (1988, p.52)

Nurses struggled to present themselves as more than craft workers. As already described above, during parents' visiting time it was common that most of the nurses retired to their working area and sat down, along with doctors, to complete their administrative work. In part this was their opportunity to have some rest but also it seemed as if this disconnected them from their (lower status) carer job and, in a way, elevated their profession to a more scientific one.

During my time in these hospitals I met many nurses who really cared about their patients, who kept up with higher studies and contributed to their units by trying to share their knowledge with their (sometimes apathetic) peers. Perhaps it was because these women stood out that they tended to face hostility and resistance in their work places; there was a perception that nurses' research protocols tended to be rejected with more frequency than those of doctors (IS20, 26, 32 and my own experience when accessing sites through nurses). Nurses who voiced their concerns about babies', families' and

their own needs were regarded as ‘difficult’ and their attitudes were ‘punished’. Sara (IS26), a neonatal nurse who also taught at a recognised university, considered she was moved to a night shift as a result of her advocating for a more humane type of care in her unit.

Some nurses took the opportunity to guide parents to care for their babies during visiting time. Elvira (IS21) used to encourage mothers to hold their very sick babies while she changed the cot bedding and Carmen (IS32) tried to promote skin-to-skin contact. However this sometimes caused problems when mothers, whose babies were not under these nurses’ care, asked to have similar opportunities. Lack of guidelines made differences in the approach of care more apparent in the units.

Discriminatory policies, stereotypical conceptions of women (as mothers and as nurses) and hierarchical structural organisation that privileged health professionals caused that disrespect for mothers was allowed and even encouraged, often by staff who feel disrespected and unsupported themselves. Structural values within this system need to be addressed in order to promote dignity and respect among all members. The next section will review some ideas about empathy and connection in the NICU or the lack of them.

5.7 Plane 4: Inner being

The fourth plane of inner being in this section describes attitudes towards babies, such as routine care, that denies babies’ individuality. In contradiction, it also describes parents’ attitudes when they give meaning to babies’ actions; attributing agency even to very sick preterm babies. This section also considers splits and contradictions when emotions are not regarded as integral part of being.

Dignity in this last section is seen as important part of well-being and flourishing, which are the central themes in the next chapter.

5.7.1 Detached carers

The form in which doctors and nurses referred to babies also seemed to objectify the latter. I came into the NICU of MDH one afternoon. The place looked chaotic, people came and went to see one baby especially. I asked nurse Ely what happened and she responded:

It's nothing, it's just our babies are very 'ugly' today (S5 from field notes)

This was a common form of referring to babies in critical conditions in this unit. It was also common to hear staff call babies by bed number rather than by name or surname.

On other occasions, staff felt babies responded positively or negatively to their care. For example, a nurse told me she felt when she made nests for them, babies 'behaved well' (IS20). In a way, it seemed that trying to make babies comfortable was considered if it was convenient to the nurse. Doctors tended not to like nests because nests interfered with their job, as reported by some nurses.

Routine care might have been another form of denying babies' individual identity. In her psychoanalytical study of anxiety in institutions, Menzies (1988) proposes routine care is used as a means to avoid treating patients as individuals. By having to complete checklists, decisions over individuals' needs are avoided.

Still, doctors were constantly confronted with painful and difficult decisions too.

5.7.2 Reasons over emotions

Doctors and nurses hardly ever spoke about their emotions. In fact, they presented themselves as detached and strong. It was common to hear them laugh, even in difficult moments, such as the death of a baby. Nurses who made explicit their interest in babies' and families' emotional well-being were not well seen by their peers, like the case of Nurse Sara above.

But it was especially parents who were asked not to reveal their emotions, and they found it hard. Indeed, a diversity of emotions took place in these NICUs. Mothers, fathers and babies met for the first time. Parents talked about mixed feelings of joy when meeting their baby but also feeling scared, frustrated and helpless when the tiny body was connected to so many machines. Parents also had to come to terms with the fact that their baby was very sick; good news and bad news happened all the time even for the same baby in a matter of minutes. Sadly, it was also a place where some parents had to say goodbye to their dying baby.

In both units there seemed to be a very strong belief about babies sensing emotional pain and anxiety from their parents, who were therefore urged to 'leave their feelings outside' so as to protect their babies from sharing those feelings.

Sonia told me:

I used to come in [to the NICU] and cried a lot with my baby, but they used to tell us to be strong and encourage our babies. (IP6)

For some mothers restraining from showing their feelings was impossible, Ana told me:

...they tell my husband not to cry because babies feel, babies perceive, but you can't hold it, I mean never, I came out crying and he told me to calm down, because he never cries, he is kind of weird, so he said 'don't cry, calm down, don't let them see you'. On that same day I went to my mother-in-law's house and I came back and I was still crying, up to this day I cry, when I talk about it I cry. (IP12)

Nevertheless expressing emotions seemed to be unacceptable in the NICU. Ana described (while crying) how she arrived one morning and started to cry as she talked with the attending doctor:

So she turns and says -You know what? Your tears don't move me at all ma'am, so stop crying and calm down- I felt even worse, I mean those repressed feelings, what is all that about?

When Julia woke up after an emergency caesarean section, she felt anxious for not having been able to hear her twin babies cry, she told me:

[While I was in recovery] they sent a psychologist to see me, like to calm me down [but my reaction was because] I didn't want them to be born [yet] I had like a revolution inside. (IP15)

The argument of staff members for not allowing parents, or themselves, to show emotions in the unit was that babies perceived and would be affected by those 'negative' feelings. However, the consequences of denying babies from having authentic positive emotional interactions did not seem to be considered.

5.7.3 The emergence of the human person in the NICU

This chapter started by reviewing the concept of dignity from a historical perspective. Although there seems to be no specific definition, spirituality, freedom, morality and respect seem to be integral parts of dignity as a concept. But when considering dignity in babies, some of the ideas such as spirituality, morality or freedom might make the concept more complex.

From a critical realist perspective, Smith (2010) proposes human beings exist in a three-level system (stratified ontology), which coincide in space and time. On the bottom level there is the embodied organism. The middle level of human causal capacities emerges from relations and interactions through the human body, these include: capacities for language use, mental representation, creativity, reflexivity and abstract thinking among many others. Personhood emerges from complex interactions at the middle level, which conform the highest level. Dignity, according to Smith, is an emergent property at the highest level of personhood, however it is not reducible to the capacities in the middle level from which it emerges, nor is it the result of exercising specific capacities. Through this argument Smith asserts that all human beings, regardless of their morality or rationality, possess dignity and that is also true for preterm, sick, sedated newborn babies in a neonatal unit (ibid, p. 456).

It has been argued staff in the NICU sometimes objectified babies, thus denying them a status of human beings. In contrast, parents seemed to give meaning to their babies' actions. For example, gaze exchanges were considered as an acknowledgement of their presence. A father said:

Every time I come to see him he opens his eyes and closes them again. (P26 from field notes)

Another mother also told me:

When I talk to her she opens her eyes and after a short time she closes them. (P23 from field notes)

Babies' amazing capacities include recognising their mothers' voice and showing preference for it (Hepper et al. 1993). Babies are also able to show when an event becomes overwhelming, for example by avoiding eye contact (Als 1982). Reacting differently to either self-tactile stimulation or to the mother or carer's stimulation is considered by Lagercrantz & Changeux (2010) as a sign of self-awareness. To this respect Sonia told me Luisito:

...finds it soothing when I touch his face but I think he doesn't like when I touch his body, he gets irritated. (IP6)

Julia described how she came to know her baby Cesar knew her already:

when I talk to him, I mean when I help him burp for example, regularly he is almost asleep but if I sing to him or I talk to him, he like, turns to me I mean, he like looks for me, he looks for my voice [and] opens his eyes. I know he might not see me well, because his sight is blurry but I am sure he knows it is me because of my voice. (IP15)

Parents considered their babies as persons and expected a gentle treatment for them. However, the physical appearance of the preterm baby was sometimes regarded as 'non-human', when I asked Ana about the first time she visited her baby in the NICU she took a big breath and said:

I saw him and I said 'and now? Where did you come from baby?' he was so little, very purple, he wouldn't move, he had the mask over his eyes, his face was smaller than my fist. (IP12)

On that same line Julia told me about her twin babies:

The girl did look more like a baby sort to say, I mean small but ok because she only had the intravenous line when I saw her, but the boy looked more like a little fetus, he was still very little. (IP15)

Parents' intuitive, non-scientific, knowledge of their babies' preferences and competencies to communicate were not valued by clinical staff.

5.8 Conclusions

In order to talk about dignity in neonatal care, there is a need to recognise the worth of preterm or sick babies as present, rather than only as future, members of the human community. Although problematic when he proposes morality as the base of human dignity, Kant's connection between value and dignity might be helpful to develop an argument: certainly a baby's unique life cannot be replaced with anyone or anything else. At least in principle, babies' lives are so worth preserving that there are dedicated spaces, such as NICUs, where doctors and nurses strive to save them with powerfully expressed recognition from the State and society that these babies' lives should be saved in marked contrast to the way most non-human animals are treated.

The concept of emergence, from a critical realist perspective, might help enhance the argument: human dignity is the result of our human capacities (whether actualised or not), which in turn, emerge from our biological being. In emergence, according to critical realism, a higher-level entity results from one or more lower-level entities; however, that ultimate result cannot be reduced back to those entities from where it emerged (Bhaskar 2008a). In this sense, dignity is inherent to being human. Certainly, mothers and fathers in this study recognised their babies as persons and gave meaning to their actions.

In order to address dilemmas that arise in bioethics Andorno (2014) argues respect for dignity on its own is not enough. To address those dilemmas, the author proposes respect for human dignity, as an overarching principle has to be combined with human rights as a practical guide.

I find that talking about children's rights in the neonatal unit is somewhat problematic, especially participation rights (Alderson et al. 2005b) when babies are seen as passive recipients of care. It could be argued that the medical team, in conversation with parents, is the best equipped to determine what the best interest of babies in the NICU are. However, this chapter makes evident that theory/practice inconsistencies pervade the type of attention babies receive in these hospitals and give rise to many contradictions and violation of their rights.

Babies' bodies in these hospitals were objectified; they were kept naked and their extremities were tied down when 'necessary'. Denying babies their natural human needs prevents their 'best interests' (article 3 UNCRC) from even being considered and opens the door for many types of degrading treatments which bring about power₂ relationships.

It could also be argued that saving their life (article 6) is the highest aim in a neonatal unit. However rights are indivisible, and respect for one right should not entail the violation of the others, when possible although rights are partly in conflict. The enjoyment of highest attainable standards of health and healthcare (article 24) and the right to a standard of living adequate for the child's physical, mental, spiritual, moral and social development (article 27) mean that attention should be given to all aspects of physical, social and emotional care.

An entitlement to life (article 6) in these settings seems to be set in opposition to the possibility of being able to form an identity (articles 7, 8 and 29), be cared by parents (articles 7, 9 and 18), be protected from physical or mental violence (article 19) and cruel treatment (article 37), the possibility to be heard (articles 12 and 13) or to rest (article 31) and ultimately to the enjoyment of highest attainable standards of care in

healthcare (article 24). Article 2 calls for no discrimination based on social origin, disability or birth, among many other statuses.

This chapter also showed how the best interests of the baby and the best interests of the mother can sometimes collide, especially within inadequate NICU care that neglects the parents' needs. In order to care for their babies, mothers needed to cease to be patients who are acknowledged to endure pain. However, through their stories, women showed the incredible determination, courage and selflessness when, in becoming mothers, they forgot about their own pain and suffering.

Chapter 4 showed how alienating the neonatal unit can be for parents when they are prevented from protecting their babies or have to wait agonising hours to hear reports about their babies' health (or the lack of it). This chapter shows further problems when information is withheld from them or when their privacy is not considered. It seems that medical staff retained control and probably status when information was not shared, but this raised the tensions with parents.

Suffering pervaded time and space in these neonatal units, however, it was constantly denied. Babies' pain and suffering was not always acknowledged, at least by the staff. Mothers were more prone than fathers to show their feelings. During interviews they talked about being sad, frustrated, emotionally drained. Although they were asked not to cry in the unit, many of them could not avoid it. Fathers endured very hard circumstances (more of this on the next chapter) but it seemed their role as males did not allow for complaints. Siblings were affected by extension when their family was split. And I think staff members also suffered greatly and in silence. It seemed as if, tacitly, it was not allowed to talk about it or to show it.

In being so terribly busy and tired, it was difficult for staff even to have time to think of 'the other' even less to consider and empathise with others' individual needs. I felt the case of Ana (IP12), who was taken to the recovery area not knowing whether her baby lived or died, exemplifies how the system exacerbates a sense of separateness from one another. Ana shared a room with many other mothers and their healthy babies. Different

staff members kept coming to see her and constantly asked where her baby was, to which Ana did not have an answer. In having to complete forms and check lists with any other duties, the staff seemed never to consider how terrible this mother could have been feeling. I think the concepts of empathy and respect need to be further analysed in this context. Cohen (2003, p.54) describes her experiences as a psychoanalyst in the neonatal unit. In analysing the notion of respect in this context she proposes:

In order to treat the baby with respect, he [the doctor] has to recognize his [sic] human status, recall his own feelings of fear and impotence, hold and deal with them himself, and treat the patient in his own right...

In doing so,

...we become more aware of our own vulnerability to others...[and of] our emotional need for them... we become affected by their lives; their pain and suffering have an impact on us... we become aware of the effect we have on them...the task of recovering our feelings is an onerous one... (Cohen 2003:54)

This brings me back to Tere's case. The morning I met them, her nurse did not know her name or sex, Tere's arms were held into the nappy, she faced to the left and her nurse stood on the right. I believe this nurse had blocked all possibilities to see Tere, I think it might have been difficult to know that she was about to inflict even more pain and suffering. Doctors and nurses in these units did not lack humanity when they treated these patients and their families, I believe doctors and nurses protected their own humanity in order to be able to do their jobs within these alienating units. If babies and parents' dignity is to be adequately respected it is essential that nurses' and doctors' dignity is also respected and that routines and structures in the hospitals and in the healthcare professions' training and support are transformed.

It will be a task of the next chapter about well-being to try to understand how empathy, solidarity and respect for dignity can be instated and re-instated in the different relations and routines that take place in the intensive care unit.

Chapter 6 Well-being

6.1 Introduction

It was visiting time in the NICU at MDH. Nurse Elvira had just changed baby Celeste's nappy and she still needed to change the bedding.

Nurse Wendy said –her mum is here, should I tell her to wait outside?

–No, tell her to come in

Cristy, Celeste's mother, approached and greeted her baby by touching her forehead. After a few minutes nurse Elvira asked:

–Would you like to hold her while I change the sheets?

–Of course I would!

Nurse Elvira lifted Celeste and passed her on to her mother's arms. Cristy started to move her body rhythmically from side to side as she held Celeste and hummed. Celeste opened her eyes and closed them back, -Hola mi amor (hello my love) said Cristy as she kissed Celeste's forehead. Celeste opened her eyes again, Cristy smiled and hummed.

As she changed the bedding, Nurse Elvira saw the episode from the corner of her eye and smiled. As I took some notes, I also found myself smiling. It was a happy moment for all. (From field notes)

Official data of well-being in Mexico is shown in reports made by international agencies, such as OECD (2015) and UNICEF (2014), as well as national ones such as INEGI (2015) and CONEVAL (2016). Well-being in all these documents is reported mostly based on the economic growth of the country. The most comprehensive report was carried out by OECD and INEGI (2015). The dimensions measured in each one of the 31 Mexican states and the Federal District were: income, jobs, housing, health, access to services, education, civic engagement and governance, environment, safety, work-life balance, community (social) connections and life satisfaction. The report highlights the striking inequalities in the country and the need to improve standards in education, safety, poverty reduction and quality of jobs, where Mexico performs well below OECD members.

While the economy of the country is important for the well-being of all citizens and the public services, there seems to be a disconnect between 'what people care about', 'the things that make them happy' and international, abstract reports.

The previous chapter looked at different aspects of dignity of babies, parents and members of the staff in MD and JDH. In an attempt to understand what it means to be treated with the highest respect as a human being while in the baby unit, I drew on the UNCRC. I argued that respecting the rights of sick newborn babies in hospital feel problematic when adult-centric views fail to consider babies as people able to participate in matters of their own health.

In its preamble, the UNCRC (1989) devotes attention to themes of well-being, happiness and what I would describe as flourishing of children (my emphasis):

Convinced that the family, as the fundamental group of society and the natural environment for the growth and *well-being* of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community,

Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of *happiness*, love and understanding,

Considering that the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of *peace, dignity, tolerance, freedom, equality and solidarity*,

So far, analysis of the data has shown that ‘in the interest’ of their well-being, babies in the NICUs are denied the possibility of being with their families, they are not treated as equals with other babies, their hands are sometimes restrained (what could be seen as a violation of their freedom), basic humane and dignified treatment is not always considered when pain relief is not provided, and parents are not supported to care for their children.

This chapter then asks, what does well-being, happiness or flourishing mean when babies are confronted with adversity in the neonatal unit?

The more I thought and read about well-being, the more I realised how little consensus there is on this theme: from objective assessable psychological well-being to subjective pleasurable experiences. It seemed that an analysis of the data through the concept of MELD could be useful because MELD can examine resolving contradictions through transformative change and processes over time.

The chapter on hygiene started to uncover contradictions. On the one hand was psychological distress for babies in forms that we can only imagine, and expressed by parents in many different forms. On the other hand, NICU routines supposedly ‘for their well-being’ were also the source of ‘ill-being’: unacceptable infection rates, forced feeding and isolation, untreated pain, very distressed parents, detached caregivers, and other adversities. In the quest of saving babies’ lives (through highly technological and costly interventions), natural processes such as breastfeeding (with its immunological factors and the closeness and intimacy with mother) are denied.

This chapter will begin by reviewing philosophical underpinnings of well-being, then it moves on to consider what aspects of well-being are important for children and it looks at programmes that have aimed at improving life for babies in the NICU. Finally, a realist account of well-being is revised.

MELD IM begins with *non-identity* and tries to resolve the error of the *epistemic fallacy*. At 2E there is an analysis of absences in the neonatal unit at seven levels: physical, biological, psychological, psycho-social, socio-economic, cultural and normative.

3L, totality brings together all the thesis chapters, it looks at connections but also at fragmentation. The impact that insecurity, poverty and corruption (as three of Mexico’s biggest challenges) have in the day-to-day activities in JH and MDH are analysed. I have also looked at how conceptions of preterm children as ‘immature’ and ‘deficient’ human beings translate into practice in these hospitals.

4D identifies possibilities to move from misery and suffering to well-being and flourishing.

6.2 1M – Well-being and non-identity

The first moment of dialectic critical realism refers to 1M – non-identity. It entails an investigation of the social and natural world, independently of our understanding of it. Characteristics of this moment are ‘intransitivity, stratification, transfactuality, multi-tiered depth, emergence (a condition of possibility of agency), multiple control and change’ (Bhaskar 2008b, p.234). 1M entails moving from the empirical and actual to real levels, so as to understand what it means to be well.

6.2.1 Well-being in Philosophy

For centuries, philosophers have wondered what well-being is and what it means for different people. The philosopher Ben Bradley (2015) asserts well-being has been related to happiness, flourishing, intrinsic goodness and caring. The problem seems to be that none of these perspectives fully grasp the concept as a whole.

I will briefly describe two contrasting lines of philosophical thought that have influenced current views of happiness and well-being, especially in philosophy and psychology: eudaimonia and hedonia. It is not the intention of this thesis to discuss these concepts in depth, but rather, to show how they have contributed to current debates in to what well-being entails.

A brief summary of the concepts is taken from the work of Henderson and Knight (2012) and Ryan and Deci (2001):

The eudaimonic perspective can be traced back to Aristotle in the fourth century BCE, and it has also been linked to other Greek philosophers including Plato. According to this position, well-being (also called human flourishing) was accessed through living a noble life; a life of contemplation. Virtues such as honesty, courage, justice and kindness, were emphasized. For Aristotle, the hallmark of a good life was achieved by developing one’s capacities in the search of meaningful and complex objectives. This

perspective has been considered to be ‘objective’ and potentially assessable from ‘the outside’, where positive emotional experiences are not prioritised.

Hedonism can also be traced back to ancient Greeks. Aristippus was a Greek philosopher from the fourth century BCE who suggested that experiencing the highest amount of pleasure was the goal of life; happiness is then the sum of all those pleasurable moments. Other influential ideas from this line of thought later came from Hobbes who thought that happiness was the result of fulfilling our human desires and Bentham, an utilitarian philosopher, who proposed that the good society is built through ‘individuals’ attempting to maximise pleasure and self-interest’ (Ryan & Deci 2001, p.144). Maximising pleasurable moments and minimising painful ones were considered to lead to ‘the good’ in one’s life. In this line of thinking, each person is best situated to determine their inner well-being and therefore it is considered to be more ‘subjective’.

A more recent line of thought has resulted from integrating concepts from these two traditions. It has been argued that well-being is a multidimensional phenomenon (Ryan & Deci 2001) which can be better understood by reconciling the eudaimonic and hedonic perspectives.

Another influential line of thought in well-being (also called welfare) is the ‘capability approach’ proposed by the economist philosopher Amartya Sen. According to Sen (2003) ‘[t]he capability of a person reflects the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection’. In other words, capabilities refer to what the person is able to do or to be fulfilled (and not to their happiness or desires). Thus, this theory considers ‘human acts and states as important in themselves’ and ‘values freedoms in the form of capabilities’ (ibid, p.4).

These philosophical frameworks inform and underpin some of the research on well-being in specific aspects of life, which is the case in many scales of children’s well-being.

6.3 Children's well-being

Different disciplines, contexts, age groups and cultures have been researched in trying to understand the concept of well-being in relation to children (Hernandez & Grineski 2012; Moore et al. 2012; Fernandes et al. 2013; see for example Bastos & Machado 2009). Not surprisingly, a one-fits-all definition has not been agreed amongst academics.

Pollard and Lee (2002) propose child well-being is a multi-dimensional concept that needs to include indicators such as physical, psychological, cognitive, social, and economic well-being. When the focus on children's well-being is on deficits rather than strengths, the authors argue, there is a risk that research and interventions may concentrate on such deficits (commonly so in psychology) rather than on identifying and promoting strengths.

Land and colleagues (2001, p.243) proposed an index to measure the well-being of children and young people in the United States through the dimensions of 'material well-being, social relationships (with family and peers), health, safety/behavioural concerns, productive activity (educational attainments), place in community (participation in schooling or work institutions), and emotional/spiritual well-being'.

More recently, Moore and colleagues (2012) proposed an index for child well-being that looks at four main dimensions: physical, psychological and social health, and educational achievement and cognitive development. Fernandes and colleagues (2013) created an index to measure the well-being of Portuguese children through the indicators of: interaction dimensions (health behaviour, school, leisure and recreation, and social relations), context dimensions (material well-being, housing and neighbourhood), and personal characteristics. A methodological difference in the latter study was that children's views were included and compared to those of parents.

So far indices of well-being show that the concept is formed by multiple dimensions. Researchers seem to agree on aspects of social relations, physical and emotional health, and economic dimension when considering the well-being of children.

Morrow and Mayall (2010, p.150) propose well-being for children might involve ‘much more than wealth and affluence’, the authors to move away from adult-centred towards children-centred views. The economist Richard Layard (2011) argues, countries’ measurement of well-being should not be based on economic exchanges (GDP) but on happiness. But then again, we seem to come back to the question, how do we measure happiness? And more importantly, how do we know if a baby is happy?

6.4 Well-being at the beginning of life

For many years, researchers have linked the well-being of children to their relationship with their primary carer(s). Probably, the most influential work in the area is from the British ethologist John Bowlby (1969) who described behaviours such as crying, as a form in which children seek proximity to their main carer. Bowlby emphasised the role of the mother in the infant’s emotional well-being.

Klaus and colleagues (1972) studied 28 mother-baby dyads in hospital. At the time, babies born in hospital in the United States, as in many other countries, were taken to the nursery while mothers recovered from giving birth. Fourteen mothers and their babies in their study (the control group) received traditional care: mothers saw their babies shortly after birth and subsequently every four hours for approximately half an hour for feeding. The experimental group, 14 mothers, had extended contact with their babies after birth and during the three subsequent days. After they went home, by 28 to 32 days after the birth the mothers in the extended-contact group showed greater maternal responsiveness, and the authors concluded that extended contact during this ‘sensitive period’ affects the emotional bond positively. Some authors have questioned the notion of ‘sensitive period’ (Svejda et al. 1980; Goldberg 1983). Still, Klaus and colleagues influenced the organisation of hospital postnatal units caring for well babies (in some countries) and questioned the traditional practice of taking babies away from their mothers.

Brazelton and colleagues (1991; 2011) have proposed the ‘earliest relationship’ between parents (notably, the father is not excluded by the authors) not only helps in parental responsiveness to babies’ physical and emotional needs but also it helps babies to make

sense of the world around them. Parent-infant attachment includes willing proximity, reciprocity and commitment (Goulet et al. 1998).

Relationships with beloved ones are important for both adults and babies. According to the social scientists Sayer (2011, p.125), commitments and attachments (which are stronger than preferences) are part of who we are and ‘if we are prevented from pursuing them, then we suffer something akin to bereavement, for we lose not merely something extended but part of ourselves’. These emotional attachments are not necessarily irrational or unreasoned, and moreover, they might go beyond our self-interest. This capacity to make commitments leaves us in a vulnerable place: human beings are able to suffer in the same way that they are able to flourish.

Having a baby in the NICU can be a difficult time when parents are babies are not able to have physical contact. We do not fully understand how the NICU environment impacts babies’ emotions, but we know the experience of having a preterm baby staying in the NICU can make mothers feel depressed (Miles et al. 2007; Singer et al. 1999; Rogers et al. 2013). Moreover, post-natal depression can affect mothers’ perception of their babies and their responsiveness (Luoma et al. 2004).

A great variety of programmes have been directed to support parents while their baby is in hospital through education, with the ultimate objective of improving babies’ well-being (Melnik et al. 2004; see for example Hane et al. 2015).

The single most studied programme directed at improving babies’ well-being in the NICU is the NIDCAP. It stands for Neonatal Individualized Developmental Care Assessment Program and is based on Heidelise Als’s ‘synactive theory of development’ described in Chapter 2. It promotes the understanding of babies’ individual needs through detailed observation, but it also takes into account the context and the family.

The programme aims at improving neuro-developmental outcomes through activities such as: promoting physiological stability, reducing stressful events and supporting babies through painful interventions, promoting (undisturbed) sleep, healthy postural

development and facilitating feeding; encouraging parental participation and considering the baby as a valued member of a family (Als & McAnulty 2006).

Not only do babies and parents benefit from the NIDCAP programme (Peters et al. 2009; van der Pal et al. 2008; Kleberg et al. 2002; Kleberg et al. 2007; Westrup & Bo 2004; Fazilleau et al. 2013; Wielenga et al. 2009; Kleberg et al. 2000; S M van der Pal et al. 2007), healthcare professionals have also reported to be more satisfied with their work when caring for babies in this fashion (Wielenga et al. 2008; Sylvia M van der Pal et al. 2007). Unfortunately, NIDCAP education and implementation is expensive and therefore inaccessible for the people who would most greatly benefit from it.

So far IM has described philosophical notions of well-being and different research methods that have been developed to understand different aspects of children's well-being. A critique of research on children's well-being as being adult-centred has been considered. The previous section looked at infant-parents interactions as an important factor of well-being in the neonatal period. The last section of IM will look at a view of well-being more embracing of both babies and adults from a realist perspective.

6.5 A more realist view of well-being?

The sociologist and critical realist Andrew Sayer proposes that well-being is not only a state of mind but rather 'our subjective feelings seem to be about things which are objective in the sense of independent to them' (2011, p.134). Furthermore, Sayer addresses well-being by de-constructing the objective/subjective (eudaimonic/hedonic), reason/value dichotomies and argues for a reflexive standpoint: values can be objective, and most importantly they can be reasoned. Our valuations might be mediated by culture and norms, but still these valuations are about real things. Our emotional reasoning is fallible in the same way that our knowledge is fallible. We need this type of emotional reasoning to enhance our well-being, which he argues ought to be considered as objective states. The problem I find is that this continues to be an adult-centred view, since emotional reasoning is not a characteristic of babies.

Bhaskar (2008b, p.283) sees well-being in relation to absence:

‘well-being with the emphasis on the absence of ills and the satisfaction of needs; and corresponding to it [and as] universal well-being’

Although Bhaskar’s thinking is also mainly adult-centred, this is probably a conception of well-being that is closer to all human beings. According to this definition, well-being might be

- a) identified by the absence of ill-being,
- b) in relation to others (*concrete universal* ↔ *singular*).

And to these I would add:

- c) it might be seen as a *product in process* (rather than as an end product) mediated by time and space (Bhaskar 2008b) and
- d) in pluralism (there are many different forms of it) but not in relativism (wellbeing is not subject to people’s views on it) (Sayer 2011).

Well-being for each (baby, parent or member of the staff) as individuals (*concrete* ↔ *singular*) belonging to a community, such as the NICU, (*concrete universal*) needs to be seen as a constant *process* in which all members work together to *absent ills*. Pluralism means that well-being might take a different form for each individual, however, the absencing of ills is real, not subject to others’ views (relativism).

The next moment of MELD, 2E, will continue by looking at absences, voids or contradictions in the care of babies at MD and JDH.

6.6 2E Negativity

The second moment of MELD, 2E, involves work to absent or negate problems. Bhaskar identifies *absence* as the most basic element in non-being. The concept of absence in critical realism entails finding gaps, spaces, voids, lacks, needs, contradictions or errors. The begoing of those identified absences happens in a dialectic movement towards

becoming. This marks the possibility of movement, change, freedom and flourishing. In this section, absence is analysed in relation to presence. What we are looking for at 2E is ‘the absent in the present’ (Bhaskar 2008b, p.241); identifying beings in the world by what they *were* and what they *are* now.

IM suggested that well-being is a complex concept that might be better understood by looking at different dimensions. Bhaskar and Danermark (2006) proposed a methodological approach within disability research. The authors suggest to identify interplaying causal mechanisms at the levels of the: **a) physical, b) biological (medical or clinical), c) psychological, d) psycho-social, e) socio-economic, f) cultural and g) normative**. This is what they call a *necessarily laminated system*, which helps to look at phenomena in context. I found that this laminated system was also appropriate in order to look at different aspects of well-being in neonatal care, especially in different aspects of the parent-infant relation.

6.6.1 Physical: the NICU environment

The physical characteristics of both NICUs were described in Chapter 4. As a summary, the material conditions in JDH and MDH were bright, noisy, busy places with reduced and over-crowded spaces and no physical space for the parents to remain.

The following sections will show the relevance of these NICU environments to different aspects of well-being. They will also show how the material context in the neonatal units contributes to structuring and reproducing power relationships, which are further mediated by discourse and ideologies.

6.6.2 Biological: baby time, NICU time

Synchrony and rhythm are at the essence of life in heart beats, breathing, digestive movements and oxygen flowing in the blood stream at the most basic elements of our biological being. A variety of medical equipment and medical care is directed towards helping babies reach stability of these vital rhythmic processes.

Most newborn babies in intensive care need to be assisted in their breathing. This is done either by passing oxygen directly into their lungs with a tube or through small prongs into their nostrils from a mechanical ventilator. Medicine and fluids are passed through thin tubes in their hands or feet. Essential nutrients are given intravenously or milk is given through a gastric tube passing through their nose or mouth; in the case of these hospitals through their mouth. Their vital signs are usually monitored via sensors attached to their bodies.

Short-term solutions with long-term consequences

Paradoxically, some of these medical and technical interventions directed at protecting babies can harm them. Monitors' alarms alert staff when something is not right in the vital signs, however if they are not silenced promptly the machines can adversely affect those vital signs.

Loud transient noises in the unit can cause 'increased heart rate, blood pressure and respiratory rate, and decreased oxygen saturation. Such changes increase the likelihood of subsequent apnoea and bradycardia episodes' (Wachman & Lahav 2011). Noise also affects babies' sleep and rest. The highest sound level in the unit (transient noise) should not exceed 65 decibels (Coughlin et al. 2009).

Table 13 represents measurements of the single highest transient noise (dB) registered next to the a) typewriter b) radio c) sink.

a) Typewriter	84.5 dB
b) Radio	79.0 dB
c) Sink	68.5 dB

Table 13 Highest transient noise

Parents knew how noise affected their babies' well-being. Jazmin told me about an incident in the NICU where:

The nurses argued over some gowns, it all became very loud and my baby got very distressed. (IP22 from field notes)

Staff members were also aware of the impact that noise could have on babies.

A doctor saw me taking sound measurements and commented 'I bet we won't get very good results, we should have a special room to work. For instance, there shouldn't be a typewriter inside the neonatal unit'. (Field notes)

Indeed, doctors in MDH had to bring the typewriter into the unit to make their notes and this normally happened during parents' visiting time, when the unit was already very busy. Because of intensive care being split into two different rooms, it was common that the typewriter was brought from one room to another constantly (which contradicted sanitation guidelines).

Light from overhead panels was turned on during day and night in both hospitals. Vital diurnal light modulation was not considered and for example, babies at the back of the room in JDH were exposed to intense sunlight from the window. Music from the radio came out from the speakers in that same area:

Baby Gael, whose cot is next to the window, was born at 27 weeks and two days of gestation weighing 900 grams and has been in intensive care for over two months. During the day he gets constant direct sunlight and his cot is the closest to the speakers with music (72.3 dB at the beginning of my observation). I wonder how much rest he gets under these conditions. (Field notes)

According to Graven (2011), before 32 weeks of gestation, skin from the eyelid is very thin and babies cannot constrict their pupils. This means that preterm babies find it difficult to filter light. At this stage, when the visual system is in a critical phase of development, the retina needs to be protected from direct light. Constant exposure to

direct light not only represents a risk in the healthy development of visual system for preterm babies, but it also interferes with sleep and rest.

Sleep has been identified as a ‘neuro-protective’ measure in the NICU (White 2015; Coughlin et al. 2009). It has been suggested that sleep and sleep cycles play a crucial role in the development of the neurosensory and motor systems, however preterm or very fragile babies might find it difficult to maintain robust sleep-awake patterns (Graven & Browne 2008).

In order to support babies with their positioning, rolled sheets in the form of nests try to replicate the containment that the womb provides. Helping babies ‘curl-up’ in their nest enhances sleep and rest and supports physical stability, among other benefits (Warren 2012). However both units lacked positioning protocols.

Lorena described the first time she saw her baby

‘...lying down, with his legs like a little frog. [He was] tiny tiny, purple, his skin was transparent, he was intubated and I was in shock’. (IP1)

In their review, Sweeney and Gutierrez (2002) describe different forms of ‘malalignment’ due to poor positioning. ‘Frog leg’ position can cause difficulties in sitting and crawling. Hyperextended neck and retracted shoulders have implications for head control and bringing hands to the middle line. Everted feet (inward roll of the foot) might lead to complications with foot position when standing and developmental delays. Head mis-shaping is another common problem due to poor positioning and it is associated with torticollis. Thus lack of support to babies in getting a comfortable position can cause problems in the long-term.

Positioning is also important to allow babies to rest. In addition to noisy and bright environment and poor positioning, routine care also affected babies’ rest. Nursing routine procedures in both hospitals consisted of nappy change, blood pressure

recording, taking the temperature, bedding changes and fluids aspiration. These procedures had to be done at specific times even if babies were sleeping or unsettled.

Babies' natural time versus NICU clock time

When mothers participated in babies' care, they were also asked to follow 'routine' procedures. Ana and I talked as she fed her baby Pedro with a syringe and said:

I think he sometimes gets very tired [when feeding], even the colour in his face changes but nurses say I need to keep trying [to feed him] and to force him a little, otherwise he won't be able to go home. (IP12 from field notes)

Later, I talked with nurse Gina, who cared for Pedro at the time. When I asked about feeding babies she said:

Because there is one nurse per five babies [in intermediate care] many of them keep feeding babies with the gastric tube, even if they are rooting [searching for the nipple as a reflex]. Babies who feed from the syringe are passed the milk without pausing, it's the only way. (IS34)

Preterm babies are not only defined by having been born before time, their weight at birth is also considered a determinant factor in their health. The classification according to weight is: low birth weight (LBW) < 2500gms; very low birth weight (VLBW) < 1500gms, extremely low birth weight (ELBW) < 1000gms. The lower the weight the higher the risk of mortality and morbidity.

Growth development then becomes a major concern for healthcare professionals and parents. Weight gain is also a condition for discharging babies. In MDH and JD babies are not discharged before weighing 1800gms, among other conditions.

Feeding and weight gain were at the core of many conversations I had with parents and healthcare professionals. When babies were able to breathe by themselves, regulate their temperature and feed at breast or with the syringe, the goal became

...only to put on weight so that we can go home. (IP17 field notes)

However, preterm babies are also at risk of developing eating disorders which might be related to prolonged stay in hospital and interventions (such as intubation), neurological immaturity, delayed oral feeding and associated factors such as respiratory problems (Hawdon et al. 2000; Johnson et al. 2016).

In order for babies to feed successfully they need to coordinate their breathing, sucking and swallowing patterns, maintain the tone in their oral muscles, keep their energy levels up and remain in an alert state while processing sensory stimuli from the environment (Browne & Ross 2011). At the beginning, babies might need to take a rest in-between the feeding to recover their energy and maintain their physiological stability. Unfortunately, their biological time does not meet with NICU management time. Babies in these hospitals needed to be discharged as soon as possible because their beds were greatly needed.

When staff thought babies were not managing (for example their oxygen levels in the blood dropped while feeding), the decision was made to return to feeding by oro-gastric tube and/or to increase oxygen supply. It was difficult for adults in these rooms to think in terms of how they could contribute or affect babies' physiological well-being.

Mothers found it frustrating when they thought these medical decisions were rushed and represented a step back for their babies. Mothers also felt frustrated when they thought their babies' individual needs were not attended to. While baby Evelyn was in the unit, she was fed every three hours. Her mother Doris said:

But I thought sometimes she got very hungry within an hour, one day I came to see her and she looked desperate. (IP4)

Flacking and colleagues (2006, p.77) conducted in-depth interviews with 25 mothers in Swedish hospitals. Their objective was to understand how women experienced their becoming a mother in the NICU in relation to breastfeeding practices. The authors found

mothers experienced routine care as problematic because they had to ‘disregard their infants’ cues and needs because of care routines’.

During my field work time in JDH and in MDH I was constantly admired with the detailed observations mothers made about their babies’ communication cues. Karen thought her baby Jose recognised her when she arrived, when I asked how she knew Karen said:

He lets me know with his breathing. (IP17)

Many observations made by parents seemed to be ‘common sense’; but then again common sense or intuitive knowledge (Gardner 1993) seems not to find a place in the medico-scientific hospital organisation.

6.6.3 Psychological: the becoming of a mother in the neonatal unit

Mothers of newborn babies expect to have powerful feelings of well-being, fulfilment and happiness, and when they are not able to have these feelings there can be an added sense of sorrow, pain and loss. During interviews mothers described a variety of feelings as they were confronted with the reality of having to leave hospital without their baby. It was difficult to make sense of becoming a mother within the NICU environment where uncertainty and lack of control pervaded. The dreams and fantasies that began with pregnancy, probably mediated by a romanticised idea of motherhood, vanished. As Eugenia described it:

I believe that ever since you learn you are pregnant you begin to have so many illusions. (IP27)

Instead, feelings of not being prepared, being a burden in the NICU and being guilty for whatever happened to their baby were common. The following section describes mothers’ experiences throughout their babies’ hospitalisation, from early days to being close to discharge.

The preterm birth: *I am not prepared*

Many mothers I talked to referred to the early birth of their children as a *shock* or the *most unexpected event* they have ever experienced. It seems that making sense of what having a very preterm birth meant took time.

When my babies were about to be born I thought 'I am not prepared, I don't have any clothes for them' because I thought I was going to leave hospital with them on the next day. (IP6)

Even if there were signs that babies could be born early, the thought of having their baby in a NICU (with a highly technological environment and a variety of interventions) was not something they had ever considered.

I knew it was a high risk pregnancy, I had had two miscarriages before that and I knew that preterm babies went into an incubator but I never thought that they had to be intubated and attached to so many things. It was horrible [when I first saw my baby]. (IP1)

The highly technological NICU environment increased feelings of uncertainty and anxiety.

And you get very anxious to see them with all those machines, I asked what they were for but they don't tell you. (IP27)

Not only did mothers need to make sense of their baby being sick, but also they were now confronted with a whole new world; a world they needed to begin to learn, sometimes without the support and guidance of the experts who cared for their babies.

Section 4.2.1 in Chapter 4 showed that doctors and nurses became annoyed when parents looked around curiously. Heerman and colleagues (2005, p.177) conducted interviews with 15 mothers in a level III NICU in the United States and found that the NICU environment 'was in the foreground of the mother's attention and her baby was in the background'. It seems that looking around (what the authors call foregrounding) was an

important evolutionary part in becoming a mother in the alienating environment in the NICU.

This is consistent with what happened in the NICU at MDH and JDH; which healthcare workers interpreted as mothers being more interested in what happened to other babies.

At birth: I heard him when he cried and when he breathed by himself

Some mothers talked about the distressing experience of realising their baby was inevitably going to be born before time. Many of them talked about looking for physical cues that their baby was alive, which seemed to give them some reassurance over the chaotic situation. Dominga recalled:

The first time that I saw him was when he was born, during my C-section they showed him to me and they brought him close, I heard him when he cried and when he breathed by himself. (IP7)

Understandably, it caused great distress to mothers when they did not get a ‘hint’ that the baby was alive:

...but he was purple, purple and I see him and he is like, like dead, I cried and then they took me to recovery [area] and I didn't see him anymore (IP12)

When babies were born very preterm or sick they were normally taken away immediately. For some mothers, the lack of knowledge about their babies' condition was extended for hours:

[On the day my baby was born] they were about to discharge her when she vomited, so they detained her and she had to stay. They didn't give us any information on that day and one gets very worried because you have to leave her here and [you wonder] is she safe? (IP4)

Doris (above) talks about her baby being ‘detained’ in hospital. A detention normally refers to a process in which a figure of authority restrains the person from leaving a

place without the need of consent. For Doris her baby was taken away, she did not fully understand the reason (except that the baby had vomited) and she went home without the certainty of what would happen to baby Evelyn.

The early days as a mother in the NICU: *feeling like a nuisance*

If they were not well, some mothers had to stay hospitalised. In these cases, the important moment of meeting their own baby was delayed by days or weeks. Alexa mentioned:

They allowed me to meet my baby two weeks after she was born, when I was discharged (IP3).

Lorena had a similar experience:

They told me I could only go and see my baby if I was able to walk by myself. I asked my husband to help me and made such a big effort to get to the baby unit by myself the day after my C-section (IP1).

Access to babies sometimes had to be negotiated with the nurses, who became primary care givers in the NICU. As shown in previous chapters, they were normally the ones who decided the length of visiting time. For example, when Julia (IP15) came to meet her twin babies for the first time the nurse told her visiting time was ‘almost’ over, therefore she could not come in anymore.

Nurses also decided when it was appropriate for mothers to hold their babies for the first time. Ana said:

The first time I held him was when he was two months old, the nurse asked if I wanted to hold him and then they let me hold him once more this week (IP12)

The mothers had given birth to one or more babies, but the baby seemed not to belong to them just yet. Once more their being as a mother seemed to be out of place in the neonatal unit. Lorena (IP1) referred to it as '*feeling like a nuisance*' in the NICU.

Not only did Lorena feel out of place and scared in the NICU, she also had a feeling that the baby

...belonged to the nurses and not to me, even after discharge I felt I needed to ask someone for permission to touch him. (IP1)

Lupton and Fenwick (2001) found similar results when interviewing mothers of preterm or sick babies in two Australian hospitals. Mothers' first experiences in the baby unit were described as traumatic and distressing, which left women 'not feeling like a mother'. The authors refer to episodes in which mothers were 'allowed or not allowed' to do things to their babies as one factor that made them feel the baby did not belong to them.

As a strategy to have access to their babies, many mothers avoided confrontation with the nurses, as Lety puts it:

We go home and the baby stays here with them, and we don't know what happens during that time (IP22)

It was common to see mothers praying. Cristy (IP10), for example, used to read passages from the bible to baby Celeste. Another mother, Karen (IP17), spoke about her baby Jose:

The priest came and baptised him. I think he will get better sooner because now he is a son of God. (Field notes)

Praying seemed to be instrumental in regaining some of the control they lost when their baby was admitted to hospital.

The emergence of a mother: *they [doctors and nurses] are specialised people but in the end, they are strangers*

Little by little, mothers began to find ways to participate in their babies' care, even with simple actions. Lupita stood next to her baby Moni, who rested on her side with her eyes closed. When I asked her whether she knew baby Moni's preferred position she replied:

Definitely on her side. Yesterday she was laying on her tummy and I moved her to her side. I thought someone was going to tell me off but they didn't [she laughs nervously]. (IP11)

Mothers in the unit talked about being 'told off' and 'being allowed' to do things to the baby, which confirmed this feeling of the baby belonging to someone else. Sonia also said:

When they give us the opportunity to change their nappy is as if we had them for a little while. (IP6)

Some mothers fought to retain ownership, Dominga told me:

They are specialised people, but in the end they are strangers to my baby. (IP7)

Dominga had an older child at home, probably due to her previous experience of being a mother she considered herself to be the person who her baby knew best and also a knowledgeable person about her baby. However, some other mothers felt they needed time to learn.

In her ethnographic study about 'learning to parent' in the United Kingdom neonatal nurse Skene (2010) found that parenting in the NICU was a 'journey' that began with parents' preferring to observe and get to know the baby on the first instance, to gradually being able to touch, participate in babies' cares and eventually leading to their feeling confident.

Looking back: *not having been able to keep my baby inside for nine months*

The process of becoming a mother to a sick or preterm baby also took place within feelings of grief and guilt, far from maternal confident well-being. Mary referred to it as:

Not having been able to keep my baby inside for nine months. (IP9)

Lorena said she constantly questioned herself for:

Having done something, or maybe not having done it, and that could have caused my baby to be born early, I don't know... (IP1)

6.6.4 Psycho-social: uncertainties

The previous section described mothers' experiences of mal-being in the relationship (or lack of it) with their babies. This section will describe women's experiences of becoming a mother in relation to the support (or lack of it) received by the staff.

The survey administered to staff in JDH and MDH showed that healthcare workers considered parents' presence to be a factor of well-being for their babies. This was later confirmed in interviews, nurse Ximena said:

We all have noticed when mothers get involved babies recover faster. (IS8)

However, 'parents getting involved' seemed to be more related to following instructions while in the NICU. Dr Brenda emphasised humility and obedience when she told me:

Parents can contribute by listening carefully, showing interest, buying the medicine that sometimes they refuse to buy because they have Seguro Popular, being available to help and keeping good hygiene... (IS27)

The survey also showed that NICU staff feared parents might need too much support from them. This is not surprising in the light of results shown in previous chapters where

healthcare workers seem to feel overwhelmed and frustrated by the amount of work, over-crowding of patients and little time to rest during breaks.

However the survey showed contrasting results. Staff also believed it was an important part of their role to support and teach parents to care for their babies. Observations in the NICU showed nurses' and parents' interactions were restricted to the minimum necessary since nurses sat down to complete their notes while parents were with babies.

Similar results were found by Gallegos and Hernandez (2014), who interviewed healthcare professionals from a level II Mexican hospital. Their study was about parental participation in the NICU. Contradictory answers showed healthcare professionals asserted parents' presence and participation in the NICU was important but thought, because they came from rural areas, parents were not able to understand medical information and could not maintain adequate hygiene.

In their study about nurses', physicians' and parents' views of parent support in four NICUs in the United Kingdom, Franck and Axelin (2013) found significant differences in nurses' perceptions of support provided and parents' perceptions of (little) support received.

Lack of support, communication and guidance to parents made mothers feel extremely anxious about discharge; uncertainty about the future well-being of their baby made the moment of leaving hospital difficult.

Time to go home: I'm thrilled but at the same time I am terrified

Having their baby transferred to the growth and development room in MDH meant their baby would be discharged from hospital soon, and might have improved mothers' sense of well-being. However, mothers talked about mixed feelings about the idea of leaving hospital:

I am obviously thrilled but at the same time I am terrified. I mean, he is used to the noises and to the people in here. No, I... I don't want to [take him home] the other day some mothers told me [that once at home] they cry all night because, I mean, they have to adapt to a new environment. And there is this mother, she said, they discharged her baby but something happened at home, the baby was not well and she came back and now the baby is here again, it's scary. (IP25).

Jazmin felt frustrated by the lack of guidance from the nurses:

For the nurses everything is normal, if they [babies] turn purple they [nurses] say 'don't worry, it's normal' if their breathing changes [they say] 'it's normal' but if that happens when we go home, if she turns purple, how will I know if it's still normal? (IP21).

Mothers faced the prospect of leaving the place where their baby had been cared for by professionals, and mothers themselves had been constantly supervised. Discharge meant being left by themselves with a baby they barely knew. Their babies' life had been saved thanks to the medicine, technology and healthcare professionals. The transition from hospital to home meant a process of babies being protected *from* parents to babies being protected *by* parents. Uncertainty has been described by one of the main worries experienced by parents of very preterm babies at discharge (Garfield et al. 2014) and it affected maternal well-being.

The future: *are you going to be a normal baby?*

Even though mothers started to get 'hints' that their baby was getting ready to be discharged, they experienced the process in both hospitals with uncertainty. After her baby Evelyn had already been discharged, Doris told me:

I started to ask when my baby would be discharged on a Friday, the doctor told me to ask again on Sunday, and they finally discharged her on Tuesday. (IP4)

Another mother said:

They told my friend her baby would be discharged soon, but it's been a week and nothing, they keep postponing it. (IP27)

The future well-being of the baby was a great concern to mothers, Lety, mother of baby Xochitl told me:

I tell my baby please start growing, are you going to be a normal baby? Are you going to be chubby and do the same things like normal babies do? [...] and when I take her to the kindergarten, will it be the same [as with other children]? (IP22)

JDH had a good referral plan and follow up for babies, these helped mothers feel reassured. MDH had no follow up programme. Mrs Irma came back to hospital to complete some paperwork after her grandchild had been discharged, she told me:

Our next medical appointment is in three months' time with the paediatrician, but nobody has told me if the baby will need any type of therapy, I hear some babies need therapy, how can I tell? (IP29 from field notes)

Parent-to-parent support: *it was such a relief to hear others feel the same*

Well-being links to social support and reassurance to overcome loneliness, and the parents constantly spoke about feeling that *only parents going through the same experiences fully understand what we are going through (IP19)* and how important it was to support each other.

Staff from JDH organised events for parents and babies in order to commemorate World Prematurity Day. The events included gathering with parents whose babies had been discharged in order to share their stories with those parents whose baby was still in hospital. For baby Gael's mother, listening to those stories was important:

It was such a relief to hear others feel the same, they had similar worries and I realised I am not the only one (IP14)

Several other mothers spoke about meeting in the lactation room with other women. Mary mentioned this was a time *to have a laugh and forget for a minute about our problems (IP9)*

However, some healthcare professionals saw this as a threat, especially when parents shared feelings during difficult situations. Dr Yola mentioned:

Parents make a collective hysteria when a baby dies and they become aggressive towards staff (ISI)

Staff in the baby unit became irritated if they thought mothers were gossiping. Ana and Julia had become good friends after several weeks of their babies' hospitalisation. Baby Pedro and baby Cesar were cared for in adjacent cots in the intermediate room. These two mothers seemed to be used to their routine in hospital. One morning they talked while they fed their babies, the doctor in charge, who sat by the desk, said:

Are you here to talk or to visit your babies? (Field notes)

In short, parent-to-parent support in these units, with the reassurance parents might receive and the happiness they might gain through helping others mutually was not encouraged and, for some healthcare workers, it was seen as a threat.

e) Socio-economic

Seguro Popular was introduced as part of the Healthcare Reform in 2004 in an effort to improve uninsured people's well-being (see Chapter 1). Normally, people who uses it are self-employment, in informal employment or unemployed. These families then face a further problem: there is no maternity cover or any other type of financial help from the government during the first weeks after the baby is born. The majority of people I interviewed had access to these hospitals through *Seguro Popular*.

The case of MDH was especially problematic. Families came from far away, incurred extra expenses of transport, food and accommodation (except for women who stayed in

the *Posada*). Parents were expected to be available 24 hours if babies' condition was very fragile and, as shown in section 4.4.1 in Chapter 4, absences of more than 72 hours were considered abandonment and reported to authorities. Claims from the Government that the provision of SP mitigates out-of-pocket expenses of the poorest families, which can lead to further impoverishment (Knaul et al. 2006) failed to consider these extra expenses which affected the poorest.

Support from the wider family (which links to the previous section of psycho-social well-being), became extremely valuable. In most of the cases, older children were cared for by relatives while their parents stayed in or near the hospital 'with' the sick baby.

In some other cases, family members loaned money to parents:

Thanks God my husband's siblings lent us the money to buy the medicine, otherwise I don't know how we would have done it. (IP27)

Manuel, an informal seller said:

I couldn't work for five days so my father gave me a hand because he is also a merchant, he said not to worry and took my stuff to sell. (IP5)

However, not all families had this support, especially if they lived very far away from the hospital. I talked with Arnoldo (IP26), father of Nadia, who had been in hospital for 20 days already. He told me he worked in the fields, in a small town five or six hours away. He needed to return to work and would not be able to come back to see his wife and his baby in the next 15 or 20 days. He had been renting a small room close to the hospital and was undecided whether to take his older child, who was five years old, back home with him. He worried the child had missed school in all this time.

Many of the participants in this study could no longer exchange their time for money, even when they were in great financial need. Since they were not allowed into the hospital except for a very restricted amount of time, parents felt their precious time was no use while they waited in the street and increased feelings of anxiety and frustration.

6.6.5 Cultural: on being a father

I chose to look at how fathers' role as an aspect of culture because I wanted to 'give' fathers a 'place' of their own in this thesis. I certainly think fathers tend to be ignored, not only physically in the NICU but also from the literature about babies. This section shows how fathers made sense of their role in the NICU and how they, and others, thought fathers contributed to their well-being of their babies

Breadwinners

Julia for example, thought that fathers should not interrupt their work because of their child's hospitalisation. She considered it was a lack of responsibility to jeopardise their jobs during this difficult time and furthermore:

We (women) are much better in caring for babies, how to say it... We have it in our instincts, I am not saying they are not good but we are better (IP15).

Indeed fathers constantly spoke about their role as providers of economic resources as a way to contribute to their families' well-being. In a focus group men discussed money and their need to go back to work as one of their main worries. From the three participants in the focus group, one continued to work because the commuting time was only over an hour (IP18), the other two fathers (IP19 and 20) lived and worked more than four hours away from hospital and had chosen to stay during the 23 and 28 days that their babies had been hospitalised respectively. This was due to the fact that their wives were still recovering from their surgery. Both fathers spoke about the financial difficulty this represented. Arnoldo (above) faced similar circumstances.

Not very good with babies

The belief that the best person to care for the baby was the mother was also confirmed by fathers:

...sometimes I don't come in because I prefer her to see the baby, and I also, I also have to work, so I just wait outside (IP18).

This was supported by doctors' attitudes. Several of my observations show, when talking to both parents (outside the NICU), doctors directed their attention to the father if they were required to make a decision (for example about surgery), or if they asked for a medicine that was not available in hospital.

Information gatherers

Another important role identified by fathers was to do with 'gathering information'. Enrique described how he preferred to see his baby briefly and wait outside the unit, so that his wife could spend most of the visiting time with the baby,

...but as soon as she leaves I ask 'did the doctor give you all the information?' (IP19).

Another father told me:

I literally had to argue with the doctor to get information about my wife and my baby when she was born. (IP23)

In their interviews with 16 fathers in Canada, Arockiasamy (2008) and colleagues found that a sense of lack of control over the situation pervaded fathers' experience of having a child in the NICU. The authors propose, gathering information contributed to feeling more in control. However, through interviews with five fathers in Dublin, Hollywood and Hollywood (2011) found information can also have negative effects when not shared with fathers consistently.

Socially, men are expected to be 'rational' and 'in control'. Results of interviews with (nine) fathers show they seemed to think they needed to be concerned with (epistemological) understanding of the situation and leave mother the (ontological) task of caring for babies.

Tough men

Fathers were also expected to endure harsh circumstances and not think of their own well-being. Another father told me:

I've been sleeping on the floor since he was born. (IP8)

Mothers in these hospitals were given a place in the lactation room (where they received some type of education) and, some of them, in the shelter at MDH. Fathers had no physical space in either hospital or any other type of support directed to them.

Doctor Mariel told me:

Many men are dirty and smelly because they sleep on the floor and have no access to showers, we can't promote kangaroo care (skin-to-skin contact) in those circumstances. (IS31).

The normative level shows skin-to-skin contact and many other interventions were seen as problematic by staff not only due to lack of resources but also due to lack of guidelines.

Unfortunately, in having to keep up with an image as 'tough' and 'unemotional', fathers might have found it difficult to be caring with their babies in the public space of the NICU.

6.6.6 Normative: lack of evidence based guidelines

Medical and nursing practice today are expected to be based on evidence. This means that clinical decision making, practice guidelines, general health service and medical education should be informed, to the best extent possible, by scientific medical literature (Korppi 2016).

The survey administered to NICU staff concluded that one barrier perceived by healthcare workers in involving parents in caring for their babies was the lack of

guidelines relating among many routines to NIDCAP standards and to promoting the well-being of babies and parents. Interviews with doctors and nurses showed guidelines not only lacked for parental participation but for many routine interventions.

Oxygen

Babies born preterm, especially those born before 32 weeks of gestation and weighing less than 1500 grams are at risk of developing retinopathy of prematurity (ROP). ROP is caused by abnormal growth of the retinal blood vessels which can ultimately cause the retina to detach. For many years it has been well known that exposure to high levels of oxygen saturation might pose a risk of ROP (Ashton et al. 1954; Avery 1992). However, the use of oxygen in MDH and JDH seemed to be indiscriminate, a doctor told me:

I have patients in private consultation with horrible consequences, some of them are blind unfortunately, and parents speak about NICU staff with resentment. Maybe, we could involve parents in reminding staff about the oxygen... (IS10)

MDH had an ophthalmologist paediatrician who specialised in the retina. He made eye checks routinely in order to prevent ROP. However, he constantly complained about the lack of adequate equipment to do the eye checks. Eye checks were not performed in JDH, patients were referred to other institutions for follow up.

Antibiotics

Because of the high volume [of patients] there are children whose [antibiotic] scheme is over and they continue [being given antibiotics] or they have not finished with the [antibiotic] scheme and they [doctors] withdraw it. That is [a] frequent [problem which] results in bacterial resistance, nephrotoxicity (poisonous effect in the kidneys) and ototoxicity (poisonous effect in the ears, specially cochlea and auditory nerve). (IS10)

There is no infection control committee in this hospital. (IS7)

Antimicrobial resistance is a problem threatening global well-being and health-care, which occurs when microorganisms develop the ability to resist drugs to which they were sensitive. This is a major problem given that the number of lethal infections and tropical diseases is increasing substantially. One cause for bacteria resistance is the indiscriminate use of antibiotics. The World Health Organisation has now called for increased efforts in infection prevention as well as enhanced guidelines for the use of antibiotics (WHO 2014a). Ironically, to call for a more controlled prescription of antibiotics, which would benefit millions of patients worldwide, might reduce interest from pharmaceutical companies in developing a new generation of antibiotics given the lower margin in profit this represents compared to long-term treatments.

Medical advances that are intended to save babies can also cause harm if used indiscriminately. Coughlin (2014) asserts, in order to minimise the risk of harm, there is a need to understand what constitutes harm; define whether it is physical, emotional or both and analyse if there is 'acceptable' risk linked to hospitalisation.

Dr Leon argued that parents needed to be made aware of those risks:

Parents have the right to know that some medicine can have consequences. Interventions in the NICU are risky and parents need to know about those risks, if parents know about them then, when we have an accident, like when a catheter breaks and the lung gets infiltrated, then they might take it [the news] with more calm and not accuse the doctor of being negligent. (IS16)

Ethics procedures that defined decision making processes and levels of involvement were not available in these units.

Skin-to-skin care

Skin-to-skin care, also known as kangaroo mother care, consists on placing the baby (naked or partially naked) on the mother's or father's chest for prolonged periods (the time varies from place to place). During this time mother or father and baby establish a truly synchronic relation, in which together, they modulate their temperature, breathing

and heart rate. Skin to skin contact can also help parents and baby to relax, and therefore it has an impact on sleep (Smith 2007) and it promotes breastfeeding.

For decades, this has been identified as a low-cost intervention that could save the lives of millions of babies around the world where adequate intensive neonatal care is not available (March of Dimes et al. 2012).

A recent review from the Cochrane Collaboration has shown that Kangaroo Mother Care (also known as skin-to-skin contact) is a safe alternative way of caring for stable low birth weight babies, with benefits such as reduced risk of infection and reduced time in hospital (Conde-Agudelo et al. 2011) among many others and is especially beneficial in developing countries, where resources tend to be scarce.

My survey to staff asked whether they believed babies benefited from kangaroo mother care, to which most of respondents answered positively.

A well organised kangaroo mother care programme would be a great programme. (Su3)

In the kangaroo mother care programme it would be ideal that the newborn stays with his/her mummy all day in a special area where the mummy gets all the comfort in order to stay, and the low weight newborn would gain the ideal weight faster, it would reduce expenses and [length of hospital] stay. (Su45)

However there was no skin-to-skin programme, it was nurses in both units who decided if and when a baby could be put on their parent's chest.

The problematics of not having guidelines affected lack of continuity in care. The 'weekend' medical shift was seen as a serious problem, especially in MDH. Doctors commented:

Saturday is no one's land, they don't even care about oxygen. (IS16)

Because it is a Saturday they don't take the blood tests or they don't remove the catheter. (IS4)

This also added to parents' anxiety:

When Friday night approaches I feel all shaky, even in my legs, just to think Saturday is coming and there will be weekend doctors. (IP7)

Absences permeated all different levels of life in the NICU. The absence of evidence in many procedures worked to the detriment of babies' biological well-being, and it also affected parents' and staff's psychological well-being. Parents felt frustrated when they saw care was not consistent, and staff might have felt split when they knew the care they provided was not of the highest standard but felt there was no alternative due to scarcity of resources (and knowledge).

An alienating environment, routine standardised care not mindful of individual needs, mothering without feeling like a mother, fathering from the distance, parenting within constant uncertainty and having to practice nursing and medicine with low standards of care connects with a wider reality outside the NICU.

6.7 3L Totality

The next stage of MELD in dialectic critical realism, 3L, refers to *totality*, which was introduced in section 3.3 in Chapter 3. This is the point where we begin to connect 'the parts to the whole', but it is also a reminder that MELD is about movement and process from 1M onwards. For Bhaskar, totalities are open and partial given that 'change and emergence of the new is always possible' (Norrie 2010, p.90).

One characteristic of *totality* is *holistic causality* (Norrie 2010, pp.93–94) which refers to that inter-relation through:

- a) transfactual efficacy, this is, the generative mechanisms at the level of structure (in the real dimension) at 1M,

- b) spatio-temporal causality, the process of becoming and being within time and space at 2E,
- c) holistic explanation at 3L which will lead to
- d) the causal power of (intentional) agency that will be discussed in 4D

3L will now look back holistically, trying to explain how some mechanisms are causing things to happen at the mega and micro levels. I will also recall examples from other chapters to show how they inter-relate to this one.

The introductory chapter of this thesis reviewed some of the social challenges Mexico faces: insecurity, corruption and poverty. 3L will analyse the effect of these problems in the neonatal unit. The literature review chapter also examined some conceptions of children as immature humans, mainly influenced by developmental psychology. It argued that prematurity is normally presented in the literature (medical and social) through deficits rather than strengths, failing to take into account of particular characteristics of children and the context. This section will also analyse the consequences of those conceptions when caring for babies in hospital.

6.7.1 Insecurity and violence

Long dreadful hours without seeing or knowing about their baby, the alienating environment in the unit, frustration at not being able to protect their own child, tense relationships with healthcare professionals, uncertainty about the future and financial concerns were among the many factors that eroded well-being and added up for parents to the distressing event of having a sick child in hospital.

Unfortunately, outside hospital the environment posed further risks to the integrity and well-being of the whole family. This was especially the case of JDH.

Violence and murder against women are everyday issues in Mexico, an example of this are feminicides defined as:

‘An extreme form of gender violence against women, product of violation to their human rights, in the public or private context; formed by a group of misogynist conducts which can lead to impunity by society and the State and could culminate in homicide and other forms of violent death of women’ (Presidencia de la República, 2007: 6 cited in Salgado 2013).

These feminicides increased notoriously from 2007 (ONU Mujeres 2011). Feminist academics suggest that gender violence responds to how women are (de)valued in a patriarchal society, but this also needs to be regarded as an intricate problem that involves social, political, economic, cultural and ideological conditions (Salgado 2013).

Femicide greatly affected the area of JDH. In recent months it was reported that dead bodies were found when sewage works were being cleaned nearby. From 21 of these bodies, 16 belonged to women from as young as 14 years old.¹⁵ Conversely some reports suggest the number of bodies found exceeded 40 but the authorities failed to report real numbers. There have also been reports of missing teenage girls for many years^{16,17} and complaints (as in the rest of the country) of authorities refusing to investigate further.

A general hospital, JDH also received people wounded during drug-related fights (normally drug cartels competing for territory). These were especially stressful moments for members of the staff, who feared cartel members could break in to rescue the patient, or enemies kill him (it was men usually involved in these events). This had never happened in JDH, but there were ‘stories’ about these events happening in other hospitals from the area.

Violence not only pervaded JDH in the form of femicide or drug-related fights. Assaults in plain daylight were also common (see for example appendix 1). Yet, instead of being protected as citizens, service users in public hospitals are treated as criminals. In order to

¹⁵ <http://www.elfinanciero.com.mx/sociedad/21-cuerpos-son-hallados-durante-el-drenado-del-gran-canal-en-edomex.html>

¹⁶ <http://www.sinembargo.mx/14-10-2014/1142343>

¹⁷ <http://m.eluniversal.com.mx/notas/estado-de-mexico/desaparecidas-en-neza-y-ecatepec-del-mismo-perfil-.html>

‘visit’ their babies, parents had to report to two or three ‘security’ check, where they were scrutinised and their belongings were reviewed, every time they went into hospital.

In MDH there were three security points parents had to report to, the first one a notebook where they printed their name, without being crossed checked against any type of identification. A mother complained about having spent several minutes queuing in order to have access to the notebook and she added:

I could have written ‘Chapulin Colorado’ (a Mexican comedy character) instead of my name and nobody would have noticed. (Field notes)

A false sense of security was portrayed. Local and Federal Governments failed to recognise deep structural problems and, instead, punished these ‘second class citizens’ (Wacquant 2009) with deficient services, bureaucratic procedures and (deficient) surveillance strategies.

Babies discharged from these hospitals, especially in JD, were saved only to come out to the street where their life and safety were constantly at risk.

6.7.2 Corruption and the system of favours

The system of favours that characterises many aspects of life in Mexico, from politics to completing a procedure in a governmental office were constantly reproduced in the day-to-day practice at hospital.

Jazmin talked about her relationship with other mothers and said:

The only one I don’t get on with is the mother of the baby in bed x. She knows someone inside [the hospital] so they let her bring her sisters to visit and they all get chairs (IP21)

In their desire to be with and protect their babies, parents looked at different alternatives. As I came one night into the baby unit at MDH, I saw a mother outside the NICU with a

tray of pastries. Quietly, she called a nurse who was passing by and handed her the tray with pastries as she said:

'Miss I brought this for the nurses' dinner' after a brief pause she continued 'please look after my [twin] babies'. (Field notes)

I could not help but wonder whether she had also given a tray to the guards at the main entrance and at the baby unit; parents were not allowed into the hospital at night. I asked the nurse whether she thought those strategies worked and she answered:

Unfortunately yes, this is not the first time she does it, the other day she brought tamales (typical Mexican food) and asked for her babies' clinical report, and the doctor gave it to her. (Field notes)

For staff, corruption was not a 'system of favours' but (consciously or not) a 'system of power'. A doctor from the morning shift complained about procedures at night, which affected her job and moreover affected babies' well-being:

The attending doctor goes to sleep and the nurses stay in charge, even if there is an emergency they have to intervene. Nurses inform him of events by the end of the shift, so that he can fill in and sign the records. (IS1)

A nurse complained about her boss:

When there are continuing education courses, she always sends the same people, who are obviously her friends (IS28)

In this hierarchical system it was difficult for staff from lower hierarchical levels to challenge more senior positions. As the 'World Prematurity Day' approached, a small group formed by nurses and doctors in JDH organised some events for parents. They visited their local radio station to advertise their celebrations. One of the journalists asked whether they could come and cover their event. Informally, they talked to one manager in the hospital who agreed. When other administrative staff realised a journalist was interviewing parents in the hospital, they asked them to leave. The nurses and

doctors who organised the event were suspended for a day for not having followed formal procedures. The senior manager who gave informal authorisation faced no repercussions. The day I came to visit they told me how ‘sad and discouraged’ they felt.

6.7.3 Poverty

As shown in Chapter 1, until 2004 more than 50% of the population in Mexico did not have access to social security. After the implementation of *Seguro Popular* through the Health Reform in 2004, the government claimed the problem of access to healthcare had been resolved:

Therefore, poverty and labour market status are no longer barriers to participating in public institutions for health insurance. (Frenk et al. 2006, p.1524)

While it might be true that more citizens can now access public hospitals, these are failing to cope with the demand for service. MDH worked in 2013 at 140% of its real capacity (IS15) and with a deficit of 12 nurses in the NICU (IS14).

In both hospitals, babies sometimes had to remain in improvised areas waiting for a cot to become available in the unit. When a bed did not become available (in MDH) babies were transferred to other hospitals, even if those were further away from parents’ communities.

By law, these hospitals should provide all the medicine needed, however it was very common that parents had to buy medicines outside because of shortages. Babies’ admittance was sometimes conditional on parents’ agreeing to cover some extra expenses:

Sonia was 31 weeks pregnant with twins when her waters broke. Access to her regional hospital was denied because they considered they did not have the resources to keep the babies alive. She travelled for two hours to get to MDH, where they said there was no space for more babies.

So I told the doctor what can I do? My waters broke and my babies are going to be born soon. The doctor replied, if you husband commits to covering for medicine that we do not have you may stay. (IP6)

It was common that, when the labour began at early gestational weeks, local and regional hospitals denied access to women. They lacked the resources to attend those cases, and individuals (rather than the deficient system) tended to be blamed when patients died.

A system of corruption takes place when individuals are interested in their own good, failing to understand how one's own well-being also entails the well-being of others.

6.7.4 Historical conceptions of children: doomed to fail

Chapter 2 briefly discussed critiques about children being seen in terms of their deficiencies and lacks (mainly from developmental psychology). The physical level in 2E described that cots in JDH displayed babies' personal information on an identification card. A second card on the cot showed the phrase 'mental retardation prevention' to indicate that the baby had already had newborn screening tests. The card was displayed only to indicate the tests were done, it was not indicative of the results. But the first time I saw the card I failed to understand what it meant, at the beginning I assumed it was part of the baby's clinical condition (I thought the baby had been diagnosed with a cognitive impairment). I then realised most of the babies had a similar card on their cot. I wondered how parents felt every time they saw this on their baby's cot or if it was placed there on purpose, so that parents kept in mind the risks their babies faced by having been born early.

But mothers not only faced this reality through the card every day, they were also constantly reminded by doctors about it. Mary, mother of baby Joel born at 27 weeks said:

I was very worried because the doctor had said that my baby, most likely, had a[n intellectual] retardation but thank God they already confirmed he doesn't. (IP9)

Lorena said:

My baby had a cerebral haemorrhage when he was born [at 29 weeks of gestation] so the doctors told me he was going to have many difficulties in the future but look at him, he is two years old and he is a normal happy boy. (IP1)

Understanding conceptualisations of babies and how they translate into practice is important because it marks the departure for change. Baby-led practices can hardly be implemented in a context that fails to recognise not only individual characteristics but also individual strengths that might be better supported by others and by the environment.

Violence, poverty and prejudices of social class, ethnic origin and gender impact hospital organisation. Added to these are historical conceptions of children as immature and prejudices of preterm babies as deficient human beings in the neonatal unit. The interplay of these not only jeopardise the present well-being of the smallest and weakest members: ill babies in the NICU, but it also poses questions about the far reaching consequences on their future well-being.

6.8 4D Flourishing – Transformative praxis

The last moment in MELD dialectic critical realism, 4D, entails a ‘return to practice’ where agency is seen as a ‘*radically transformed transformative praxis, oriented to rationally groundable projects* – ultimately flourishing in freedom’ (Bhaskar 1993:9 emphasis in original) – or well-being.

This section will look back again at 1M, 2E and 3L in a reflective process. It will particularly address absences identified in 2E and propose alternative ways to resolving contradictions and inconsistencies.

I will begin by describing successful initiatives taken by staff directed to improve the well-being of patients by sharing knowledge or overcoming problems through creativity.

Subsequently, I will propose further actions to enhance those initiatives and practical solutions that could lead to the well-being of babies in the short and the long term.

6.8.1 Education through shared knowledge

Comments about lack of opportunities for continuing education were common in these units, especially among nurses, many of whom were eager to keep learning. In the light of such shortages of resources, many nurses found strategies to share knowledge.

Two nurses in JDH learned a new technique to insert catheters into babies, a procedure that only doctors would perform in the hospital. Little by little, they started to teach others. The nurse who started with the idea, Roxana (IS17), told me very proudly that her colleagues now approached them and asked her to teach them. Both nurses were now in the process of writing guidelines.

Another example is the ‘quiet campaign’. When people started to realise I was measuring noise in the unit, they started to turn off music and speak quietly as they saw me enter the room with the decibel-metre. After a few days, some nurses in JDH became interested in knowing the results, every day after I measured noise levels I informed them where the highest transient noise was recorded and what seemed to cause it. Nurses in JDH decided then to make a ‘quiet’ campaign and we designed posters to inform others about the benefits of reducing noise levels. They learned how to use the noise-metre and one of the doctors bought it and donated it to the hospital. Later, they found a sound engineer who agreed to collaborate in the project. A small team of nursing students took on the project as part of their degree practice.

The impact of the physical space (ventilation system, doors opening and closing, plumbing lines, surface materials on floor) need to be taken into consideration in order to truly decrease noise levels in a NICU (Philbin & Gray 2002). The equipment used to measure noise only allowed us to detect transient single noises. In order to know whether the ‘quiet’ campaign worked we needed more sophisticated equipment that allowed us to measure and record noise during discreet time periods. However, this

initiative was important because it showed that nurses became aware of and reflected on how they could contribute to having more appropriate spaces for the patients and designed a strategy to inform others about it.

In MDH nurses and doctors also became interested in knowing more about noise levels in the unit. One of the physicians started to read more about the topic and included it in her classes to resident doctors and presentations during general sessions.

White and Reiss (2013, p.14) have shown the role of education in the flourishing of people ‘when fully and successfully engaged in intrinsically worthwhile activities of all sorts’. Staff in JDH and MDH seemed to thoroughly enjoy and feel rewarded when they felt their actions were meaningful and their work was valued. Their initiatives represented well-being for them personally and for the people around babies, parents and colleagues.

Knowledge, shared education and the ‘Eureka moment’ might also contribute to overcoming lack of resources through creative processes.

6.8.2 Creativity

In critical realist term creativity is ‘the capacity to produce something new and valuable’ (Hartwig 2007, p.86) and therefore of absencing an absence. This takes place through a process of emergence. Bhaskar (2002) proposes that creativity develops in a process where, in a first moment (1M) – knowledge or capacities are unmanifest or enfolded (the potential of being), which moves to a second moment (2E) of emergence (something new). At a third moment (3L) creation or elaboration takes place within human characteristics of solidarity, bonding, compassion, care, consideration which leads finally (4D) to agency and action (transformational change).

During my fieldwork in Mexico I had the opportunity of witnessing creative processes several times.

In MDH, the unit lacked decorations. Staff felt they needed to make it feel cosy and inviting for babies and parents. Some nurses came up with the idea of asking parents to bring personalised decorations for the cots. Some of them brought pictures framed with cardboard made by the siblings, others brought the name of the baby and baby decorations in foami and others brought religious stamps. Parents' creativity was also evident throughout the activity. This gave the opportunity to participate and be present in an alternative form.

Nurse Magdalena (see Chapter 5 section 5.6.2) was invited to give a conference at JDH, she talked about her work with parents and babies. She learned about the nests many years ago, her hospital had no resources to make them. She designed her own nests with materials she had at home. When her colleagues saw them, they bought more materials and got together to make sufficient nests for all babies in their unit. It is now a practice in her hospital to ask parents whether they would like to bring the material to make their own nests. Some parents donate their nests for other babies after discharge.

Skin-to-skin contact or kangaroo mother care is an excellent example of creativity in neonatal care. Dr Edgar Rey Sanabria started the 'Kangaroo Mother Care' programme at Instituto Materno Infantil in Bogota Colombia in 1978 in response to scarcity of resources (incubators) and high morbidity and mortality of babies born with low birth weight (Charpak et al. 2005). As with any new ideas, Dr. Rey faced reticence from his colleagues, however, to date this programme is widely used in developed and developing countries and it has saved millions of lives.

Creative ideas could help to ensure there are always basic resources in JD and MD hospitals such as soap and antibacterial gel, to care for babies in the unit.

6.8.3 Inter- and multi-disciplinarity, the way forward

The critical realist view of 'disciplinarity' is a 'specialized creative and transformative work (in the transitive dimension) necessary for the identification of the previously

unknown deep structures and causal mechanisms of the world (in the intransitive dimension)' (Bhaskar 2010, p.3).

In both units the doctor (neonatologist) decided when to move each baby from gastric tube to oral feeding. This decision was normally taken on the basis of physiological readiness. However, as reviewed before, babies' ability to feed are also linked to their neurological development, capacity to coordinate and integrate sensory stimuli from environment and maintain physiological stability. For a preterm baby, this is extremely difficult to attain. In this case a multidisciplinary team might be formed by:

- The doctor, who will make the decision based on the baby's clinical condition.
- The nurse, who spends most of the time with the baby and can detect signs that the baby is beginning to root for food and start to suck. The nurse is also normally the person who guides parents so that they can get involved in the process.
- The nutritionist, who normally works together with the nurse and also supports mothers in the process of breastfeeding.
- If there is one, the speech and language therapist also identifies signs of readiness and helps the baby through the process.
- The parents, are part of the team. The mother extracts her milk and eventually takes over from the nurse even if the baby is bottle fed. Both parents learn about their baby's unique cues if given time to observe.
- Babies should also be considered as part of the team, when they communicate about their own well-being through subtle signs.

By working together, the team enhances the possibility for the baby to: have a good intake of milk, gain weight (indispensable for discharge), establish the foundations for healthy eating in the future; be discharged at an appropriate time. This can free up a (much needed) hospital bed. It might also help parents feel involved and ready for when the baby goes home.

This would all save babies suffering from being forced to eat when they are not ready. By having brief multidisciplinary ‘team’ meetings and discussing issues about the baby from different perspectives, the baby is kept in mind.

Listening to parents’ views could also help overcome some of the absences at 2E physical, for example pacing the feed when the baby is tired, and it could address parents’ fear of the transition to home.

This chapter has revealed the need for evidence based protocols and agreed guidelines that are mindful of babies’ individuality not only as embodied being but also as members of a family and of humanity and that are based on promoting well-being in numerous ways.

6.9 Conclusions

Well-being is a very wide term, normally seen from an adult-centred perspective. Thinking about babies in hospital, identifying absences and lacks that represent ill-being might help to identify the counterpart, well-being. For example, in the absence of the mother a baby cries; we could then interpret that the presence of the mother makes the baby feel happy.

At a very basic level, intensive care units need to be sanitised, well ventilated and well-lit spaces in order to promote health. At the same time light and noises need to be moderated to promote an environment that allows the patients to rest. The physical level shows that neonatal units in both hospitals lacked these very basic standards. Units were over-crowded, bright and noisy. Day/night cycles did not exist within those walls.

Reduced spaces, lack of chairs, over-crowding, under-staffing and absence of parents (at a physical level) discouraged activities that involve parents, such as skin-to-skin contact and breastfeeding, which might be very enjoyable for babies.

Socially constructed clock time helps organise activities but unfortunately it does not coincide with babies' natural rhythm. Similarly, scientific knowledge intended to help babies thrive becomes problematic when babies' individual needs are not acknowledged or met. An environment that is intended to create a 'healing' space seemed to become alienating for staff, parents and babies. As Adam asserts, time-management activities in general are 'out of sync with the generative times of the body and as such they affect our physiological well-being' (1995, p.53).

Power₂ relationships arise when babies are seen as 'faulty' embodied pre-human beings who need to be fixed in the neonatal unit, without considering how the adult-infant relationship can contribute to babies' well-being if babies' responses are considered.

Power₂ relations are also present when mothers' knowledge and natural capacity to 'tune-in' with their babies and their skills to care for them are ignored and overlooked by medico-scientific forms of knowledge.

And a third type of power relations that combines the physical and biological levels is the alienating environment in the NICU to which all people were exposed, but especially babies and nurses.

Becoming a mother in the neonatal unit seemed to be mediated not only by feelings of lack of preparation, fear, guilt and grief, but also by the physical environment and by the relationship with staff, especially with the nurses. Observations suggest that mothers needed time to digest events. They were scared, in shock and found the NICU environment alienating. Becoming a mother seemed to be put on hold while nurses became primary carers and gate keepers to the babies. This inevitably entailed power₂ relationships when both groups claimed ownership of the baby. For example, it was very common to hear nurses calling patients 'my baby'.

Anxiety and stress might also have been exacerbated by bureaucratic and security processes even before entering hospital (in MDH having to sign in a notebook with no apparent purpose).

Traditional roles were assigned to mothers and fathers; the former ‘cared’ for babies (by providing milk and visiting) while the latter provided for the family and endured harsh circumstances. These reproduce some of the practices described in the introduction through puericulture. Men did not find a place inside hospital (in JDH they were not allowed in during the morning), gathering information seemed to be the form in which they maintained contact with their babies.

Previous studies showed that women reported having felt ‘as a mother’ when they held their baby for the first time (Reid 1986), which none of the mothers mentioned in this study. This was probably due to having had to wait for weeks or months before holding their babies for the first time.

Moreover, in studies made elsewhere (Lupton & Fenwick, 2001; Skene, 2010) mothers were able to stay in the NICU for much longer periods during each day and began to participate in their babies’ care more actively. It seems that mothers in MD and JD found other forms of ‘participating’ such as praying or slightly moving the baby, which shaped their identity as a mother in the NICU. Although some mothers resisted being ‘left out’, the general feeling seemed to be that they did not belong and were a burden in the NICU.

Healthcare professionals saw support and education for parents as a burden, and probably as a pointless activity. The general perception was that parents were ignorant, so probably this was a waste of their very precious time. Fragmented communication as seen in Chapter 5 continued even after discharge.

Parents’ gatherings and exchanges of information were seen as a threat, a belief that their anxieties were exacerbated developing in a ‘collective hysteria’, but these were inevitable. Parents sought to support each other and, in many cases, were in solidarity with each other.

People talked about lack of human and economic resources, however restricting parents from ‘becoming parents’ in the unit could create further social and financial crisis. For

example: babies and parents feeling distressed when separated for extended periods of time, parents being restricted from participating in the basic care increased the workload for nurses, staff members feeling overwhelmed by the amount of work in the unit, cross infection through poor hygiene practices related to over-workload, and many others.

1M showed that parents-baby relations are important. Parents in the NICU might require extra-support in order to begin to care for their babies little by little, but when they go home they can feel better qualified and ready to begin to fully become parents.

3L began to show how each case (as open totality) interacts with a system pervaded by violence, sexism, insecurity and corruption. It also shows how individuals interact with each other and with the system and the causal consequences of those interactions. The social order in the neonatal units reproduces the social order in the Mexican Republic. The system of favours and corruption prevents people from working together. Relationships of trust are a two-way process in that each partner understands the importance of every body's well-being.

Poverty also permeates different aspects of the healthcare system, with a government system that prefers to deny deep structural problems rather than addressing them.

People also showed their creative capacity and joy in sharing knowledge which led to power₁ relationships of trust, solidarity, unity and greater well-being. These show that there is an alternative and they have important implications for policy and practice that will be discussed in the final chapter.

Powerful groups tend to start at 2E with negations/interventions to solve problems, but without the 1M search for underlying causes. For example, staff try to resolve their tensions with parents by excluding them most of the time from the units. Useful social research examines causes, values and routines that underlie these tensions and that need to be changed if the tensions are to be reduced, but this involves changing the power balance between the stronger staff and weaker parents besides the still stronger hospital regimes and management. These and other ideas will be reviewed further in the next and

last chapter, were practical proposals to overcome theory/practice inconsistencies will be presented.

Chapter 7 Conclusions

The main aim of this study was to understand why preterm babies in Mexican hospitals are cared for as they are. I drew on an original combination of research theories and methods, when planning the research, collecting data, and analysing and reporting the findings.

Childhood studies, unlike child development, treats young children as agents and rights-holders (Alderson et al. 2005a). I have extended this approach into considering babies in this study as service users; and to reflect not only on the impact that the healthcare system organisation has on them, but also on how they impact on the healthcare system organisation. Insights into their experiences have been addressed from adult interpretations (either from their parents, staff or mine as observer) informed from imaginative innovative research with babies and their ‘views’ and responses, such as by Als (1999) and Brazelton (2011 [1973]).

As part of this study, I was interested in understanding what the perceptions and beliefs about babies are and how these impact on healthcare practices. To some extent, this research has studied bodily relations between adults and children. These relations are part of the adult-child ‘inter-generational’ processes ‘whereby children’s lives are constructed and reconstructed and whereby their contributions to social arenas (home, school, neighbourhood, health services) may be enabled and respected, or may be hindered and rejected’ (Mayall 2015, p.313). Observing interactions between adults and babies was instrumental in identifying discrepancies between medicalised discourses and practices in caring for babies.

Another important objective of this research was to address wider factors that underpinned hospital organisation. The concept of ‘biopolitics’ (Foucault et al. 2010) informed this study and was helpful in considering the different strategies used to regulate day-to-day aspects of life in the neonatal units.

My ethnographic study of two cases investigated views and practices through interviews, participant observation (that included measurements of noise and mapping people's movements), observation of babies and a survey to staff.

A critical approach to ethnography invited me to consider the political, economic and social national context during my fieldwork period; my field notes include relevant news of events that directly or indirectly impacted on the Mexican healthcare system. Through a personal diary, I constantly reflected on my position as researcher and on how my values and beliefs might have influenced the decisions I made throughout this research.

A critical realist framework contributed to a deep analysis of the data by enabling me to consider hidden forces such as: neoliberal practices, social class, ethnicity, corruption, poverty, religion and patriarchy, among others, that caused events to happen at the empirical level. The critical realist concept of *four planar social being* became vital in the analysis of data, as it enabled me to consider events at individual, inter-personal, social and intra-personal levels. The concept of *transformational model of social activity (TMSA)* added to the analysis at the social (structural) level, making evident the ongoing interactions between agents and structures. The concept of *MELD* was useful in order to identify mechanisms that might lead to a change in practice mindful of babies and their individual needs.

Findings from my analysis suggest that there is a rhetoric about 'protecting' babies that, in many different forms, influences hospital organisation and validates disrespectful attitudes towards service users (babies and their families). Throughout this thesis I have presented evidence that discourses about hygiene, good parenting and babies' best interests sit in contradiction to current practices and reveal a series of theory/practice inconsistencies that, in many instances, exacerbate ill-being inside and outside the neonatal unit. Moreover, I have found evidence to suggest that the quality of care for newborn critically ill babies in these public hospitals is highly deficient and many of the non-evidence based traditional practices work to the detriment of babies' right to the highest attainable standard of health care (UNCRC 1989 Article 24).

My objective in this final section is to bring those findings together and create a further argument in favour of change in practice in neonatal care units in public hospitals in Mexico.

The first section of this closing chapter presents a discussion of main findings responding to the question: why are preterm babies in Mexican hospitals cared for as they are? The second section reviews the critical realist concept of the Self, as a preamble to the final section. The third section discusses ways forward in implementing baby-led care practices within three specific themes: nurses as agents of change, enhanced communication at all levels and normative procedures. Implications for practice, education, policy and future research are discussed throughout. The chapter concludes by describing wider implications of this research and future directions.

7.1 Why are preterm babies cared for as they are in Mexican hospitals? A discussion of findings

This thesis has described the physical conditions of the NICU at MDH and JDH, as well as the physical conditions in which babies were cared for through standardised routine care. I have tried to show how the macro (economic, political and cultural) context impact on the local organisation of hospital.

Through the theoretical framework presented in chapter two I argued long-standing traditions in the care of babies, and in particular the view of developmental processes as linear towards becoming a mature adult have contributed to a view of babies as future, rather than present citizens and, in this case service users. This thesis has shown evidence of a view of preterm babies whose lives are determined not only by their immature being but also by their low class status, and these ideas greatly determined the type of care they received.

A discourse around scarcity pervaded practice at all levels and contributed to degrading treatment to babies, to their families and to healthcare professionals. Discrimination related to social class, ethnicity and gender in the provision of care contributed to

deficient care. These findings are consistent with other studies in public Mexican hospitals (Smith-Oka 2015; Gallegos-Martínez & Reyes-Hernández 2014). However, the present study adds to the literature by analysing how other underlying mechanisms, such as religious beliefs, ideas about moral hygiene and gendered violence contributed to power imbalances.

Chapter one described the historic evolution of the Mexican healthcare system. The Mexican Government claims that *Seguro Popular* (SP) gives access to healthcare for a segment of society who would have previously been denied specialised care due to their work status. This is true for many of the participants in this study. However, SP has been heavily criticised by experts. For example, Laurell (2007, p. 522) contends that with the incorporation of these families ‘a new segment has been established in the already fragmented public health care system’ that will lead to insufficient health infrastructure and staff to guarantee provision of the service. It seems that Laurell’s predictions became real for hospitals such as MDH, which could not cope with the demand for services and faced constant shortages of medicine: parents constantly had to incur in ‘out of pocket expenses’ when they were asked to buy medicine elsewhere. Socially, SP creates deep imbalances when prejudices about gender, social class or ethnicity are not addressed and they become integral parts of the system. Chapter six argued that this deficient care might save some lives, however it poses a risk to the present and future health and well-being of babies.

Furthermore, belonging to a low economic social group tended to be associated by staff with filth and ignorance in these units. Infection control was the most common reason that participants in this study (both clinicians and parents) used to explain why the social life in the neonatal unit was organised to exclude parents so much. Yet, infection rates were unacceptably high.

While it is true that scarcity of resources acted as a barrier in fighting infection, lack of communication, lack of understanding of basic epidemiological control and a lack of awareness about how clinicians contributed to cross infection increased the risk of acquired nosocomial infection.

Despite their hard work and high aims to save life, the staff were frustrated by the scarcity of resources at all levels, high demand on the service and a sense of lack of time and little recognition by others of the value of their work. Unacceptably high mortality (one in four babies) and morbidity rates (almost all babies became infected) made doctors and nurses feel anxious and frustrated and seeming to need to blame the parents.

A system that failed to meet the most basic needs of healthcare workers also contributed to the provision of deficient care. Evidence about how parents might contribute to the well-being of their children in the NICU (reviewed in chapters two and six) sits in contradiction with the belief that parents are dangerous and might bring disease into the unit. My observations show that most of the parents in this study followed all measures of hygiene that were required to protect babies. I propose that rules not allowing parents into the unit were partly made in response to the needs of staff to feel protected from being seen as negligent when they (willingly or unwillingly) failed to comply with sanitary measures that were presented to parents as essential.

These findings present important implications for policy, education, research and practice. At policy level, hospitals need to make sure that the resources that do exist are used in the best possible form. Healthcare professionals need to be educated in basic epidemiology so as to understand how and why it is that they might pose a risk of cross-infection, and they also need to be trained in hand-washing. This will be further discussed in the final section.

Antimicrobial resistance poses an enormous risk, not only to each individual child but at a global level. Urgent calls are being made by scientists and members of the public to find new forms to fight infection without over-reliance on the development of new antibiotics¹⁸. At research level there is an urgent need to understand how breastfeeding (not only breast milk) and skin-to-skin care might contribute to strengthening babies'

¹⁸ <http://www.theguardian.com/society/2016/may/24/what-we-must-do-to-avert-antibiotic-catastrophe>

immune system in the Mexican context, accompanied by the social changes that are essential if practices are to improve.

I have presented evidence that the efforts these hospitals made to ‘promote’ breastfeeding were reduced to rhetoric. Far from being friendly towards babies and mothers, the imposition of the international ‘Baby Friendly’ programme created further problems when it was intended to be implemented as a generic 10-step guide, which failed to recognise the very particular needs of preterm or sick babies and the characteristics of each NICU context. Inconsistencies and contradictions appeared when bottles and teats were banned for they posed a threat to establishing breastfeeding successfully, and yet, restricting mothers from being with their babies (which threatened breastfeeding in deeper forms) was considered to be normal and correct.

For breastfeeding to be truly recognised as the best form to feed babies, neonatal units need to be organised so as to avoid increasing stress, anxiety and inconvenience for mothers. Furthermore, they need to ensure clean comfortable spaces for them to rest, and to sit with their baby, clean drinking water, nutritious food, a calm relaxing atmosphere and respect from the staff working as partners with parents in the babies’ care. In short, successful breastfeeding depends on a great amount of respect and support that these institutions denied to mothers, giving raise to further theory/practice inconsistencies. This study will contribute to an urgent international debate about the implementation of successful breastfeeding programmes at practice level.

My analysis suggests hospital organisation affected parents’ identities as mothers and fathers. The reduced amount of time they spent in the unit and lack of opportunity to practice parenting skills made them feel unprepared, a danger to the baby or a nuisance in the unit. It also impacted on their mental health when it made them feel scared or anxious about uncertainty of the baby’s present and future well-being. Unusually for a neonatal study, my work on the economic and political contexts appreciates further great stressors for parents: loss of income, costs of travel and staying in the city, often on the streets, where there is endemic violence. It is not known how all this affected their relationship with the baby in the short and the long term. It is important to recognise that

there was little time and space to deepen in an analysis of parents' experiences, status and identity in the neonatal unit, therefore more research in this area is needed to further understand these complex processes.

Parents' time in hospital revolved around a regime of constant queuing and waiting. Hospital organisation at MDH and JDH seemed to be consistent with a form of State domination (power₂ relations) of the poor analysed by Auyero (2012) in which 'street level bureaucrats' (in this case security guards, social workers, nurses and doctors who work at public hospitals) create and re-create continual episodes of waiting; and to which they themselves were subject when having to complete paperwork (such as requesting annual leave, I also experienced it during the process of accessing research sites). These 'temporal processes in and through which political subordination is reproduced' are representative of the politics in many Latin American countries (ibid p. 4 emphasis in original). If people wanted to receive medical attention from these public institutions, the message was clear, they had to be extremely patient and in being so, as Auyero puts it, they become patients of the State.

Different extracts from the data show the interactions and tensions between agency and structures. Many of the activities in these hospitals were directed at regulating parents, and in particular women. Extraction of breastmilk is an example of how women were sometimes left feeling 'powerless' when they had to comply with a tight agenda in the lactation room that prevented them from being with their baby. However, it also shows how they constantly exercised their agency when they contended with inconsistent practices or negotiated access to their babies with healthcare professionals.

Oppressive power₂ relationships and inconsistencies permeated all levels (interpersonal and structural) of hospital organisation, bringing about oppression, inequality, symbolic and physical violence, mistrust and ultimately ill-being. Moreover, these inconsistencies gave rise to dualisms such as: body/mind, reasons/emotions, public/private, society/individual and theory/practice, which are problematic because they split and alienate human beings.

So far I have described evidence of power₂ imbalances and biases created by healthcare organisation in these units, however throughout this study I have also found evidence of power₁ possibilities (described throughout chapters four, five and six), which open the door to transformational change.

The following section presents one more critical realist concept, the Self, which I consider essential to review in order to then discuss some possible ways towards transformational change.

7.2 Reconciling dualisms: a critical realist perspective

I propose Bhaskar's (2008b; 2002) concept of the *Self* and the *concrete universal* ↔ *singular* might help to begin to resolve some of these dualisms. This will set the basis for a practical proposal on the way forward, which follows this section. According to Bhaskar (2002), the Self is formed by the concepts of: the *ego*, the *embodied personality* and the *transcendental real self*.

The ego

The ego, as a concept of the Self, involves self-identity and has a sense of separateness from other beings; this motivates human behaviour and causes us to act in a specific fashion. The ego claims to be independent from any other Self and therefore it is an illusion, a false reality or 'demi-real', since human beings cannot exist in isolation from each other. The sense or illusion of separateness makes it causally inefficacious especially at the level of ideologies.

When a baby is born too early, she depends on medical and technological care to survive and she also needs contact with loving carers to fulfil her emotional needs. Once at home, the baby needs her parents or primary carers to provide (physically and emotionally) for her. Some babies are cared for by other family members, a nanny or in nurseries, so that parents can go out and work, but still the baby remains in connection with others. Even when she grows and becomes 'independent' this young woman needs

to remain in contact with others, she needs to be part of the banking system for example, in order to use her credit card. She needs to use natural and other material resources and to develop relationships (of love or work) with other people. This means, we are never completely separate from others and to think so is an illusion that has effects because it makes us act, for example, selfishly.

The embodied personality

The second concept of the ‘nature of the Self’ is the embodied personality. Bhaskar (ibid, p. 71) proposes that embodied personalities are ‘complex, relationally defined and constituted entities, themselves stratified differentiated and changing’ and therefore ‘relative reals’. This means, a preterm baby will become a toddler, and eventually he will come to speak, walk and even read. This is a relative real because, even though he remains the same person, his embodied personality will change (psychologists would say develop) to become a (student) teenager, (teacher) adult, and so on. Thus, the embodied personality is ‘relative, limited, bounded and perspective-dependent’ (ibid, p. 78).

Dualisms or contradictions take place when we act as if we are separated from everything and everyone, or when we believe that the embodied personality is all that we are. The concept of *emergence* introduced in Chapter 3 explained that, as stratified beings, our mind emerges from the brain and this emerges from the body, however the mind cannot be reduced to the body, nor can it be treated as independent of it.

The transcendentally real self

The transcendentally real self is the third concept of ‘the nature of the Self’. Bhaskar contends that this is the ‘I’ of causal agency; it flows and connects with other selves and with everything else in the world. Also called the ‘Alethic self’ it is ‘a source of energy, creativity and intelligence, love, joy and freedom, spontaneity, un-conditionality and agency.... it is concrete and singularised’ (ibid). It is also particular for everyone is different in the innermost being.

Each person in the NICU is unique and, at the same time, interconnected with others. As such, the well-being of each member is connected to the well-being of the community in the NICU and outside the NICU.

The concept of the *transcendental real self* involves non-dualism, that is, unity in our most inner being (with our emotions and feelings) but also a sense of connectedness with others. It allows us to feel empathy and solidarity with others. Chapter 6, section 6.8 showed that creativity, shared knowledge and solidarity are possible in these hospitals.

Concrete universal ↔ singular

The *concrete universal ↔ singular* is represented in figure 9. It is characterised by *concrete singularity* (the particular, unique individual) and *dialectical universality* (bounded to everyone else as part of humanity). This means that the concrete singular embodies a universal component and specific mediations: geo-historical trajectory and uniqueness. Each baby is a particular, unique person (concrete singular), member of humanity and connected with others in very deep forms (dialectical universality).

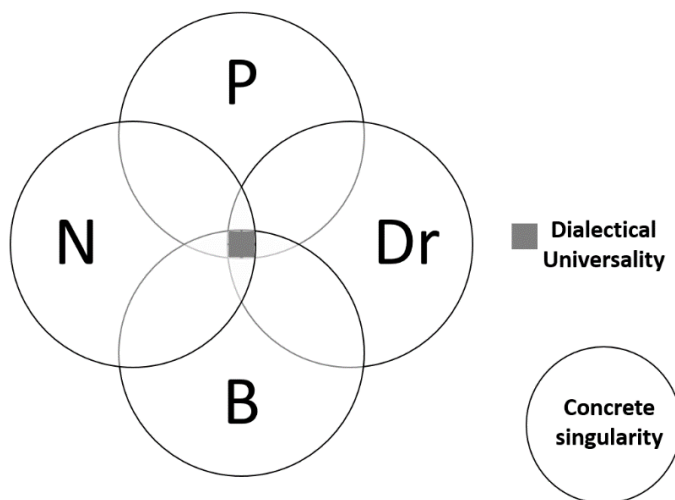


Figure 9 concrete universal ↔ singular

3L from MELD (section 6.7) showed how structural problems that affect Mexico as a country, such as corruption, poverty and violence, also have an effect on babies, families and the staff. At the same time, babies impact on wider structures such as politics and economics when governments have to invest millions in dedicated spaces (like NICUs), or when international pressure makes governments commit to reducing neonatal deaths.

7.3 A possible way forward

Having developed the concept of the *transcendental real self* and the *concrete universal* ↔ *singular* as a basis, I now move to the final section in this chapter where I propose a more practical way towards change of practice.

7.3.1 Nurses as agents of change

Nurses play a pivotal role in supporting parents in the NICU for they are the healthcare workers that normally spend the longest periods of time with babies, and have most direct contact with parents. Moreover, several examples from this thesis have shown that positive changes in the NICUs at both hospitals have been initiatives of nurses.

It seems difficult to ask nurses to be supportive, understanding and caring of parents when they feel overwhelmed and exhausted by long working periods with reduced breaks. Having their coffee break inside a unit that has no ventilation system (as in MDH) works not only to the detriment of the nurses but also (and very importantly) to the detriment of patients.

By providing education and training to parents so that they can perform basic care, nurses' workload could be alleviated. Nurses' concerns about activities that are suitable for parents to participate in need to be taken into consideration. Clear guidelines for activities that involve parents such as: syringe and breastfeeding, skin-to-skin care, washing and soothing babies and changing nappies, need to be developed. Instead of their status being reduced (power₂), nurses could become more respected when they teach and support parents and are freer to concentrate on the more skilled nursing

(positive power₁), instead of giving so much basic care. This has important **implications for policy not only in healthcare but also in nurses' training and education.**

Nurses in this study, as in others (Lupton & Fenwick 2001; Fenwick et al. 2001) acted as gate-keepers and decided when parents could have contact with their babies. Lack of guidelines, as well as powerful professional traditions and personal beliefs intersected and contributed to negative attitudes towards parents. This thesis has given examples of nurses who endeavoured to support babies and families in spite of difficulties and lack of resources.

More personal positive interactions with parents (power₁) might help reduce nurses' stress and anxiety further, and the need to constantly elevate their status in the NICU by oppressing parents. Positive interactions might also help increase trust and staff satisfaction in their work. Furthermore, to work it would have to involve a gradual change in beliefs and attitudes towards parents. Basic training for nurses, at degree level and beyond, needs to involve awareness of bias in social class, ethnicity and gender; the ethics of care and on how to achieve change.

Evidence-based research that comes from the nursing practice is relatively new compared to evidence in medicine (Glasper & Ireland 2000) that began in the 90s. I agree with Savage and Callery (2000) when they advise caution when selecting research evidence to support nursing interventions. In working with families, the 'gold standard' evidence in medicine, RCTs (which are mainly about biochemical interactions, not about complex social interactions) might overlook important information about people's experiences, attitudes or relationships. Qualitative studies are less popular with policy makers but can be very relevant to inform policy on complex interpersonal nursing procedures.

The need to help nurses to find appropriate evidence to support innovative interventions is evident, especially when interventions are perceived as controversial (such as the use of nests in these units). However, bringing theory and practice together might not be as

easy. Long and Asbury (2000) point to the need to equip nurses with the skills required to integrate knowledge into their practice through reflection and to overcome long-held traditions and prejudices. Although the authors refer to assessment during degree courses, I think this can be brought into nurses' continuing education.

As happens already in many hospitals around the world, Mexican hospitals could appoint a 'lead' nurse or other professional trained in baby-led care, who would be in charge of teaching the staff and parents about babies' cues and cue-based care. This seems like an inconsistent suggestion when one of the main problems in these hospitals is lack of economic and human resources. However, having a person who teaches staff and parents, addresses concerns and contributes to developing guidelines, could contribute to more efficient processes and cost-effective practices in the unit, such as less cross-infection, more care-work performed by parents and earlier discharge. For this, a much cheaper, open-access, Spanish speaking, online version of a programme like NIDCAP training is needed.

A gradual process of identifying activities in which parents can participate, with continuing education on cue-based care, development of guidelines and designating a person to guide baby-led practices in the units, might open a space for two-way relationships between nurses and parents, in which the latter can contribute to the well-being of their babies, feel more able to take them home, alleviate the work-load in the unit and share in improving the quality of care.

However, it is not only parent-nurse relationships that need to be addressed.

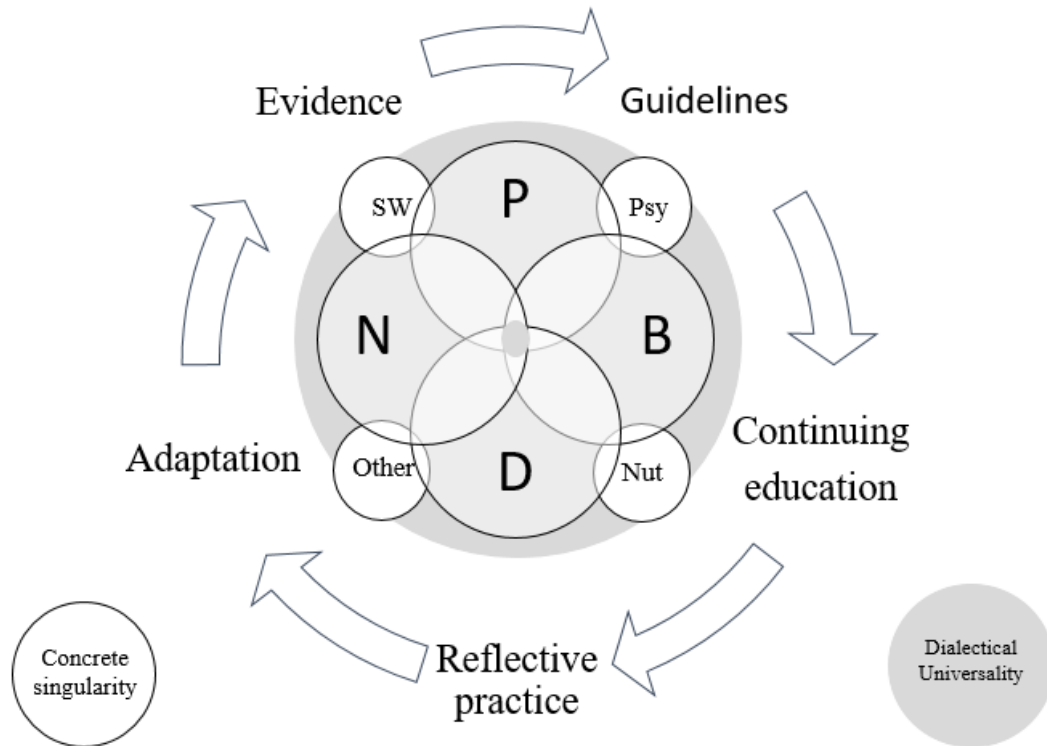
7.3.2 Enhanced communication at all levels

Facilitating communication among all members: staff (including managers), parents and babies is paramount. This might contribute to enhancing decision-making processes that are more encompassing of babies' integral needs.

Multidisciplinary teams should include not only doctors and nurses but other healthcare professionals such as social workers, psychologists, nutritionists, physiotherapists (when available) and others. Parents might gradually be incorporated into the multi-disciplinary teams along with reports of babies' views.

The work of the multidisciplinary team should be informed by research evidence and a constant assessment through discussion of cases that lead to reflection and adaptation, by listening to babies' needs, through observing babies' reactions and listening to parents' views. Enhanced communication and reflection might lead to more empathic power₁ relations where staff and parents are able to understand each other's concerns and implement strategies to support each other.

Figure 10 Enhanced communication through multi-disciplinary work shows how the multidisciplinary team might work. The concept of *concrete universal* ↔ *singular* becomes relevant again when babies are acknowledged as unique individuals with specific needs and at the same time members of the NICU community, able to communicate with others. All healthcare professionals need to remain in contact with the baby, sometimes by direct observation, some other times through discussions about others' views. Thus, they also need to remain in constant communication. Evidence based guidelines and continuing education need to inform care, a process of permanent reflection of the unique capacities and needs of each baby might lead to adaptation of cares.



- | | |
|-------------|--------------------|
| P – parents | Psy – psychologist |
| B – baby | Nut – nutricionist |
| D – doctor | SW – social worker |
| N – nurse | |

Figure 10 Enhanced communication through multi-disciplinary work

7.3.3 Normative procedures

‘Best practice’ in neonatal care refers to interventions that are supported by the best evidence available and which support clinicians in the decision making process in caring for each individual patient.

Clear guidance needs to be developed for the use of oxygen and antibiotics, and for infection control. Hospitals need to appoint committees for the prevention of infections.

Managers must make sure basic resources, such as soap, are available. Hand-washing techniques need to be taught, with illustrated posters, and follow up programmes established for all the professionals and visitors such as priests.

High standard procedures should not be equated to standardised, routine care that is impersonal, clock-led and fails to acknowledge babies' individuality and uniqueness. High standards involve protocols, guidelines and agreed standards, as well as inspection criteria, intended to elevate the quality of care and promote the best use of resources.

Neonatal intensive care in developing countries, such as Mexico, raise difficult questions about the cost-effectiveness of providing extremely expensive care to a reduced number of babies, when the same amount of resources could benefit millions of children by providing clean drinking water, nutritious food and basic healthcare. In their study on clinical benefits, costs, and cost-effectiveness of neonatal intensive care in Mexico, Profit and colleagues (2010, p.e100379) conclude 'it offers exceptional value for money even in the youngest GA group'. The authors argue, there are many practices in the NICU that have proved to be successful such as 'ventilation with bubble continuous positive airway pressure, temperature support, blended oxygen, kangaroo care, early initiation of breast milk feeding, and infection control measures that include family members as stakeholders'. It is extremely worrying that these kinds of unrealistic reports and statistical analyses that inform the Mexican policy making and administration of public resources are so disconnected from stark realities in the country. As this research shows, healthcare programmes originally directed at reducing socio-economic disadvantages and social class inequalities, inadvertently become part of political systems that exacerbate them.

It is not the intention of this thesis to make an analysis of the cost-effectiveness of neonatal care provision in Mexico, but the results of this sociological study do warrant a much deeper understanding and rigorous evaluation of effective use of resources, hospital organisation and medical practices that truly promote well-being. Furthermore this thesis provides the case for future multidisciplinary research in the area.

Future directions for this study might be to implement an action research project in Mexican hospitals in order to reduce morbidity and mortality by implementing baby-led care practices that are respectful not only towards babies but also towards parents and healthcare professionals

7.4 Conclusion

This study has contributed to a better understanding of why preterm babies are cared for as they are in Mexico. In a way, it opens the door to a discussion about how babies might be better understood as service users who are worthy of respect and dignified treatment, even when sedated and breathing through a machine. It calls for an understanding of newborn babies as a social group in their own right and emphasises the need to continue to try to understand childhood from a new paradigm, for this field is still very much under-theorised.

The study also shows how critical realism enhances research in the social sciences by reconciling the seemingly opposing traditional paradigms in research and addressing deep social problems that are real but only seen through their causal effects. To my knowledge, this is the first study that combines critical realism and childhood studies to do social research in neonatal care.

I need to acknowledge time and resources for this project were limited. The amount of data collected was large and overwhelming at times. My understanding of important deep philosophical aspects that emerged, such as the long-standing discussion about personhood, need to be further refined. I hope I will continue to reflect on these and other important aspects.

References

- Adam, B., 1995. *Timewatch: the social analysis of time*, Cambridge: Polity Press.
- Aita, M. & Snider, L., 2003. The art of developmental care in the NICU: a concept analysis. *Journal of Advanced Nursing*, 41(3), pp.223–32.
- Alcaraz, C., Chiquiar, D. & Salcedo, A., 2015. *Informality and segmentation in the Mexican labor market*, Mexico D.F.
- Alderson, P., 2013. *Childhoods real and imagined: an introduction to critical realism and childhood studies*, London: Routledge.
- Alderson, P. et al., 2004. *Foretelling futures: dilemmas in neonatal neurology. End of project report to the Wellcome Trust.*, London.
- Alderson, P., 1983. *Special care for babies in hospital*, London: NAWCH.
- Alderson, P., 2016. *The Politics of Childhoods Real and Imagined: practical application of critical realism and childhood studies*, London: Routledge.
- Alderson, P., Hawthorne, J. & Killen, M., 2005a. Are premature babies citizens with rights? Provision rights and the edges of citizenship. *Journal of Social Sciences*, (9), pp.71–81.
- Alderson, P., Hawthorne, J. & Killen, M., 2005b. The participation rights of premature babies. *International Journal of Children 's Rights*, 13, pp.31–50.
- Alderson, P., Sutcliffe, K. & Curtis, K., 2006. Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91, pp.300–303.
- Alinejad-Naeini, M. et al., 2014. The effect of facilitated tucking during endotracheal

- suctioning on procedural pain in preterm neonates: a randomized controlled crossover study. *Global Journal of Health Science*, 6(4), pp.278–284.
- Allegranzi, B. & Pittet, D., 2009. Role of hand hygiene in healthcare-associated infection prevention. *The Journal of Hospital Infection*, 73(4), pp.305–15.
- Als, H., 1986. A synactive model of neonatal behavioural organization: framework for the assessment of neurobehavioural development in the preterm infant and for support of infants and parents in the neonatal intensive care unit J. K. Sweeny, ed. *Physical and Occupational Therapy in Pediatrics*, 6, pp.3–55.
- Als, H., 1999. Reading the premature infant. In E. Goldson, ed. *Developmental interventions in the neonatal intensive care nursery*. New York: Oxford University Press, pp. 18–85.
- Als, H., 1982. Toward a synactive theory of development: promise for the assessment and support of infant individuality. *Infant Mental Health Journal*, 3(4), pp.229–243.
- Als, H., Lester, B.M. & Brazelton, T.B., 1979. Dynamics of the behavioural organization of the premature infant: A theoretical perspective. In S. Goldberg & H. H. Shulman, eds. *Infants Born at Risk*. New York: Spectrum, pp. 173–192.
- Als, H. & McAnulty, G., 2006. Developmental care guidelines for use in the newborn intensive care unit (NICU).
- Altimier, L., 2015. Compassionate family care framework: a new collaborative compassionate care model for NICU families and caregivers. *Newborn and Infant Nursing Reviews*, 15(1), pp.33–41.
- Amuchástegui, A. et al., 2010. Politics, religion and gender equality in contemporary Mexico: women’s sexuality and reproductive rights in a contested secular state.

Third World Quarterly, 31(6), pp.989–1005.

Andorno, R., 2014. Human dignity and human rights. In H. ten Have & B. Gordijn, eds. *Handbook of Global Ethics*. Springer Netherlands, pp. 45–57.

Anspach, R.R., 1993. *Deciding who lives: fateful choices in the intensive-care nursery*, Berkeley: University of California Press.

Arksey, H. & O'Malley, L., 2005. Scoping Studies : towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), pp.19–32.

Arockiasamy, V., Holsti, L. & Albersheim, S., 2008. Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics*, 121(2), pp.e215-22.

Ashton, N., Ward, B. & Serpell, G., 1954. Effect of oxygen on developing retinal vessels with particular reference to the problem of retrolental fibroplasia. *The British Journal of Ophthalmology*, 38(7), pp.397–432.

Avery, M.E., 1992. A 50-year overview of perinatal medicine. *Early Human Development*, 29(1–3), pp.43–50.

Axelin, A. et al., 2009. Oral glucose and parental holding preferable to opioid in pain management in preterm infants. *The Clinical Journal of Pain*, 25(2), pp.138–45.

Bastos, A. & Machado, C., 2009. Child poverty: a multidimensional measurement. *International Journal of Social Economics*, 36, pp.237–251.

Batton, D.G., Barrington, K.J. & Wallman, C., 2006. Prevention and management of pain in the neonate: an update. *Pediatrics*, 118(5), pp.2231–41.

Beech, B., 2006. At Last - An NMC Home Birth Circular. *AIMS Journal*, 18(1).

Available at:

<http://www.aims.org.uk/Journal/Vol18No1/NMCHomebirthCircular.htm>.

- Bellieni, C. V., Bagnoli, F. & Buonocore, G., 2003. Alone no more: pain in premature children. *Ethics & Medicine*, 19(1), pp.5–9.
- Bellieni, C. V & Buonocore, G., 2008. Neonatal pain treatment: ethical to be effective. *Journal of Perinatology*, 28, pp.87–88.
- Bellieni, C. V & Johnston, C.C., 2015. Analgesia, nil or placebo to babies, in trials that test new analgesic treatments for procedural pain. *Acta Paediatrica*, 105(2), pp.129–136.
- Bencko, V., 2006. From Ignaz Semmelweis to the present: crucial problems of hospital hygiene. *Indoor and Built Environment*, 15(1), pp.3–7.
- Bhaskar, R., 2008a. *A realist theory of science* Rev. Ed. w., London: Routledge.
- Bhaskar, R., 2008b. *Dialectic: the pulse of freedom*, Routledge.
- Bhaskar, R., 2010. *Interdisciplinarity and climate change : transforming knowledge and practice for our global future* R. Bhaskar et al., eds., Routledge.
- Bhaskar, R., 2002. *Reflections on Meta-Reality: transcendence, emancipation and everyday life*, New Dheli: SAGE Publications.
- Bhaskar, R., 1998. *The possibility of naturalism* 3rd ed., London: Routledge.
- Bhaskar, R. & Danermark, B., 2006. Metatheory, interdisciplinarity and disability research: A Critical Realist perspective. *Scandinavian Journal of Disability Research*, 8(4), pp.278–297.
- Blaikie, N., 2007. *Approaches to social enquiry: advancing knowledge* 2nd ed., Cambridge: Polity.
- Bourdieu, P., 1999. *The weight of the world: social suffering in contemporary society*,

Oxford: Polity.

Bowlby, J., 1969. *Attachment and loss*, London: Hogarth Press: Institute of Psychoanalysis.

Bradley, B., 1989. *Visions of Infancy: a critical introduction to child psychology*, Oxford: Polity Press.

Bradley, B., 2015. *Well-being*, Cambridge: Polity Press.

Braun, V. & Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Reserach in Psychology*, 3(2), pp.77–101.

Brazelton, T.B. & Cramer, B.G., 1991. *The earliest relationship: parents, infants, and the drama of early attachment*, Karnac Books.

Brazelton, T.B. & Nugent, J.K., 2011. *Neonatal behavioral assessment scale 3rd.*, London: MacKeith Press.

Broom, A. & Willis, E., 2007. Competing paradigms and health research. In M. Saks & J. Allsop, eds. *Researching Health : qualitative, quantitative and mixed methods*. London: SAGE Publications, p. 422.

Browne, J. V & Ross, E.S., 2011. Eating as a neurodevelopmental process for high-risk newborns. *Clinics in Perinatology*, 38(4), pp.731–43.

Bryman, A., 2012. *Social research methods* 4th ed., Oxford, New York: Oxford University Press.

Buonocore, G. & Bellieni, C.V., 2008. *Neonatal pain: suffering, pain, and risk of brain damage in the fetus and newborn*, Milan: Springer.

Burman, E., 2008. *Deconstructing developmental psychology* 2nd ed., Routledge.

- Carbajal, R. et al., 1999. Randomised trial of analgesic effects of sucrose, glucose, and pacifiers in term neonates. *British Medical Journal*, 319(7222), pp.1393–7.
- Cassel, E.J., 1992. The nature of suffering and the goals of medicine. *The New England Journal of Medicine*, 306(11), pp.639–645.
- Castillo Fernandez, D. & Arzate Salgado, J., 2016. Economic crisis, poverty and social policy in Mexico. *Critical Sociology*, 42(1), pp.87–104.
- Castro, R., 2003. Ciencias sociales y salud en México: movimientos fundacionales y desarrollos actuales. *Ciencia & Saude Coletiva*, 8(1), pp.47–62.
- Castro, R., 2014. Health care delivery system Mexico. *The Wiley Blackwell Encyclopedia of Health, Illness, Behaviour, and Society*, pp.836–842.
- Castro, R., 2001. Sociología médica en México: el último cuarto de siglo (Medical sociology: the last quarter of a century). *Revista Mexicana de Sociología*, pp.271–293.
- Castro, R. & Erviti, J., 2003. *Sociologia de la practica medica autoritaria: violencia obstetrica, anticoncepcion inducida y derechos reproductivos.*, Mexico D.F.: LIBRUNAM.
- Chapman, H. a. & Anderson, A.K., 2012. Understanding disgust. *Annals of the New York Academy of Sciences*, 1251(1), pp.62–76.
- Charpak, N. et al., 2005. Kangaroo Mother Care: 25 years after. *Acta Paediatrica*, 94(5), pp.514–522.
- Cipolla, D. et al., 2011. Prevention of nosocomial infections and surveillance of emerging resistances in NICU. *Journal of Maternal-Fetal and Neonatal Medicine*, 24(1), pp.23–26.

- Cleveland, L.M., 2008. Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 37(6), pp.666–91.
- Cohen, M., 2003. *Sent Before My Time: a child psychotherapist's view of life on a neonatal intensive care unit.*, London: Karnak.
- Concar, D., 1996. Into the mind unborn - We know that fetuses can hear, taste and smell while still in the womb. But controversy is raging over the idea that they may also feel pain. *New Scientist*. Available at: <https://www-newscientist-com.libproxy.ucl.ac.uk/article/mg15220524-200-into-the-mind-unborn-we-know-that-fetuses-can-hear-taste-and-smell-while-still-in-the-womb-but-controversy-is-raging-over-the-idea-that-they-may-also-feel-pain-david-concar-reports/> [Accessed September 8, 2015].
- Conde-Agudelo, A., Belizan, J.M. & Diaz-Rossello, J., 2011. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *The Cochrane Library*, (3), pp.1–115.
- Cone, T.E.J., 1983. Perspectives in Neonatology. , pp.9–33. Available at: <http://www.neonatology.org/classics/mj1980/ch02.html> [Accessed June 2, 2016].
- CONEVAL, 2016. Líneas de bienestar y canasta alimentaria. Available at: <http://www.coneval.gob.mx/Medicion/MP/Paginas/Lineas-de-bienestar-y-canasta-basica.aspx> [Accessed March 8, 2016].
- Coughlin, M., 2014. *Transformative Nursing in the NICU: trauma-informed age-appropriate care*, Springer Publishing Company.
- Coughlin, M., Gibbins, S. & Hoath, S., 2009. Core measures for developmentally supportive care in neonatal intensive care units: theory, precedence and practice. *Journal of Advanced Nursing*, 65(10), pp.2239–48.

- Cross, J., 2015. Neuroprotective core measure 7: optimizing nutrition—breastfeeding, human milk and attachment. *Newborn and Infant Nursing Reviews*, 15(3), pp.128–131.
- Crotty, M., 1998. *The foundations of social research : meaning and perspective in the research process*, London: SAGE.
- Cruz, M.D., Fernandes, A.M. & Oliveira, C.R., 2015. Epidemiology of painful procedures performed in neonates: a systematic review of observational studies. *European Journal of Pain*, 20, pp.489–498.
- Curtis, V., 2011. Why disgust matters. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 366(1583), pp.3478–3490.
- Curtis, V.A., 2007. Dirt, disgust and disease: a natural history of hygiene. *Journal of Epidemiology and Community Health*, 61(8), pp.660–4.
- Curtis, V., de Barra, M. & Aunger, R., 2011. Disgust as an adaptive system for disease avoidance behaviour. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 366(1563), pp.389–401.
- Davies, C.A., 2008. *Reflexive ethnography: a guide to researching selves and others* 2nd ed., London: Routledge.
- Davis, L., Mohay, H. & Edwards, H., 2003. Mothers' involvement in caring for their premature infants: an historical overview. *Journal of Advanced Nursing*, 42(6), pp.578–586.
- Douglas, M., 1966. *Purity and danger: an analysis of the concepts of pollution and taboo*. 2nd ed., London: Routledge & Kegan Paul.
- Dube, A. & Garcia-Ponce, O., 2013. Cross-border spillover: US gun laws and violence

- in Mexico. *American Political Science Review*, 107(3), pp.397–417.
- Eidelman, A. & Schanier, R., 2012. Breastfeeding and the use of human milk. *Pediatrics*, 129(3), pp.600–3.
- Erasmus, V. et al., 2010. Systematic review of studies on compliance with hand hygiene guidelines in hospital care. *Infection Control and Hospital Epidemiology*, 31(3), pp.283–294.
- Ernesto, J. & Córdova, L., 2016. Productivity in Mexico : trends , drivers , and institutional framework. *International Productivity Monitor*, (30), pp.28–42.
- Fazilleau, L. et al., 2013. NIDCAP in preterm infants and the neurodevelopmental effect in the first 2 years. *Archives of Disease in Childhood. Fetal and Neonatal Edition*. Published Online First. Available at:
<http://www.ncbi.nlm.nih.gov/pubmed/24179114> [Accessed November 15, 2013].
- Feasey, N. & Molyneux, E., 2011. Keep it clean: hospital-acquired infections in children. *Lancet*, 378(9808), pp.1982–3.
- Feder, Y., 2015. Contamination appraisals, pollution beliefs, and the role of cultural inheritance in shaping disease avoidance behavior. *Cognitive Science*, pp.1–25.
- Fenwick, J., Barclay, L. & Schmied, V., 2008. Craving closeness: a grounded theory analysis of women’s experiences of mothering in the Special Care Nursery. *Women and Birth*, 21(2), pp.71–85.
- Fenwick, J., Barclay, L. & Schmied, V., 2001. Struggling to mother: a consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal & Neonatal Nursing*, 15(2), pp.49–64.
- Fernandes, L., Mendes, A. & Teixeira, A., 2013. A weighted multidimensional index of

- child well-being which incorporates children's individual perceptions. *Social Indicators Research*, 114(3), pp.803–829.
- Field, K.J., 2006. The immunological components in human milk and their effect on the immune development of infants. *The Journal of Nutrition*, 27(10), pp.1–4.
- Finch, H., Lewis, J. & Turley, C., 2014. Focus Groups. In J. Ritchie et al., eds. *Qualitative research practice: a guide for social science students and researchers*. Los Angeles, London: Sage, pp. 211–242.
- Flacking, R. et al., 2006. Trustful bonds: a key to “becoming a mother” and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science and Medicine*, 62(1), pp.70–80.
- Flyvbjerg, B., 2006. Five misunderstandings about case-study research. *Qualitative Inquiry*, 12(2), pp.219–245.
- Forfar, J. & McCabe, A., 1958. Masking and gowning in nurseries for the newborn infant. *British Medical Journal*, (1), p.76.
- Foucault, M., 1982. The subject and power. *Critical Inquiry*, 8(4), pp.777–795.
- Foucault, M., François, E. & Fontana, A., 2010. *The birth of biopolitics: lectures at the Collège de France, 1978-1979* M. Senellart, ed., New York: Palgrave Macmillan.
- Franck, L.S. & Axelin, A., 2013. Differences in parents', nurses' and physicians' views of NICU parent support. *Acta Paediatrica*, 102(6), pp.590–596.
- Frenk, J. et al., 2006. Comprehensive reform to improve health system performance in Mexico. *Lancet*, 368(9546), pp.1524–1534.
- Gallegos-Martínez, J. & Reyes-Hernández, J., 2014. Meanings, beliefs and attitudes of the neonatal unit staff in México about the parents' participation in a neonatal unit:

- a qualitative approach. *Journal of Nursing Education and Practice*, 4(5), pp.159–170.
- Gardner, H., 1993. *The unschooled mind: how children think and how schools should teach*, London: Fontana Press.
- Garfield, C.F., Lee, Y. & Kim, H.N., 2014. Paternal and maternal concerns for their very low-birth-weight infants transitioning from the NICU to home. *The Journal of Perinatal & Neonatal Nursing*, 28(4), pp.305–312.
- Gerull, R. et al., 2013. Physiological parameters after nonpharmacological analgesia in preterm infants: a randomized trial. *Acta Paediatrica*, 102(8), pp.368–373.
- Gillham, B., 2000. *Case study research methods*, London: Continuum.
- Gillham, B., 2007. *Developing a questionnaire* 2nd ed., London; New York: Continuum.
- Glasper, E.A. & Ireland, L., 2000. *Evidence-based child health care: challenges for practice* E. A. Glasper & L. Ireland, eds., Basingstoke: Macmillan.
- Goldberg, S., 1983. Parent-infant bonding: another look. *Child Development*, 54(6), pp.1355–1382.
- Goldman, A.S., 2007. The immune system in human milk and the developing infant. *Breastfeeding Medicine*, 2(4), pp.195–204.
- Gómez, C.A., 2012. Puericultura, higiene y control natal. La visión de Esperanza Velázquez Bringas sobre el cuidado materno-infantil en México, 1919-1922. *Revista Historia Autónoma*, (1), pp.107–120.
- González-Pier, E. et al., 2007. Definición de prioridades para las intervenciones de salud en el Sistema de Protección Social en Salud de México. *Salud Publica Mex*, 49(I:S37-S52), pp.37–52.

- Gough, D., Oliver, S. & Thomas, J., 2012. *An Introduction to Systematic Reviews*, Los Angeles, London: Sage.
- Goulet, C. et al., 1998. A concept analysis of parent-infant attachment. *Journal of Advanced Nursing*, 28(5), pp.1071–1081.
- Graham, H. & Oakley, A., 1981. Competing ideologies of reproduction: medical and maternal perspectives on pregnancy. In H. Roberts, ed. *Women, Health & Reproduction*. London : Routledge & Kegan Paul, pp. 50–74.
- Graven, S. & Browne, J., 2008. Sleep and brain development: the critical role of sleep in fetal and early neonatal brain development. *Newborn and Infant Nursing Reviews*, 8(4), pp.173–179.
- Graven, S.N., 2011. Early visual development: implications for the neonatal intensive care unit and care. *Clinics in Perinatology*, 38(4), pp.671–83.
- Hall, R.W. & Anand, K.J.S., 2014. Pain management in newborns. *Clinics in Perinatology*, 41(4), pp.895–924.
- Hammersley, M., 1992. *What's wrong with ethnography?: methodological explorations*, London: Routledge.
- Hane, A.A. et al., 2015. Family Nurture Intervention improves the quality of maternal caregiving in the Neonatal Intensive Care Unit: evidence from a randomized controlled trial. *Journal of Developmental & Behavioral Pediatrics*, 0(0), pp.1–9.
- Harris, J., 1985. *The value of life*, Routledge & Kegan Paul.
- Hartwig, M., 2007. *Dictionary of critical realism* M. Hartwig, ed., Routledge.
- Hawdon, J.M. et al., 2000. Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine and Child Neurology*, 42(4), pp.235–

9.

Heerman, J.A., Wilson, M.E. & Wilhelm, P.A., 2005. Mothers in the NICU: outsider to Partner. *Pediatric Nursing*, 31(3), pp.176–181.

Heinemann, A.-B., Hellström-Westas, L. & Hedberg Nyqvist, K., 2013. Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room. *Acta Paediatrica*, 102(7), pp.695–702.

Henderson, L.W. & Knight, T., 2012. Integrating the hedonic and eudaimonic perspectives to more comprehensively understand wellbeing and pathways to wellbeing. *International Journal of Wellbeing*, 2, pp.196–221.

Henn, M., Weinstein, M. & Foard, N., 2009. *A critical introduction to social research* 2nd., Los Angeles, London: SAGE Publications.

Hepper, P.G., Scott, D. & Shahidullah, S., 1993. Newborn and fetal response to maternal voice. *Journal of Reproductive and Infant Psychology*, 11(3), pp.147–153.

Hernandez, A.A. & Grineski, S.E., 2012. Disrupted by violence: children's well-being and families' economic, social, and cultural capital in Ciudad Juarez, Mexico. *Revista Panamericana de Salud Pública*, 31(5), pp.373–379.

Hollywood, M. & Hollywood, E., 2011. The lived experiences of fathers of a premature baby on a Neonatal Intensive Care Unit. *Journal of Neonatal Nursing*, 17(1), pp.32–40.

Holsti, L. et al., 2008. Is it painful or not? Discriminant validity of the Behavioral Indicators of Infant Pain (BIIP) scale. *The Clinical Journal of Pain*, 24(1), pp.83–8.

Hylander, M.A., Strobino, D.M. & Dhanireddy, R., 1998. Human milk feedings and infection among very low birth weight infants. *Pediatrics*, 102(3), pp.e38–e44.

INEGI, 2009. *Mujeres y Hombres en México 2009* 13a ed., Aguascalientes.

INEGI, 2015. Vidor Dinamico de Bienestar. Available at:

<http://www3.inegi.org.mx/sistemas/biblioteca/ficha.aspx?upc=702825075132>

[Accessed March 8, 2016].

Institute for Patient- and Family-Centered Care, 2012. Institute for Patient- and Family-Centered Care. Available at: <http://www.ipfcc.org/faq.html>.

James, A. & Prout, A. eds., 2015. *Constructing and reconstructing childhood: contemporary issues in the sociological study of childhood* 3rd ed., London: Routledge.

Johnson, S. et al., 2016. Eating difficulties in children born late and moderately preterm at 2 y of age: A prospective population-based cohort study. *American Journal of Clinical Nutrition*, 103(2), pp.406–414.

Johnston, C. et al., 2014. Skin-to-skin care for procedural pain in neonates (Review). *Cochrane Database of Systematic Reviews*, (1), p.Art. No.: CD008435.

Kant, I., 1972. *Groundwork of the Metaphysic of Morals* 2nd ed., London: Hutchinson University Library. Available at: <http://www.gutenberg.org/ebooks/5682>.

Klaus, M. et al., 1972. Maternal attachment: importance of the first post-partum days. *The New England Journal of Medicine*, 286(9), pp.460–463.

Klaus, M.H. & Kennell, J.H., 1970. Mothers separated from their newborn infants. *Pediatric Clinics of North America*, 17(4), pp.1015–1037.

Kleberg, A. et al., 2002. Indications of improved cognitive development at one year of age among infants born very prematurely who received care based on the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Early*

Human Development, 68(2), pp.83–91.

Kleberg, A., Hellström-Westas, L. & Widström, A.-M., 2007. Mothers' perception of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared to conventional care. *Early Human Development*, 83(6), pp.403–411.

Kleberg, A., Westrup, B. & Stjernqvist, K., 2000. Developmental outcome, child behaviour and mother-child interaction at 3 years of age following Newborn Individualized Developmental Care and Intervention Program (NIDCAP) intervention. *Early Human Development*, 60(2), pp.123–135.

Knaul, F.M. et al., 2006. Evidence is good for your health system: policy reform to remedy catastrophic and impoverishing health spending in Mexico. *Lancet*, 368(9549), pp.1828–1841.

Kolb, B. & Gibb, R., 2011. Brain plasticity and behaviour in the developing brain. *Journal of the Canadian Academy of Child & Adolescent Psychiatry*, 20(4), pp.265–276.

Korppi, M., 2016. What are evidence-based guidelines and what are they not? *Acta Paediatrica*, 105(1), pp.11–12.

Kuhse, H. & Singer, P., 1985. *Should the baby live? The problem of handicapped infants*, Oxford University Press.

Lagercrantz, H. & Changeux, J.-P., 2010. Basic consciousness of the newborn. *Seminars in Perinatology*, 34(3), pp.201–6.

Lamas, M., 2001. Movimiento feminista y discurso político: los derechos sexuales y reproductivos en la construcción de una ciudadanía moderna. In J. G. Figueroa & C. Stern, eds. *Encuentros y Desencuentros en Salud Reproductiva: Políticas Públicas, Marcos Normativos y Actores Sociales*. Mexico: El Colegio de Mexico,

p. 236.

Land, K.C., Lamb, V.L. & Mustillo, S.K., 2001. Child and youth well-being in the United States, 1975 – 1998: some findings from a new index. *Social Indicators Research*, 1(June), pp.241–320.

Laurell, A.C., 2007. Response to the Lancet Series on Mexico - Health system reform in Mexico: a critical review. *International Journal*, 37(3), pp.515–535.

Laurell, A.C., 2015. Three decades of neoliberalism in Mexico: the destruction of society. *International Journal of Health Services*, 45(2), pp.246–264.

Lawhon, G. & Hedlund, R.E., 2008. Newborn Individualized Developmental Care and Assessment Program training and education. *The Journal of Perinatal & Neonatal Nursing*, 22(2), pp.133–44.

Layard, R., 2011. *Happiness: lessons from a new science* 2nd ed., London: Penguin Books.

Liamputtong Rice, P. & Ezzy, D., 1999. *Qualitative research methods: a health focus*, Melbourne, Oxford: Oxford University Press.

Liaw, J.J. et al., 2012. Non-nutritive sucking and facilitated tucking relieve preterm infant pain during heel-stick procedures: a prospective, randomised controlled crossover trial. *International Journal of Nursing Studies*, 49(3), pp.300–309.

Lickliter, R., 2011. The integrated development of sensory organization. *Clinics in Perinatology*, 38(4), pp.591–603.

Long, T. & Asbury, J., 2000. Demonstrating evidence-based clinical nursing practice: providing the evidence. In E. A. Glasper & L. Ireland, eds. *Evidence-Based Child Health Care: challenges for practice*. Basingstoke: Macmillan, pp. 13–25.

- López-Arellano, O. & Blanco-Gil, J., 2001. La polarización de la política de salud en México. *Cad. Saúde Pública*, 17(1), pp.43–54.
- Luoma, I. et al., 2004. A longitudinal study of maternal depressive symptoms, negative expectations and perceptions of child problems. *Child Psychiatry and Human Development*, 35(1), pp.37–53.
- Lupton, D. & Fenwick, J., 2001. “They’ve forgotten that I’m the mum’: constructing and practising motherhood in special care nurseries. *Social Science and Medicine*, 53(8), pp.1011–1021.
- Macklin, R., 2003. Dignity is a useless concept. *BMJ (Clinical research ed.)*, 327(7429), pp.1419–20.
- Mannheim, K., 1936. *Ideology and utopia*, London: Routledge & Kegan Paul.
- March of Dimes et al., 2012. *Born too soon: The Global Report on Preterm Birth*. C. Howson & M. Kinney, eds., Geneva: World Health Organization. Available at: http://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf.
- Marshall, J.L., Godfrey, M. & Renfrew, M.J., 2007. Being a “good mother”: managing breastfeeding and merging identities. *Social Science and Medicine*, 65(10), pp.2147–2159.
- Mayall, B., 1996. *Children, health and the social order*, Buckingham: Open University Press.
- Mayall, B., 2000. The sociology of childhood in relation to children’s rights. *International Journal of Children’s Rights*, (8), pp.243–259.
- Mayall, B., 2015. Understanding inter-generational relations: the case of health maintenance by children. *Sociology of Health and Illness*, 37(2), pp.312–324.

- McNaughton Nicholls, C., Mills, L. & Kotecha, M., 2014. Observation. In J. Ritchie et al., eds. *Qualitative research practice: a guide for social science students and researchers*. Los Angeles, London: Sage, pp. 244–268.
- Melnyk, B.M. et al., 2004. Creating Opportunities for Parent Empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*, 113(6), pp.e597–e607.
- Mendus, S., 1987. Kant: “An honest but narrow-minded bourgeois”? In E. Kennedy & S. Mendus, eds. *Women in Western Political Philosophy*. Brighton: Wheatsheaf, pp. 21–43.
- Menzies Lyth, I., 1988. *Containing Anxiety in Institutions*, London: Free Association Books.
- Mianaei, S.J. et al., 2014. The effect of Creating Opportunities for Parent Empowerment program on maternal stress, anxiety, and participation in NICU wards in Iran. *Iranian Journal of Nursing Midwifery Research*, 19(1), pp.94–100.
- Miles, M.S. et al., 2007. Depressive symptoms in mothers of prematurely born infants. *Journal of Developmental and Behavioral Pediatrics*, 28(1), pp.36–44.
- Mills, C.W., 2000. *The sociological imagination*, Oxford: Oxford University Press.
- Molyneux, M., 2006. Mothers at the service of the new poverty agenda: the Progres/Oportunidades Mexico’s conditional transfer programme. *Social Policy & Administration*, 40(4), pp.425–449.
- Montagu, A., 1986. *Touching: the human significance of the skin* 3rd ed., New York; London: Harper & Row.
- Moore, K.A., Murphey, D. & Bandy, T., 2012. Positive child well-being: an index based

- on data for individual children. *Maternal and Child Health Journal*, 16, pp.S119–S128.
- Mörelus, E. et al., 2015. A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding. *Early Human Development*, 91(1), pp.63–70.
- Morris, S., 2012. Corruption, Drug Trafficking, and Violence in Mexico. *Brown Journal of World Affairs*, XVIII(II), pp.29–43.
- Morrow, V. & Mayall, B., 2010. Measuring children’s well-being: some problems and possibilities. In A. Morgan, E. Ziglio, & M. Davies, eds. *International health and development: investing in assets of individuals, communities and organizations*. London: Springer, pp. 145–165.
- Nadesan, M.H., 2011. *Governmentality, biopower, and everyday life.*, New York, London: Routledge.
- Newburg, D.S. & Walker, W.A., 2007. Protection of the neonate by the innate immune system of developing gut and of human milk. *Pediatric Research*, 61(1), pp.2–8.
- Nightingale, F., 1980. *Notes on Nursing: What it Is, and what it is Not*, Edinburgh, London: Churchill Livingstone.
- Norman, I. & Griffiths, P., 2014. The rise and rise of systematic reviews. *International Journal of Nursing Studies*, 51, pp.1–3.
- Norrie, A., 2010. *Dialectic and Difference: dialectical critical realism and the grounds of justice*, London: Routledge.
- O’Brien, K. et al., 2013. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 13(Suppl

1), p.S12.

OCDE, 2012. *Serie “Mejores Políticas”: Mexico mejores politicas para un desarrollo incluyente*, Mexico, DF.: OCDE Mexico. Available at:
[http://www.oecd.org/mexico/Mexico 2012 FINALES SEP eBook.pdf](http://www.oecd.org/mexico/Mexico%202012%20FINALES%20SEP%20eBook.pdf).

OECD, 2016a. Health spending (indicator). Available at:
<https://data.oecd.org/healthres/health-spending.htm> [Accessed February 16, 2016].

OECD, 2016b. Infant mortality rates. Available at:
<https://data.oecd.org/healthstat/infant-mortality-rates.htm> [Accessed February 5, 2016].

OECD, 2015. *Measuring Well-Being in Mexican States*, Paris: OECD Publishing.
Available at: http://www.keepeek.com/Digital-Asset-Management/oecd/urban-rural-and-regional-development/measuring-well-being-in-mexican-states_9789264246072-en#page33.

Ohlinger, J. et al., 2003. Development of potentially better practices for the Neonatal Intensive Care Unit as a culture of collaboration: communication, accountability, respect, and empowerment. *Pediatrics*, 111(4), pp.e471–e481.

Olsson, E., Ahlsen, G. & Eriksson, M., 2015. Skin-to-skin contact reduces near-infrared spectroscopy pain responses in premature infants during blood sampling. *Acta Paediatrica, International Journal of Paediatrics*, (105), pp.376–380.

ONU Mujeres, 2011. *Feminicidio en México. Aproximación, tendencias y cambios, 1985-2009* Primera., Chiapas. Available at:
<http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Feminicidio+en+México.+Aproximación,+tendencias+y+cambios,+1985-2009#0> [Accessed September 30, 2014].

- Ormston, R. et al., 2014. The foundations of qualitative research. In J. Ritchie et al., eds. *Qualitative research practice: A guide for social science students and researchers*. Los Angeles, London: Sage, pp. 1–25.
- Osorio, J., 2013. *Democratization and drug violence in Mexico*, Available at: http://eventos.itam.mx/sites/default/files/eventositammx/eventos/aadjuntos/2014/01/democratizacion_and_drug_violence_osorio_appendix_1.pdf [Accessed September 29, 2014].
- Oswalt, K.L., McClain, D.B. & Melnyk, B., 2013. Reducing anxiety among children born preterm and their young mothers. *The American Journal of Maternal/Child Nursing*, 38(3), pp.144–149.
- van der Pal, S.M. et al., 2008. Health-related quality of life of very preterm infants at 1 year of age after two developmental care-based interventions. *Child: Care, Health and Development*, 34(5), pp.619–25.
- van der Pal, S.M. et al., 2007. Parental experiences during the first period at the neonatal unit after two developmental care interventions. *Acta Paediatrica*, 96(11), pp.1611–6.
- van der Pal, S.M. et al., 2007. Staff opinions regarding the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Early human development*, 83(7), pp.425–32.
- Pessoa-Silva, C.L. et al., 2007. Reduction of health care associated infection risk in neonates by successful hand hygiene promotion. *Pediatrics*, 120(2), pp.e382-90.
- Peters, K.L. et al., 2009. Improvement of short- and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial. *Pediatrics*, 124(4), pp.1009–20.
- Philbin, M.K. & Gray, L., 2002. Changing levels of quiet in an Intensive Care Nursery.

Journal of perinatology : official journal of the California Perinatal Association, 22(6), pp.455–60.

Philip, A.G.S., 2005. The evolution of neonatology. *Pediatric Research*, 58(4), pp.799–815.

Pinker, S., 2015. The moral imperative for bioethics - The Boston Globe. Available at: <https://www.bostonglobe.com/opinion/2015/07/31/the-moral-imperative-for-bioethics/JmEkoyzITAu9oQV76JrK9N/story.html> [Accessed August 27, 2015].

Pittet, D. & Boyce, J., 2001. Hand hygiene and patient care: pursuing the Semmelweis legacy. *The Lancet Infectious Diseases*, (1), pp.9–20.

Poppy Steering Group, 2009. *Family-centred care in neonatal units. A summary of research results and recommendations from the POPPY project.*, London: NCT.

Price, J. & Nicholl, H., 2013. Interviewing parents for qualitative research studies: using an ABCD model to manage the sensitivities and issues. *Child Care in Practice*, 19(2), pp.199–213.

Profit, J. et al., 2010. Clinical benefits, costs, and cost-effectiveness of neonatal intensive care in Mexico. *PLoS Medicine*, 7(12), p.e1000379.

Qvortrup, J., Corsaro, W.A. & Honig, M.-S. eds., 2009. *The Palgrave handbook of childhood studies*, Basingstoke: Palgrave Macmillan.

Raiskila, S. et al., 2014. Trends in care practices reflecting parental involvement in neonatal care. *Early Human Development*, 90(12), pp.863–867.

Reid, T., 1986. Maternal identity in preterm birth. *Journal of Child Health Care*, 4(1), pp.23–29.

Reis Monteiro, A., 2014. *Ethics of human rights*, London: Springer.

- Robson, C. & McCartan, K., 2016. *Real world research: a resource for users of social research methods in applied settings* 4rd ed., Chichester: Wiley.
- Rogers, C.E. et al., 2013. Identifying mothers of very preterm infants at-risk for postpartum depression and anxiety before discharge. *Journal of Perinatology*, 33, pp.171–6.
- Roofthoof, D.W.E. et al., 2014. Eight years later, are we still hurting newborn infants? *Neonatology*, 105(3), pp.218–226.
- Rose, N., 1999. *Governing the soul: the shaping of the private self* 2nd ed., Free Association Books.
- Rothhaar, M., 2010. Human dignity and human rights in bioethics: the Kantian approach. *Medicine, Health Care, and Philosophy*, 13(3), pp.251–7. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20411338> [Accessed November 27, 2014].
- Ryan, R.M. & Deci, E.L., 2001. On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology*, 52, pp.141–166.
- Salgado, M., 2013. Femicidio y violencia de género en México: omisiones del Estado y exigencia civil de justicia. *Iztapalapa: Revista de Ciencias Sociales y Humanidades*, 74(34), pp.11–39.
- Salinas-Beristain, L., 2001. La salud reproductiva como problema de derechos humanos. In J. G. Figueroa & C. Stern, eds. *Encuentros y Desencuentros en Salud Reproductiva: Políticas Publicas, Marcos Normativos y Actores Sociales*. Mexico: El Colegio de Mexico, p. 236.
- Savage, E. & Callery, P., 2000. Parental participation in the care of hospitalised children: a review of the research evidence. In E. A. Glasper & L. Ireland, eds.

Evidence-Based Child Health Care: challenges for practice. Basingstoke: Macmillan, pp. 57–89.

Sayer, A., 2011. *Why things matter to people*, Cambridge: Cambridge University Press.

Schore, A.N., 2005. Attachment, affect regulation, and the developing right brain: linking developmental neuroscience to pediatrics. *Pediatrics*, 26(6), pp.204–217.

SEGOB, 1983. DOF - Diario Oficial de la Federación. *Diario Oficial de la Federacion*.

Available at:

http://dof.gob.mx/nota_detalle.php?codigo=4794103&fecha=03/02/1983 [Accessed February 15, 2016].

Selee, A.D., 2011. *Decentralization, democratization, and informal power in Mexico*, Penn State Press.

Sen, A.K., 2003. Capability and well-Being. In M. Nussbaum & A. Sen, eds. *The Quality of Life*. Oxford Scholarship Online, pp. 1–40.

Shah, P.S., Aliwalas, L.I. & Shah, V., 2012. Breastfeeding or Breast Milk for Procedural Pain in Neonates. *Cochrane Database of Systematic Reviews*, (12), p.CD004950.

Shields, L., Pratt, J. & Hunter, J., 2006. Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*, 15(10), pp.1317–23.

Singer, L.T. et al., 1999. Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *Jama*, 281(9), pp.799–805.

Skene, C., 2010. *Learning to Parent : an ethnographic study of parental involvement in comfort care in the NICU*. Scheffield.

Slater, R. et al., 2010. Evoked potentials generated by noxious stimulation in the human infant brain. *European Journal of Pain*, 14(3), pp.321–326.

- Smith-Oka, V., 2015. Microaggressions and the reproduction of social inequalities in medical encounters in Mexico. *Social Science and Medicine*, 143, pp.9–16.
- Smith, C., 2010. *What is a person?: rethinking humanity, social life, and the moral good from the person up.*, University of Chicago Press.
- Smith, K., 2007. Sleep and kangaroo care : clinical practice in the newborn intensive care unit. *Journal of Perinatal and Neonatal Nursing*, 21(2), pp.151–157.
- Spencer, R.L., Greatrex-White, S. & Fraser, D.M., 2015. “I thought it would keep them all quiet”. Women’s experiences of breastfeeding as illusions of compliance: an interpretive phenomenological study. *Journal of Advanced Nursing*, 71(5), pp.1076–1086.
- Stake, R.E., 2003. Case studies. In N. K. Denzin & Y. S. Lincoln, eds. *Strategies of qualitative inquiry*. London: Sage, pp. 134–164.
- Stake, R.E., 1995. *The art of case study research*, Thousand Oaks; London; New Delhi: SAGE Publications.
- Stern, A.M., 1999. Responsible mothers and normal children: eugenics, nationalism, and welfare in post-revolutionary Mexico, 1920–1940. *Journal of Historical Sociology*, 12(4), pp.369–397.
- Stern, D., 1977. *The first relationship: infant and mother*, Fontana.
- Stevens, B. et al., 2013. Sucrose for analgesia in newborn infants undergoing painful procedures (Review). *Cochrane Database of Systematic Reviews*, (1 Art. No.: CD001069).
- Svejda, M.J., Campos, J.J. & Emde, R.N., 1980. Mother-infant “bonding”: failure to generalize. *Child Development*, 51(3), pp.775–9.

- Sweeney, J.K. & Gutierrez, T., 2002. Musculoskeletal implications of preterm infant positioning in the NICU. *The Journal of Perinatal & Neonatal Nursing*, 16(1), pp.58–70.
- Sweet, L., 2006. Breastfeeding a preterm infant and the objectification of breastmilk. *Breastfeeding Review*, 14(1), pp.5–13. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/16800061>.
- Sydnor, E.R.M. & Perl, T.M., 2011. Hospital epidemiology and infection control in acute-care settings. *Clinical Microbiology Reviews*, 24(1), pp.141–173.
- Symington, A. & Pinelli, J., 2006. Developmental care for promoting development and preventing morbidity in preterm infants (Review). *The Cochrane Database of Systematic Reviews*, (2), p.CD001814.
- UNESCO, 2005. *Universal Declaration on Bioethics and Human Rights*,
- UNICEF, The Baby-Friendly Hospital Initiative. Available at: <http://www.unicef.org/programme/breastfeeding/baby.htm> [Accessed April 4, 2016].
- UNICEF México, 2014. *Informe Anual 2014*, Mexico D.F.
- United Nations, 1989. *Convention on the Rights of the Child*,
- Vincent, J.-L., 2010. We should abandon randomized controlled trials in the intensive care unit. *Critical Care Medicine*, 38(10 Suppl), pp.S534-8.
- Visscher, M. & Narendran, V., 2014. Neonatal infant skin: development, structure and function. *Newborn and Infant Nursing Reviews*, 14(4), pp.135–141.
- Wachman, E.M. & Lahav, A., 2011. The effects of noise on preterm infants in the NICU. *Archives of Disease in Childhood. Fetal and neonatal edition*, 96(4),

pp.F305–F309.

Wacquant, L., 2009. *Punishing the poor: the neoliberal government of social insecurity*, London: Duke University Press.

Warren, I., 2012. Foundation toolkit for family centred developmental care: background to developmental care.

Warren, I. et al., 2016. The validity and reliability of the Evaluation of Intervention Scale (EVIN): Preliminary report. *Acta Paediatrica*, 105, pp.618–622.

Warren, I. & Bond, C., 2010. *A guide to infant development in the newborn nursery* 5th ed., London.

Weaver, T. et al., 2012. The neoliberal transformation of Mexico. In T. Weaver et al., eds. *Neoliberalism and commodity production in Mexico*. Boulder: University Press Colorado, pp. 1–32.

Weber, A.M., Harrison, T.M. & Steward, D.K., 2012. Schore's Regulation Theory: maternal-infant interaction in the NICU as a mechanism for reducing the effects of allostatic load on neurodevelopment in premature infants. *Biological Research for Nursing*, 14(4), pp.375–86.

Welch, M.G. et al., 2015. Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial. *Journal of Child Psychology and Psychiatry*, 56(11), pp.1202–1211.

Westrup, B., 2007. Newborn Individualized Developmental Care and Assessment Program (NIDCAP) - family-centered developmentally supportive care. *Early Human Development*, 83(7), pp.443–9.

- Westrup, B. & Bo, B., 2004. Preschool outcome in children born very prematurely and cared for according to the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). , pp.498–507.
- White, J. & Reiss, M., 2013. *An aims-based curriculum [electronic resource]: the significance of human flourishing for schools*, London: Institute of Education Press.
- White, R.D., 2015. Neuroprotective core measure 4: safeguarding sleep — its value in neuroprotection of the newborn. *Newborn and Infant Nursing Reviews*, 15(3), pp.114–115.
- Whittemore, R. & Knafl, K., 2005. The Integrative Review : updated methodology. *Journal of Advanced Nursing*, 52(5), pp.546–553.
- WHO, 2009. *Guidelines on Hand Hygiene in Health Care*, Geneva: WHO Press.
- WHO, 2014. WHO | Preterm birth. Available at:
<http://www.who.int/mediacentre/factsheets/fs363/en/> [Accessed August 27, 2014].
- Wielenga, J.M. et al., 2009. Development and growth in very preterm infants in relation to NIDCAP in a Dutch NICU: two years of follow-up. *Acta Paediatrica*, 98(2), pp.291–7.
- Wielenga, J.M., Smit, B.J. & Unk, K. a, 2008. A survey on job satisfaction among nursing staff before and after introduction of the NIDCAP model of care in a level III NICU in the Netherlands. *Advances in Neonatal Care*, 8(4), pp.237–45.
- Woodhead, M., 2015. Psychology and the cultural construction of children’s needs. In A. James & A. Prout, eds. *Constructing and reconstructing childhood : contemporary issues in the sociological study of childhood*. London: Routledge, pp. 54–73.

World Medical Association, 2013. Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. Available at: <http://www.wma.net/en/30publications/10policies/b3/> [Accessed April 29, 2016].

Wyatt, J., 1998. *Matters of life and death: today's healthcare dilemmas in the light of Christian faith*, Leicester: Inter-Varsity Press.

Yin, R.K., 2009. *Case study research: design and methods* 4th ed., Los Angeles, London: Sage.

Appendices

Appendix 1: Excerpts from field notes on getting to JDH

Appendix 2: Ethics approval obtained from the (former) Faculty of Children & Learning in the Institute of Education

Appendix 3: Information leaflet

Appendix 4: Parents' Consent Form

Appendix 5: Staff Member's Information Sheet

Appendix 6: Staff Member's Consent Form

Appendix 7: A survey of neonatal staff views in Mexican NICU

Appendix 8: Results of NICU survey MDH

Appendix 9: Results of NICU survey JDH

Appendix 10: Interview guide staff

Appendix 11: Interview guide parents

Appendix 12: Guide to observing babies

Appendix 13: NICU lay-out

Appendix 14: NICU square footage

Appendix 1: Excerpts from field notes on getting to JDH

August 27th 2013

I started visiting JDH a couple of months ago. I have been getting from Puebla to Mexico City by bus (to the eastern bus station called TAPO), and I continue my journey using the 'metro' until the line ends, I then change to the over-ground for four more stations and, in the last station I take a taxi (it takes me up to an hour to get from TAPO to JDH, plus two hours from Puebla to TAPO). Today I realised it is extremely difficult to identify legal taxis from illegal ones; illegal taxis park at the permitted taxi area (only for registered taxis) to pick up people! I told this to doctor C in the hospital and she thinks this is not a safe option given that I am not a local with a 'good eye' to identify legal taxi drivers. M, the psychologist will take me to the TAPO today in her car, I will have to find an alternative way, probably peceros (van) or a local bus.

September 10th 2013

So I decided to swap from taxis to 'peceros'. Today I was on my way to TAPO on the pecero when a couple of people boarded it. One of them was very distressed and said they had just been assaulted with a gun in another pecero (it was around 3pm, on plain daylight!). As these poor people told their story, we had a (minor) traffic accident; the driver was exceeding speed, it stopped suddenly and we all went flying, some passengers suffered from bruises (fortunately not me). I have now decided I will take a taxi from the bus station (these are safer because they are registered taxis), however this means I will only visit the hospital every two weeks given that the cost of my journey will increase significantly.

**Appendix 2: Ethics approval from (former) Faculty of Children &
Learning, Institute of Education.**

Ms Pui Sin
Faculty of Children & Learning
Dean of Faculty: Professor Richard Andrews

Tel +44 (0)20 7612 6957
Fax +44 (0)20 7612 6927
Email p.sin@ioe.ac.uk



**Leading education
and social research**
Institute of Education
University of London

20 Bedford Way
London WC1H 0AL
Tel +44 (0)20 7612 6000
Fax +44 (0)20 7612 6126
Email info@ioe.ac.uk
www.ioe.ac.uk

By Email
Rosa Maria Mendizabal-Espinosa

5th February 2013

Dear Rosa

Ethics approval

Project title: Enhancing early relationships between preterm infants and their parents in Mexican Neonatal Intensive care Units (NICU): an analysis of feasibility and impact

I am pleased to formally confirm that ethics approval has been granted by the Institute of Education for the above research project.

This approval is effective from 21st January 2013.

I wish you every success with this project.

Yours sincerely

Pui

+++++

Pui Sin
Research Student Administrator
On behalf of the Faculty of Children & Learning Research Ethics Committee

cc: Priscilla Alderson
Sandy Oliver
IOE Research Ethics office

Appendix 3: Information leaflet

<p style="text-align: center;">INSTITUTE OF EDUCATION UNIVERSITY OF LONDON</p> <p style="text-align: center;">Name of the Hospital and Neonatal Unit A research project about parents and staff members working together in 2 neonatal units. Start and end dates</p> <p style="text-align: center;">Would you like to take part in this study?</p> <p>Some staff members and I are doing a little research project in the unit. This leaflet gives you some details about the study. We would be pleased to give any more information you might need before you decide if you want to take part on it.</p> <p>Please contact us, (Project leader) or Rosa, if you want more details. Contact details.....</p> <p>Thank you for reading this leaflet and for considering taking part in this study. Rosa Mendizabal, Research leader.</p>	<p>What is the research about? We would like to know more about how parents and staff members can work together to care for small fragile babies who are in the NICU.</p> <p>Why is this research being done?</p> <ul style="list-style-type: none">• When babies are born early or sick they need to be cared for by doctors and nurses in the hospital.• And they also need the loving care from their parents.• Parents and staff members can support each other to care for small or sick babies in the NICU.• We want to find out what parents' and staff members' views are on different ways of working together when caring for babies in the hospital, so we are asking for their views.• We aim to understand what parents' and staff members' needs are when working together and find some strategies that can be useful when doing so.• This project is part of my PhD studies with Institute of Education from University of London. <p>How will the study involve parents and staff members? I will be quietly observing what goes on in the Unit, and talking informally to parents and staff. I will also interview some parents and staff members who agree to it, this takes about an hour, or else two or more shorter sessions.</p> <p>Do I have to take part? You only have to take part if you wish to. If you say no, this won't affect your baby's care.</p> <p>Even if you say "yes", you can drop out at any time.</p>
--	--

What will happen to me or my baby if I take part?**Observations:**

I hope you will not mind me being around, observing what goes on in the Unit and talking to people. If at some point I am near you and you would like me to move away please just say it or ask the nurse to tell me, I won't mind!

If I ask you to take part in an interview, you will have time to ask me questions and think about it before you decide. I prefer to tape-record so as to have an accurate record.

If you agree, I will ask you to sign a consent form and give you a copy to keep.

During the interview:

You can decide if you want to answer a question or, if you prefer not to answer you might let me know, I won't ask you for any reasons.

If you need to take a break, stop the interview or opt out from the research please let me know.

I will keep the tapes and the records in a lockable place and I won't share them with anybody, and I will delete tapes after the study is over. I might use your comments to write my PhD thesis or to publish a report of the study; however I will make sure that if I repeat them you will not be identified.

If you would like to have a copy of your taped interview let me know, if after the interview you want me to change or remove any information please let me know as well.

We will write a short report of this study and share it with you when we finish it.

Will taking part in this study benefit me or my baby?

The benefits of this study might not be immediate, yet we hope parents and staff members from this unit will find some new ways to support each other when caring for babies.

The main objective of this study is to gather information from parents and staff members of 3 different units that will help us understand their views and needs when working together; this might help babies, parents and staff members from many other neonatal units in the future in Mexico.

How might the research affect parents?

Most parents enjoy talking about their experiences, but this might be difficult at times. If this happens they can choose to have a break or stop.

Approval

This study is supported by..... in the neonatal Unit and approved by the hospital ethics committee and the ethic committee from Institute of Education from University of London.

Who are the researchers?

The lead researcher from this project is Rosa Mendizabal who is a PhD student from Institute of Education from University of London.

The project leader from this unit is:.....

Appendix 4 Parents' Consent Form

Please initial each box once you have read and understood the statement.

I have read the leaflet about the study, I was given a clear oral explanation about the study and I have had the opportunity to ask questions about it.

I understand that the researcher will observe my interactions with staff members and with my baby and make notes.

I understand that the researcher might interview me and I give my permission for this to be recorded.

I have been informed that all the research records about me and my baby will be kept confidential (this means this information will not be shared outside the research team) and anonymous (this means that neither your name nor your baby's name will be revealed).

I understand that I can withdraw from this study at any stage by contacting the project leader _____ or the researcher Rosa Maria Mendizabal-Espinosa and that no actions will be taken against me or my baby.

Parent's Name _____ Signature _____

Researcher's Name _____ Signature _____

Date of consent _____

Appendix 5: Staff Member's Information Sheet

- Fragile babies such as preterm ones need special medical attention and specific care that is provided in Neonatal Intensive Care Units (NICU) by trained staff.
- We now know that vulnerable infants also benefit from the loving care that their parents can provide.
- Different studies have increased our understanding of how parents and staff can support each other and work as a team when caring for fragile babies and some strategies have been developed.
- This is known as “Family-Centred Care” approach; however this has not been studied in Mexican NICUs so far.
- You are being invited to participate in a study in this field.

I have written some information about this study which will help you decide if you would like to participate, please read them carefully, feel free to discuss them with others and ask me should you have any questions. Before taking a decision it is very important that you know what this study is for and what it involves.

What is the purpose of the study?

- To investigate ways to implement a Family-Centred Care programme in Mexican NICUs.
- This involves finding strategies that allow parents and staff members to work as a team when caring for fragile babies as well as to understand the views and needs of staff members and parents during this process.
- We will do this by comparing information collected in two different hospitals in Mexico City.

How will it be done?

- During (start date-finish date) I will be: observing staff members and parents' interactions when caring for babies, observing staff members and babies' interactions and observing parents and babies' interactions, the researcher will also make some questions to staff members and parents to learn about their views and needs when working as a team.

What will be observed?

I will be observing events such as conversations, activities taken place around babies, people's views and other events; however it is important to tell you that I **will not** be “scoring” how you do your job.

Do I have to participate?

You only have to participate if you wish to, if you choose not to participate in this study no actions will be taken against you or your job.

If I decide to participate, what will I have to do?

You do not need to do any extra activity; you will be invited to “reflect” on ways in which you can work with parents as a team in your day-to-day activities when caring for babies.

If I decide to participate, will my involvement be kept confidential?

Yes, your participation will be confidential (no information will be shared outside the research team) and anonymous (your name will not be identified if we decide to quote any of your comments in the results).

What are the possible disadvantages or risks of this study?

- I have not found any research that reports risks for babies being posed by Family-Centred Neonatal Care, but many studies report advantages.
- Since you will be part of a reflective process, this might change the way you see babies, families and even colleagues which can be distressing at times, however most people say they feel good when working with this approach of care.

What are the possible benefits of this study?

Taking part in this study might not have immediate benefits for babies, families or staff members, although it has been reported from other studies that staff members tend to gain satisfaction when incorporating this type of approach to their practice.

By participating in this study you would be helping us to understand some views and needs that staff members and parents of fragile babies have when working together in the NICU; this information would be helpful for your unit or other units in Mexico in order to implement a Family-Centred Care programme. Understanding how to better support parents in the NICU, and making them part of the multidisciplinary team, might benefit many fragile babies and their families in Mexico in the future.

What will happen to the result of this study?

- Once the data has been analysed the results of the study will be presented to all participants in a report.
- They will also be shared through academic papers such as my PhD thesis, medical/nursing journals, conferences and seminars.

Who is organising and funding this study?

This study is part of my PhD studies in Institute of Education from London University, I have been funded by the “Consejo Nacional de Ciencia y Tecnologia” (CONACyT) Mexico for this purpose.

Contact Information

If you have any questions/comments please contact me (contact details to be added)

Thank you for considering taking part in this study.

Appendix 6
Staff Member's Consent Form

Please initial each box once you have read and understood the statement.

I have read the leaflet about the research project. I was given a clear oral explanation about the research project and I have had the opportunity to ask questions about it.

I understand that the researcher will observe my interactions with other staff members, parents and neonates and make notes.

I understand that the researcher might interview me and I give my permission for this to be recorded.

I have been informed that all the research records about me will be kept confidential (this means this information will not be shared outside the research team) and anonymous (this means your name will not be revealed).

I understand that I can withdraw from this study at any stage by contacting the project leader _____ or the researcher Rosa Maria Mendizabal-Espinosa and that no actions will be taken against me.

Staff Member's Name _____

Signature _____

Researcher's Name _____

Signature _____

Date of consent _____

Appendix 7: A survey of neonatal staff views in Mexican NICU

- New ways for caring for fragile babies have been proposed, some of these look at how staff members and parents can work together in the NICU.
- Surveys about parents' and staff members' views and needs have been mainly carried out in Europe and the USA. These surveys have been very useful for understanding how neonatal care can be improved.
- Little is known about Mexican NICUs.

Through this questionnaire we are interested in knowing staff members' views and needs in Mexican units. By completing it you will be helping us to understand some of these views and needs and study alternatives for caring for fragile babies in Mexico.

This is a pilot being done in 2 Mexican NICUs and will serve to prepare for a larger national survey. This study is being lead by Rosa Maria Mendizabal and the results will also inform her PhD studies at Institute of Education from University of London, about families in the NICU in Mexico. She is currently being funded by Consejo Nacional de Ciencia y Tecnologia (CONACyT) to do it.

We would be very grateful if you would kindly complete this anonymous questionnaire and return it in the envelope provided to [project leader] by [date]. Please seal the envelope before returning it.

The survey has been approved by REC/IRB and by management in (named) hospitals. **All reports will be anonymous, and names of the units will be altered to protect confidentiality.** Once we have finished collected and analysing all responses we will send a short report to each hospital.

Many thanks for helping us.
Rosa Maria Mendizabal

Please tick the boxes that most nearly fit your views:

A. I think parents in the neonatal unit can:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Be helpful members of the neonatal caring team:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Demand too much staff support:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Soothe and comfort their baby:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Increase risks of infection:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Help their baby to grow and thrive:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Tire babies and interrupt their rest:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Be able to learn essential basic information about neonatal care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Support staff:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Support other parents:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Upset staff:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Upset other parents:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Help to make the unit more calm and peaceful:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Be easily distressed by some procedures:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Find it easy to recognise their baby's cues:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Other view, please add:

Please tick the boxes that most nearly fit your views:

B. I think that premature babies:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Mainly need rest and sleep:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Benefit from parents being with them:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are too frail to be touched except by trained staff:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Are able to communicate their needs in many different ways:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Need very gentle care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Are able to recognise parents from other carers:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Respond if we talk to them:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Find it very easy to sleep and rest in the unit:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Can only communicate discomfort by crying:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Can only relax when sleeping:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Benefit from kangaroo care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Are affected by bright light and noise in the unit:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Can identify their parents' voice:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Can identify their parents' odour:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Other view, please add:					

Please tick the boxes that most nearly fit your views:

C. I think that NICU staff:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Should only focus on the baby:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Should take time to teach parents about their baby's care:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the primary caregiver while the baby is in the unit:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have an important role in facilitating parent-infant relationships:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Benefit from listening to parents' views:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Are too busy and don't have much time to talk to parents:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Can offer support to parents:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Can be supported by parents:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Can easily be distracted by having many parents in the unit:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Find it easy to recognise baby's cues:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Should provide the same type of care to all the babies:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. May adjust care according to the baby's and family's needs:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Work better in a quiet/peaceful environment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Work better in a bright environment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Other view, please add:					

Please tick the boxes that most nearly fit your views:

D. In our neonatal unit there is:	Too Much	Enough	Too Little	None
1. Space around the cots:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Intensive care equipment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. In-service training for staff:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Support for staff from managers:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Lighting over the cots:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Noise near the cots:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Space to store spare equipment:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Space for staff to eat:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Space for staff to rest:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Space for parents to sit by the cots:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Space for parents to rest:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Comfortable sitting for parents and visitors near the unit:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Good communication among staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. People willing to help each other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Interest in new ways for caring for babies:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Respect for staff member's opinions:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Respect for parent's opinions:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Respect for babies' cues:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Opportunities to make changes:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Other view please add:				

Please choose the 5 things that you would most like change or improve in the unit by ticking the box, remember you may **only tick 5 boxes**:

E. What I would like change or improve in my unit is:

1. NICU environment: light and sound
2. Space for staff to eat/rest
3. Space for parents to sit next to the cots
4. Communication among staff
5. Space for parents to eat/rest
6. In-service training for staff
7. Support for parents from staff
8. Support for parents from other parents
9. Communication with the family
10. Parents-infant interactions
11. Support for staff from staff
12. Training for parents in the unit
13. Support for staff from managers
14. Parents-staff interactions
15. Other view please add:

F. Do you have anything to add, such as about an important aspect of your Unit the questions have not covered?

G. Please tick the box that best describes your role in the unit:

- | | | | |
|---------------------------|--------------------------|------------------------|--------------------------|
| Doctor | <input type="checkbox"/> | Occupational Therapist | <input type="checkbox"/> |
| Nurse | <input type="checkbox"/> | Physiotherapist | <input type="checkbox"/> |
| Psychologist | <input type="checkbox"/> | Social Worker | <input type="checkbox"/> |
| Breast feeding consultant | <input type="checkbox"/> | Volunteer | <input type="checkbox"/> |

Other (please specify):

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE!

Today's date: _____

Rosa Maria Mendizabal

Email: xxx

Appendix 8: Results of NICU survey MDH

Neonatal care: staff, babies and parents A survey of neonatal staff views in Mexican NICU

November 2013

Methodology

Survey main objective

To get to know more about the perceptions that staff members from intensive and intermediate care units have about working together with parents when caring for fragile babies, in order to develop strategies that will allow parents to be more actively involved in the care of their baby in the NICU based on these perceptions.

Research questions

- What are the perceptions that staff members have of parents of premature infants in the NICU?
- What are the perceptions that staff members have of the preterm infant in the NICU?
- What are the perceptions that staff members have of their own role in facilitating parents-infant relationships in the NICU?
- What are staff members' fears and perceived threats when working together with parents for fragile infants in the NICU?

Setting

Mercedes Duron Hospital (MDH) is a level III referral hospital, administered by Secretaria de Salud del Estado de Puebla (Health Ministry of Puebla State). It serves population from many different regions in Puebla State and therefore many people have to travel between half an hour and five hours in order to get to the hospital. The obstetric demand in MDH is large and complex; the main cause of babies' admission is prematurity.

Neonatal care is divided in three main areas: Intensive Care, Intermediate Care and Growth & Development. There are two Intensive Care rooms with space for up to 17 babies. Visiting hours in these rooms are from 11.30am to 12.00pm.

Intermediate Care is divided into four rooms with 50 cots in total, and there is one Growth & Development room with space for fifteen babies. In total, eighty two babies are treated in this department. Additionally, given that all of the rooms tend to be full at all times, some other patients are also cared for in the area where obstetric surgery takes place, called *area tocoquirurgica* while they wait to be transferred to one of the neonatal rooms.

Psychology Department is in charge of giving emotional support for parents, there are three psychologists who work in the department but they are in charge of many different programmes such as violence prevention, alcoholism, HIV support group, and many others, so they find it difficult to give a more personalised attention to parents from neonatal ward. There is an antenatal group ran by one of the male psychologists, women in risk of preterm birth are detected in that group and help is offered.

Additionally four students enter the neonatal units once a week and identify parents in need of help, this help consists mostly in talking to them. A parent-to-parent support group was started on Saturdays but stopped because of lack of attendance.

It is important to mention that, during interviews or informal conversations, NICU staff have been asked whether they are aware of any support group or any other type of emotional help for parents, none of the participants so far knew about them.

Participants

A total of 83 out of 90 surveys were returned, this means 92% of response rate. NICU and intermediate care staff from all shifts available between 10th and 17th of September 2013 participated in responding this questionnaire. Three of the attending doctors were in charge of handing in the questionnaires to all staff and the same doctors collected all the questionnaires. All questionnaires were returned in sealed envelopes with the legend 'confidential', most of them on the same day.

Questionnaire components

The survey was formed by seven sections.

It is important to mention that, in some cases, final results in these three sections do not add 100%, since some answers were invalidated.

The main objective from section A in this questionnaire was to get to know the points of view from staff about the role of parents in the NICU. A summary of results is shown in chart A.

A. I think parents in the neonatal unit can:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1a. Be helpful members of the neonatal caring team:	45.1%	39.0%	4.9%	6.1%	1.2%	96.3%
2a. Demand too much staff support:	31.7%	42.7%	11%	11%	0%	96.3%
3a. Soothe and comfort their baby:	61%	28%	3.7%	2.4%	1.2%	96.3%
4a. Increase risks of infection:	14.6%	29.3%	22%	26.8%	4.9%	97.6%
5a. Help their baby to grow and thrive:	61%	22%	7.3%	4.9%	2.4%	97.6%
6a. Tire babies and interrupt their rest:	4.9%	13.4%	11%	4.8%	18.3%	96.3%
7a. Be unable to learn essential basic information about neonatal care:	4.9%	4.9%	14.6%	46.3%	25.6%	96.3%
8a. Support staff:	26.8%	46.3%	12.2%	8.5%	3.7%	97.6%
9a. Support other parents:	29.3%	50%	3.7%	13.4%	1.2%	97.6%
10a. Upset staff:	9.8%	24.4%	29.3%	18.3%	14.6%	96.3%
11a. Upset other parents:	15.9%	24.4%	26.8%	17.1%	13.4%	97.6%
12a. Help to make the unit more calm and peaceful:	17.1%	32.9%	24.4%	20.7%	2.4%	97.6%
13a. Be easily distressed by some procedures:	29.3%	35.4%	13.4%	13.4%	6.1%	97.6%
14a. Find it easy to recognise their baby's cues:	24.4%	45.1%	13.4%	13.4%	1.2%	97.6%

Table 1: chart A

Question 15a from this section asked participants to add any relevant information which was not addressed by the questions 1a to 14a, the answers were coded and clustered by categories and sub-

categories. These suggest that there are some factors that staff members consider important when working together with parents:

- **Characteristics of parents:**

- **Socio-economic and cultural level**

- *"[Parents in the neonatal unit can] Understand their patient's stay in the NICU if they are given clear and opportune information according to their level of understanding"*

- *"Parents in the Mexican Republic, as well as the socioeconomic status our population belongs to and their low levels of study, make it difficult to inform and help them conduct themselves carefully in the NICU, which evidently increases the risk of infection"*

- **Attitude**

- *"It depends on the type of parents that collaborate given that some parents are very problematic"*

- *"They should be more polite and respectful with nurses"*

- **Needs in order to achieve integration:**

- **Training for parents**

- *"It is possible to have a positive participation with good training for parents"*

- **Training for staff**

- *"They can support in many different ways but there is a need of training for doctors, nurses and psychologists"*

- **Adequate communication**

- *"It would be of great help if they [parents] are taught and receive an explanation because what they want is the fast recovery of their children"*

- **Clear guidelines and respect to rules**

- *"I think that the parents' visit is important with well structured guidelines"*

- *"It is important to have good communication, working as a team, with rules, respecting them to be able to work"*

- **Benefits vs risks**

- *"Parents can be, as we say colloquially, a "double-edged sword" because they can be a support for the well-being and recovery of their baby but, if they are not adequately guided in the procedures that staff members need to perform on their patient, they can cause instability in their care and management"*

- *"Parents must be well informed and need authentic support from medical staff; however our population lacks hygiene culture and commitment. There have been two cases in which parents have been asked for support and they ask why they should do the nurses' job"*

Section B intended to get to know staff members' perceptions about abilities and needs of the preterm infant as well as how they believe the baby interacts with the physical and social environment in the NICU. Chart B shows the summary of results for this section.

B. I think that premature babies:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1b. Mainly need rest and sleep:	42.7%	34.1%	7.3%	14.6%	1.2%	100%
2b. Benefit from parents being with them:	51.2%	36.6%	7.3%	2.4%	2.4%	100%
3b. Are too frail to be touched except by trained staff:	8.5%	29.3%	15.9%	39%	7.3%	100%
4b. Are able to communicate their needs in many different ways:	46.3%	43.9%	4.9%	4.9%	0%	100%
5b. Need very gentle care:	74.4%	24.4%	1.2%	0%	0%	100%
6b. Can't recognise parents from other carers:	4.9%	18.3%	12.2%	41.5%	23.2%	100%
7b. Respond if we talk to them:	47.6%	40.2%	6.1%	3.7%	1.2%	98.8%
8b. Find it very easy to sleep and rest in the unit:	6.1%	13.4%	18.3%	43.9%	17.1%	98.8%
9b. Can only communicate discomfort by crying:	11%	22%	11%	43.9%	11%	98.8%
10b. Can only relax when sleeping:	7.3%	23.2%	13.4%	45.1%	8.5%	97.6%
11b. Benefit from kangaroo care:	64.6%	24.4%	6.1%	4.9%	0%	100%
12b. Are affected by bright light and noise in the unit:	76.8%	18.3%	1.2%	1.2%	2.4%	100%
13b. Can identify their parents' voice:	64.6%	31.7%	3.7%	0%	0%	100%
14b. Can identify their parents' odour:	61%	24.4%	9.8%	4.9%	0%	100%

Table 2: chart B

15b. Other view, please add. Open answers from this question were coded as follows:

Staff members' perception about babies in the NICU could be categorised in:

- **Babies' needs:**
 - **Handling**
"They are affected by constant handling"

"They could have a faster recovery with multi-disciplinary managing between family and staff, and not being so invaded and distressed by neonatologists and nurses"
 - **Closeness with parents**
"They need to have more contact with their parents in order to have a faster recovery. They need their parents to spend more time with them"

"It is beneficial for them to stay with their parents, because only them [parents] can give them the love they need"

The objective for section C was to gain a better understanding of how staff members perceive their role in facilitating parents-infant interaction in the NICU. Results are shown in chart C.

C. I think that NICU staff:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1c. Should only focus on the baby:	30.5%	19.5%	7.3%	37.8%	3.7%	98.8%
2c. Should take time to teach parents about their baby's care:	46.3%	46.3%	4.9%	2.4%	0%	100%
3c. Are the primary caregiver while the baby is in the unit:	58.5%	30.5%	3.7%	7.3%	0%	100%
4c. Have an important role in facilitating parent-infant relationships:	57.3%	39%	1.2%	2.4%	0%	100%
5c. Benefit from listening to parents' views:	43.9%	31.7%	13.4%	9.8%	1.2%	100%
6c. Are too busy and don't have much time to talk to parents:	20.7%	18.3%	17.1%	34.1%	9.8%	100%
7c. Can offer support to parents:	43.9%	48.8%	7.3%	0%	0%	100%
8c. Can be supported by parents:	34.1%	46.3%	11%	7.3%	1.2%	100%
9c. Can easily be distracted by having many parents in the unit:	18.3%	24.4%	17.1%	32.9%	7.3%	100%
10c. Find it easy to recognise baby's cues:	26.8%	39%	23.2%	9.8%	1.2%	100%
11c. Should provide the same type of care to all the babies:	45.1%	30.5%	6.1%	11%	4.9%	97.6%
12c. May adjust care according to the baby's and family's needs:	46.3%	41.5%	7.3%	3.7%	1.2%	100%
13c. Work better in a quiet/peaceful environment:	48.8%	31.7%	11%	4.9%	3.7%	100%
14c. Work better in a bright environment:	6.1%	4.9%	24.4%	40.2%	24.4%	100%

Table 3: chart C

15b. Other view, please add. Open answers about the perception that staff members have of their own role in caring for the fragile baby and the collaborative work with parents are constituted by the following categories and sub-categories:

- **Resources**

- **Training**

"I think that not all staff in this unit is well trained, even though they have studies"

- **Human resources**

"If the ratio of staff members and patients was properly followed, staff members could also take actions in order to support parents; and there are other departments that could also do this like social work or psychology (only if they are properly trained)".

"They tend to be very busy so as to give the ideal personalised attention in order to train parents and which would be really helpful"

"There are times in which best care cannot be provided since there are some shifts in which only 4 or 5 nurses stay"

- **Attitude**

"Staff members could work better if there was empathy towards each other"

"They need to be more humane and do their job with much LOVE"

“It is true that there is much need in infrastructure, but I think that the most important thing is ATTITUDE among the healthcare team and that the doctors are more humane, that they treat and inform parents with uncomplicated language in a timely and empathic way”

In section D, staff members were asked to choose whether they considered the unit had too much, enough or too little of different aspects regarding the physical and social environment. Values were given to the three options: 1=too little, 2=enough, 3=too much. Chart D show results for this section.

D. In our neonatal unit there is: 1= Too little, 2= Enough, 3= Too much	
Space around the cots:	1
Intensive care equipment:	1
In-service training for staff:	1
Support for staff from managers:	1
Luz sobre las incubadoras/cunas:	2
Noise near the cots:	3
Space to store spare equipment:	1
Space for staff to eat:	1
Space for staff to rest:	1
Space for parents to sit by the cots:	1
Space for parents to rest:	1
Comfortable sitting for parents and visitors near the unit:	1
Good communication among staff	2
People willing to help each other:	2
Interest in new ways for caring for babies:	2
Respect for staff member’s opinions:	2
Respect for parent’s opinions:	2
Respect for babies’ cues:	2
Opportunities to make changes:	1

Table 4: chart D

Open answers for question 20d. Other view, please add provided the categories and subcategories:

- **Resources**

- **Human resources**

“The occupancy in this hospital is above levels, which leads to bad quality of attention to the neonate, there isn’t early intervention, physical therapy or rehabilitation programmes”

- **Infrastructure**

“In reality the area is not adequate and therefore we don’t have the best”

“[There is] Bad quality in areas for doctors, patients and relatives”

“Unfortunately the hospital lacks good organisation in infrastructure as well as the small, improvised spaces which results in patients overcrowding, bright lights, excessive sound of monitor alarms, fragile chairs, lack of personnel and electro-medical equipment”.

- **Economic resources**

“There are budget issues that affect”

○ **Attitude**

“Some of the doctors treat mothers badly”

“The unpleasant thing about “us” is that we don’t give our best”

● **Support**

“There are plenty of opportunities to perform changes in the unit and in the care of patients, unfortunately the leaders in these units don’t care or are not interested in getting better, they don’t take advantage of the “opportunities” to change what is possible, for the better care and development of patients and staff members respectively”

“Sadly, observations among colleagues are not taken well, unless they are friends”

Staff members were also asked to choose five things they would like to change from their unit in section E, with the objective of identifying possibilities for improvement.

E. Please choose the 5 things that you would most like change or improve in the unit:	
NICU environment: light and sound	70.73%
Space for staff to eat/rest	54.88%
Space for parents to sit next to the cots	48.78%
Communication among staff	28.05%
Space for parents to eat/rest	7.32%
In-service training for staff	53.66%
Support for parents from staff	21.95%
Support for parents from other parents	8.54%
Communication with the family	14.63%
Parents-infant interactions	43.90%
Support for staff from staff	31.71%
Training for parents in the unit	42.68%
Support for staff from managers	62.20%
Parents-staff interactions	18.29%

Table 5: chart E

Finally, chart F shows the role for each respondent:

F. Your role in the unit	
Nurse	45.24%
Doctor	33.33%
Psychologist	3.57%
Breastfeeding Consultant	1.19%
Physiotherapist	1.19%
Social Worker	4.76%
Other	1.19%
Not specified	9.52%

Table 6: chart F

Analysis of results

Categories identified from the data above have been proposed as follows:

1. The parents as a factor of well-being for the fragile infant:

89% of respondents to this survey think that parents can soothe and comfort their babies; 83% of them also think that parents can help their baby to grow and thrive and 55% don't think that parents can tire babies and interrupt their rest.

2. Fears and threats perceived by staff when working together with parents:

One issue that staff members could perceive as a problem when working together with parents is the fact that the latter might need too much staff support, as shown by 74.4% of staff members that completely agree and agree with this. Additionally 50% of them think they should only focus on the patient.

The fear that parents might increase the risk of infections seems to be split since 29.3% of staff members agree and 26.8% disagree, another 18% neither agree nor disagree.

The fact that parents might be easily distressed by some procedures seems to be an important barrier perceived by staff members, the numbers in this survey show that 64.7% of respondents completely agree or agree with this; however this has also been a very constant theme that emerges during informal conversations with staff. A nurse said very recently *"I don't think parents can be present during procedures, we either take care of the patient or prevent the parents from fainting"*.

Another possible barrier so as to involve parents more actively with their babies is the fact that 89% of staff members who answered this survey think they are the primary caregivers while the baby is in the unit. This is very evident during observations when nurses refer to the babies as "my baby on cot 3".

The lack of human and economic resources seems to be another problem perceived by staff, which comes up constantly through their comments:

“If the ratio of staff members and patients was properly followed, staff members could also take actions in order to support parents; and there are other departments that could also do this like social work or psychology (only if they are properly trained)”.

“They tend to be very busy so as to give the ideal personalised attention in order to train parents and which would be really helpful”

“There are times in which best care cannot be provided since there are some shifts in which only 4 or 5 nurses stay”

“In reality the area is not adequate and therefore we don't have the best”

“[There is] Bad quality in areas for doctors, patients and relatives”

“Unfortunately the hospital lacks good organisation in infrastructure as well as the small, improvised spaces which results in patients overcrowding, bright lights, excessive sound of monitor alarms, fragile chairs, lack of personnel and electro-medical equipment”.

“There are budget issues that affect”

3. Parents as a helpful human resource in the NICU:

84.1% of participants think that parents can be helpful members of the neonatal caring team.

On the other hand 71.9% don't believe that parents are unable to learn essential basic information about neonatal care. However this information comes in contrast with open questions comments such as:

“[Parents in the neonatal unit can] Understand their patient's stay in the NICU if they are given clear and opportune information according to their level of understanding”

“Parents in the Mexican Republic, as well as the socioeconomic status our population belongs to and their low levels of study, make it difficult to inform and help them conduct themselves carefully in the NICU, which evidently increases the risk of infection”

73.1% of respondents believe that parents can support staff and 79.3% think parents can support other parents. On the same line 80.4% of staff members think that they can be supported by parents. Again, this might be in contradiction with answers to items such as parents might upset staff, where only 32.9% of respondents disagree and parents might upset other parents where 30.5% disagree. Additionally, comments from informal conversations and formal interviews suggest that staff members feel “observed and judged” by parents if they are in the unit and fear that when they leave they will “accuse” them with other parents for upsetting their babies.

75.6% of respondents think that staff members benefit from listening to parents' views. Once more this comes in contrast with observations from the unit, where hardly ever does a staff member interact with parents for more than greeting, giving instructions or giving information about the baby's day.

50% of staff members consider that parents can help to make the unit more calm and peaceful and 69.5% believe that parents find it easy to recognise their baby's cues.

4. Factors of well-being for the fragile infant:

76.8% of the participants consider that preterm babies mainly need rest and sleep, 87.8% believe preterm babies benefit from parents being with them, 98.8% think they need very gentle care and 89% also think babies benefit from kangaroo care.

Some comments that support these views are:

“They could have a faster recovery with multi-disciplinary managing between family and staff, and not being so invaded and distressed by neonatologists and nurses”

“They need to have more contact with their parents in order to have a faster recovery. They need their parents to spend more time with them”

“It is beneficial for them to stay with their parents, because only them [parents] can give them the love they need”

Once more some of these answers are in contrast with the observations within the unit, there is no kangaroo care programme in the unit at all, neither is there in intermediate or growth & development care rooms; visiting time for parents is very restricted, a doctor commented *“in the past it was supposed to be for an hour but I don’t know who decided to make it half an hour, so five to twelve nurses start asking parents to leave the room”*; handling of the baby is not gentle, another doctor mentioned *“we don’t use any pain relief strategy, we don’t have guidelines for this and nurses don’t even know that aspiration might be painful... “when nurses tap their back so as to bring mucous out it looks like baby shaking”*.

5. Factors that affect the fragile infant:

61% of staff members think that preterm babies find it difficult to sleep and rest in the unit; additionally 95.1% consider that preterm babies are affected by bright light and noise. Again, in contrast with these views the radio tends to be on in both rooms, or nurses listen to the radio on their mobile phone.

6. Preterm infants’ abilities:

90.2% from staff members consider that preterm babies are able to communicate their needs in many different ways, 64.7% do not believe that they are unable to recognise parents from other carers, 87.8% think babies respond if we talk to them, 54.9% don’t think that they only communicate discomfort by crying, 96.3% believe babies identify their parents’ voice and 85.4% believe babies can identify their parents’ odour.

7. Necessary attitudes from NICU staff in order to work together with parents in caring for fragile infants:

96.3% from staff members think they have an important role in facilitating parent-infant interactions, 75.6% consider that they can benefit from listening to parents’ views, 43.9% don’t think they are too busy and lack time to talk to parents and 92.7% believe they can offer support to parents.

In addition to this, answers to open questions suggest that some staff members feel that doctors need to be more “humane” with parents and empathic with parents and with colleagues:

“Staff members could work better if there was empathy towards each other”

“They need to be more humane and do their job with much LOVE”

“It is true that there is much need in infrastructure, but I think that the most important thing is ATTITUDE among the healthcare team and that the doctors are more humane, that they treat and inform parents with uncomplicated language in a timely and empathic way”

8. Staff members’ needs:

Participants in this survey think that, in order to work together with parents, both staff and parents need to have more training. For example, results from section D show that staff members consider there is very little training and 53.66% (in section E) thought they would like this to change.

There are also some comments that support this view:

“It is possible to have a positive participation with good training for parents”

“They can support in many different ways but there is a need of training for doctors, nurses and psychologists”

70.73% also chose to improve or change light and noise levels. This is also supported by the view that babies are affected by bright light and noise in the unit.

Other factors which seem to be important for staff are communication and clear guidelines. This was identified in comments such as:

“It would be of great help if they [parents] are taught and receive an explanation because what they want is the fast recovery of their children”

“I think that the parents’ visit is important with well structured guidelines”

“It is important to have good communication, working as a team, with rules, respecting them to be able to work”

It also seems that staff members, especially nurses, want to feel respected and expect a positive attitude from parents:

“It depends on the type of parents that collaborate given that some parents are very problematic”

“They should be more polite and respectful with nurses”

62.20% of participants said they would like to have more support from managers and an appropriate space for staff and parents to eat and rest.

Discussion of results

After discussing these results and analysis with the research team, a second analysis was performed using a SWOT matrix so as to identify: strengths, weaknesses, opportunities and threats. This matrix was chosen in consensus with the team members as they considered Directors and colleagues would find it easy to understand.

Strengths

It seems that staff members from MDH are aware about the needs of fragile babies to be with their parents. The results also suggest that staff members consider parents as a factor of well-being and health for the fragile baby. Respondents to this survey seem to be willing and enthusiastic with the idea of making improvements in the unit.

Weaknesses

There seem to be many contradictions between survey answers and the day-to-day practice in the unit. This could be a weakness because there is a possibility that respondents did not give a real answer but instead they might have given an answer that they considered to be the best.

There is also a possibility that answers do reflect what they think or what they would like to have in their unit and that they are aware of parents' and infants' needs. However in reality they find it difficult to really work together with parents because of a variety of factors such as an ingrained idea that there is a lack of economic and human resources combined with ignorant population which are determinant of a low quality service, and the perception of lack of support and interest from managers.

Observations also suggest that staff members are aware of babies' and parents' needs but sometimes these are in contrast with their own needs or preferences. For example, staff members normally have the radio on but when there is sound auditing by the researcher they hurry and turn it down.

In any case this will have to be researched further with observations, interviews and other research strategies.

The lack of communication among departments is very evident, for example staff members in the NICU do not know about programmes from Psychology Department intended to help parents, and therefore they do not refer families to them. This in turn makes it difficult for the psychologists to gather parents.

It seems that staff members do not feel valued, apparently they feel to lack support from managers and nurses might feel they lack respect from parents.

Opportunities

Contradictions between survey results and observations of the daily routine in the unit could also be turned into opportunities. The results show that the parents might be considered as a factor of well-being for the fragile infant and a helpful human resource in the NICU, and staff members considered that they play an important role in facilitating parent-infant interactions. It could also be suggested that staff from this unit consider that preterm babies are able to communicate in different ways and identify their parents from other carers.

Threats

Apparently, the main concern for staff members is that parents might be very demanding and also they can be easily altered by some procedures, this would add to the overload of work that they have. On the other hand, parents' presence in the unit seems to make staff uncomfortable and feel judged. In addition to this, the lack of guidelines also seems to be considered as a problem by staff. Another possible threat is the fact that a high number of respondents thought that staff members are the primary carers of the baby in the unit, since this could prevent them from inviting parents to participate in cares.

Conclusions

Even though it seems that NICU staff from MDH consider parents presence in the NICU as helpful for the recovery and well-being of babies and therefore recognise them as important members, there also seems to be a number of barriers that prevent them from integrating them into the daily care of the children such as: lack of personnel, lack of resources and deficient infrastructure, ideas about parents being very demanding and judgemental, and feelings of not having support from managers, among others.

There seem to be some contradictions between survey results compared to observations and informal conversations in the unit; these will need to be addresses carefully in the following months.

Appendix 9: Results of NICU survey JDH

Neonatal care: staff, babies and parents A survey of neonatal staff views in Mexican NICU

December 2013

Methodology

Survey main objective

To get to know more about the perceptions that staff members from intensive and intermediate care units have about working together with parents when caring for fragile babies, in order to develop strategies that will allow parents to be more actively involved in the care of their baby in the NICU based on these perceptions.

Research questions

- What are the perceptions that staff members have of parents of premature infants in the NICU?
- What are the perceptions that staff members have of the preterm infant in the NICU?
- What are the perceptions that staff members have of their own role in facilitating parents-infant relationships in the NICU?
- What are staff members' fears and perceived threats when working together with parents for fragile infants in the NICU?

Setting

Juan Dautt Hospital (JDH) is a secondary level referral unit located in Estado de Mexico and it belongs to the Instituto de Salud del Estado de México - ISEM (Health Institute from Estado de Mexico). This hospital attends to local families from Ciudad Netzahualcóyotl, Ecatepec, Chalco, Chimalhuacán and Amecameca, which are in nearby communities.

There are two units for caring for fragile or sick babies in this hospital. The intensive care neonatal unit has a capacity for eight babies and the intermediate care unit a capacity for 12 babies. When needed, spaces for babies are improvised in the surgery recovery area.

According to members of staff, there are two programmes, intended for integral well-being of the family in the unit:

1. The hospital is under the process of being certified as “Baby Friendly” by UNICEF, therefore staff members are working together with mothers to improve breastfeeding rates, and they have guidelines for accomplishing this in the NICU. At the entrance of this unit they have adapted an area for mothers to express milk, with chairs and a small refrigerator. This area is separated from the entrance of the NICU by screens. The Psychologist of the unit, who is also trained in breastfeeding, supports mothers in this process.

2. The same Psychologist has also developed a programme called: “Individualised and Family Centred Care”. A protocol written by her details the process of receiving, informing and teaching parents. This project works together with the breastfeeding one and it is in its early stages.

According to a chart located at the entrance of the room, visiting hours for mothers in the NICU are from 1.00 to 3.00 pm, and for fathers from 4.00 to 5.00 pm. Mothers who are expressing their milk can also come into the lactation room every three hours, or if they are breastfeeding they are allowed to enter the unit every three hours. During the rest of the time parents are required to wait outside the hospital. Normally, if their home is far, they wait in the street.

Participants

A total of 57 questionnaires were handed to staff from the intensive and intermediate care units from all shifts that were available between October 1st and 8th 2013.

The Chief of nurses was in charge of handing in the questionnaire along with an envelope with the legend ‘confidential’. Instructions were given to staff in the first page of the questionnaire. Staff were required to fill in the survey, putting it in the envelope and sealing it, envelopes were collected in a closed box at the entrance of intermediate care room.

The researcher met with a group of nurses, five in total, from the morning shift, in order to talk more about their perceptions after having answered the survey.

Twenty eight from the 57 questionnaires were returned, which is 49.1% response rate.

Questionnaire components

The survey was formed by seven sections.

The main objective from section A in this questionnaire was to get to know the points of view from staff about the role of parents in the NICU. A summary of results is shown in chart A.

A. I think parents in the neonatal unit can:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1a. Be helpful members of the neonatal caring team:	50.0%	39.3%	0%	3.6%	7.1%	100%
2a. Demand too much staff support:	35.7%	46.4%	10.7%	3.6%	3.6%	100%
3a. Soothe and comfort their baby:	67.9%	25.0%	0%	3.6%	3.6%	100%
4a. Increase risks of infection:	14.3%	25.0%	14.3%	28.6%	17.9%	100%
5a. Help their baby to grow and thrive:	71.4%	21.4%	3.6%	0%	3.6%	100%
6a. Tire babies and interrupt their rest:	14.3%	21.4%	14.3%	28.6%	21.4%	100%
7a. Be unable to learn essential basic information about neonatal care:	14.3%	7.1%	7.1%	57.1%	14.3%	100%
8a. Support staff:	14.3%	60.7%	3.6%	14.3%	7.1%	100%
9a. Support other parents:	39.3%	32.1%	17.9%	7.1%	3.6%	100%
10a. Upset staff:	10.7%	25.0%	25.0%	28.6%	7.1%	96.4%
11a. Upset other parents:	17.9%	39.3%	7.1%	25.0%	7.1%	96.4%
12a. Help to make the unit more calm and peaceful:	14.3%	28.6%	32.1%	21.4%	3.6%	100%
13a. Be easily distressed by some procedures:	25.0%	53.6%	3.6%	14.3%	3.6%	100%
14a. Find it easy to recognise their baby's cues:	17.9%	50.0%	14.3%	10.7%	3.6%	96.4%

Table1: chart A

Section B intended to get to know staff members' perceptions about abilities and needs of the preterm infant as well as how they believe the baby interacts with the physical and social environment in the NICU. Chart B shows the summary of results for this section.

B. I think that premature babies:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1b. Mainly need rest and sleep:	60.7%	28.6%	3.6%	7.1%	0%	100%
2b. Benefit from parents being with them:	46.4%	42.9%	3.6%	3.6%	3.6%	100%
3b. Are too frail to be touched except by trained staff:	17.9%	17.9%	28.6%	32.1%	3.6%	100%
4b. Are able to communicate their needs in many different ways:	53.6%	42.9%	0%	3.6%	0%	100%
5b. Need very gentle care:	71.4%	28.6%	0%	0%	0%	100%
6b. Can't recognise parents from other carers:	3.6%	10.7%	10.7%	64.3%	10.7%	100%
7b. Respond if we talk to them:	39.3%	50.0%	3.6%	7.1%	0%	100%
8b. Find it very easy to sleep and rest in the unit:	7.1%	25.0%	14.3%	46.4%	7.1%	100%
9b. Can only communicate discomfort by crying:	3.6%	7.1%	17.9%	60.7%	10.7%	100%
10b. Can only relax when sleeping:	14.3%	17.9%	25.0%	39.3%	3.6%	100%
11b. Benefit from kangaroo care:	53.6%	42.9%	3.6%	0%	0%	100%
12b. Are affected by bright light and noise in the unit:	71.4%	28.6%	0%	0%	0%	100%
13b. Can identify their parents' voice:	60.7%	39.3%	0%	0%	0%	100%
14b. Can identify their parents' odour:	60.7%	28.6%	10.7%	0%	0%	100%

Table 2: chart B

The objective for section C was to gain a better understanding of how staff members perceive their role in facilitating parents-infant interaction in the NICU. Results are shown in chart C.

C. I think that NICU staff:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Total
1c. Should only focus on the baby:	25.0%	28.6%	10.7%	35.7%	0%	100%
2c. Should take time to teach parents about their baby's care:	32.1%	57.1%	10.7%	0%	0%	100%
3c. Are the primary caregiver while the baby is in the unit:	57.1%	35.7%	3.6%	3.6%	0%	100%
4c. Have an important role in facilitating parent-infant relationships:	64.3%	32.1%	3.6%	0%	0%	100%
5c. Benefit from listening to parents' views:	32.1%	50.0%	14.3%	3.6%	0%	100%
6c. Are too busy and don't have much time to talk to parents:	10.7%	21.4%	32.1%	25.5%	7.1%	96.4%
7c. Can offer support to parents:	39.3%	53.6%	0%	0%	3.6%	96.4%
8c. Can be supported by parents:	32.1%	46.4%	14.3%	0%	3.6%	96.4%
9c. Can easily be distracted by having many parents in the unit:	7.1%	32.1%	10.7%	35.7%	14.3%	100%
10c. Find it easy to recognise baby's cues:	25.0%	57.1%	14.3%	3.6%	0%	100%
11c. Should provide the same type of care to all the babies:	42.9%	25.0%	3.6%	25.0%	3.6%	100%
12c. May adjust care according to the baby's and family's needs:	46.4%	42.9%	7.1%	3.6%	0%	100%
13c. Work better in a quiet/peaceful environment:	42.9%	39.3%	14.3%	3.6%	0%	100%
14c. Work better in a bright environment:	3.6%	7.1%	21.4%	46.4%	21.4%	100%

Table 3: chart C

It is important to mention that, in some cases, final results in these three sections do not add 100%, since some answers were invalidated.

In section D, staff members were asked to choose whether they considered the unit had too much, enough or too little of different aspects regarding the physical and social environment. Values were given to the three options: 1=too little, 2=enough, 3=too much. Chart D show results for this section.

D. In our neonatal unit there is: 1= Too little, 2= Enough, 3= Too much	
Space around the cots:	1
Intensive care equipment:	2
In-service training for staff:	2
Support for staff from managers:	1
Luz sobre las incubadoras/cunas:	2
Noise near the cots:	3
Space to store spare equipment:	1
Space for staff to eat:	1
Space for staff to rest:	1
Space for parents to sit by the cots:	1
Space for parents to rest:	1
Comfortable sitting for parents and visitors near the unit:	1
Good communication among staff	2
People willing to help each other:	2
Interest in new ways for caring for babies:	2
Respect for staff member's opinions:	2
Respect for parent's opinions:	2
Respect for babies' cues:	2
Opportunities to make changes:	1.5

Table 4: chart D

Staff members were also asked to choose five things they would like to change from their unit in section E, with the objective of identifying possibilities for improvement.

E. Please choose the 5 things that you would most like change or improve in the unit:	
NICU environment: light and sound	84%
Space for staff to eat/rest	79%
Space for parents to sit next to the cots	32%
Communication among staff	47%
Space for parents to eat/rest	16%
In-service training for staff	79%
Support for parents from staff	26%
Support for parents from other parents	5%
Communication with the family	0%
Parents-infant interactions	63%
Support for staff from staff	42%
Training for parents in the unit	58%
Support for staff from managers	63%
Parents-staff interactions	37%

Table 5: chart E

Finally, chart F shows the role for each respondent:

F. Your role in the unit	
Nurse	82%
Doctor	7%
Did not specify	11%

Table 6: chart F

There was also a section where participants could add any information they wanted. The answers for that section were clustered in categories and added to the analysis.

Method of analysis

Research questions were kept in mind throughout this process, in order to carry out this analysis. SPSS software version 20 was used in order to do a descriptive analysis for measures of frequency and central tendency.

After doing a first analysis, the researcher met with the advisory team to discuss results and hear their points of view. This was important because the researcher does not belong to the unit unlike the rest of team members. After hearing their opinions, the researcher carried out a second analysis and grouped results in categories.

The identified categories are:

- 1. The parents as a factor of well-being for the fragile infant:**

Results from this survey suggest that staff members identify parents as a factor of well-being for their child. For example, 67.9% completely agreed and 25.5% agreed that parents can soothe and comfort their baby. Additionally 71.4% and 21.4% completely agreed or agreed, respectively, that parents can help their baby to grow and thrive.

This was also supported by some of the additional information staff provided:

“Parents can collaborate for a faster recovery of their child whenever they are appropriately guided by staff members”

“I think there are cares that parents can provide and which will be beneficial for their fast recovery, improving with that their quality of life”

2. Parents as a helpful human resource in the NICU:

50% of staff completely agree that parents can be helpful members in the unit, additionally 39.3% agree on this same aspect. On the other hand, 60.7% agree that parents can support staff, plus 14.3%, who completely agree on this same topic. This idea is confirmed in another section of the survey in which 32.1% of staff completely agree and 46.4% agree that they can be supported by parents. Moreover 57.1% disagree and 14.3% completely disagree that parents are unable to learn basic information about neonatal care.

3. Fears and threats perceived by staff when working together with parents:

Apparently, staff members fear that parents might demand too much support from them, for which 35.7% completely agree and 46.4% agree. In relation to this same aspect 32.1% agree or completely agree that they are very busy and don't have time to talk to parents, compared to a 32.6% who disagree or completely disagree.

“From my point of view we try to generate more interactions between parents and their babies, but sometimes the lack of time and insufficient staff make us take things easier, but I think that the task of informing, helping, guiding and interacting with parents and amongst staff from different areas is done even having less time, we try to accomplish with our objective which is taking care of whom most needs it”

The perception that parents might increase the risk of infection in the unit also seems to be divided amongst 39.3% who agree or completely agree with this versus 46.5% who disagree or completely disagree and 14.3% who neither agree nor disagree.

Another fear from staff could be the fact that parents in the unit can upset other parents, for which 57.2% completely agree or agree. Added to this, 25% from staff members completely agree and 53.6% agree that parents can be easily distressed by some procedures.

Some of the comments staff made about this are:

“They might be distressed by some procedures, but by giving them adequate attention and with the appropriate words I don't think that will be a problem”

“There are certain cares they can understand but sometimes they [babies] need to go under procedures or events they [parents] cannot understand, and it is then when parents get confused”

“There are procedures that can alter their objectivity and therefore it is better for them to go outside during the execution of some procedures”

4. Factors of well-being for the fragile infant:

46.4% and 42.9% of staff members completely agree or agree that fragile infants benefit from being with their parents.

On the other hand 100% of staff completely agree or agree that preterm infants need very gentle care. In relation to this one person added:

“Minimal handling for the critically ill preterm newborn”

96.5% of staff also believe that preterm infants benefit from kangaroo mother care and commented:

“A well organised kangaroo mother care programme would be a great programme”

“In the kangaroo mother care programme it would be ideal that the newborn stays with his/her mummy all day in a special area where the mummy gets all the comfort in order to stay, and the low weight newborn would gain the ideal weight faster, it would be less expenses and [hospital] stay”

5. Factors that affect the fragile infant:

High levels of light and noise were identified by 100% of staff members as factors that affect the well-being of their patients.

6. Preterm infants’ abilities:

A very high percentage of staff members: 96.5% consider that newborn preterm babies can communicate in different ways.

In regard to preterm infants’ ability to identify their parents from other carers, 75% of staff completely disagree or disagree that infants lack this ability. Moreover 89.3% agree or completely agree that preterm infants respond if they talk to them, additionally 100% of them think that the infant can identify their parents’ voice and 89.3% think they can identify their parents’ odour.

7. Necessary attitudes from NICU staff in order to work together with parents in caring for fragile infants:

89.2% from staff members agree or completely agree that they should take time to teach parents about their babies' care. Additionally 96.4% from staff members recognise the importance of their role in facilitating parent-infant relationships in the NICU. On the other hand 82.1% of them believe that they can benefit from listening to parents' opinions.

In relation to adjusting care according to patient's and family's needs, 46.4% completely agree and 39.3% agree with this. However 42.9% of them completely agree and 25% agree that they should provide the same type of care to all babies. A supposition from the researcher is that the latter was understood as "all babies deserve the same level of care", however this will have to be researched further. Staff members also commented:

"Each baby is unique, cares are not given in the same way, we provide care according to every person's needs so that in less time he/she can be incorporated to the family environment"

"The point against this is the lack of staff so as to support parents; care for the Newborn babies can't be the same, given that we are all different"

8. Staff members' needs:

82.2% of them think they work better in a quiet/peaceful environment. This seems to be supported with the 84% from staff members who would like to modify the levels of light and noise in the unit. In addition to this 79% of them would like to have space for them to eat and rest, 79% would like to have in-service training for staff, 63% would like to improve parents-infant interactions and 63% would also like to have more support from managers.

Discussion of results:

This Project seeks to identify strategies which will allow parents to be more actively involved in the care of their fragile baby while in the NICU, hence taking into account the points of view, needs but more importantly fears from staff is considered vital as to reach that goal. It is important to mention that these are preliminary results, which will be complemented with interviews and observations.

In regard to staff members' perceptions about parents, results suggest that the latter are viewed as a factor of well-being for their fragile baby. Staff also recognise the fact that parents can soothe and comfort their babies and help them grow and thrive. On the other hand, it seems that parents might be perceived as a potential human resource, being able to support staff and learn basic information about neonatal care. During the reunion with nurses, they appeared enthusiastic about the idea of involving parents more actively in the NICU. However these results are in contrast with what happens currently in JDH, where parents' freedom to touch their babies is limited to restricted visiting hours. The only way in which mothers seem to participate is by bringing their milk. Additionally, staff members report that there is very little space and facilities for parents to be with their babies, eat or rest. Additionally, the low response rate for this survey could also be seen as a lack of interest from some staff members in this topic.

Results about staff members' views of the preterm infant in the NICU suggest that they recognise the newborns' abilities such as communicating in different ways, identifying their parents from other carers and recognising their parents' voice and odour. These data are important, because they could propose that staff members see the preterm infant as capable of interacting with his or her physical and social

environment. In addition to this, staff members identify some factors which are beneficial for the infant such as having their parents close to them; gentle care and kangaroo mother care. All these include parents' participation. Furthermore, staff members are aware that fragile babies are affected by high levels of light and noise and they also think that the current space between cot and cot is reduced. Once again, the day-to-day type of care that is provided in the unit does not reflect this view. It seems that staff members are aware of all these beneficial activities but that does not necessarily mean that the activities are carried out. For example, on a day when they were having supervision from the ISEM the unit was very quiet, every baby had a screen and all staff members were concentrated in their work, however that is not the norm in the unit.

It also seems that staff members consider themselves as playing an important role in the facilitation of parents-infant relationship. However, most participants in this survey also considered themselves to be the primary carer of the baby while in the NICU. The attitudes that are identified as important in working together with parents are: taking the time to teach parents about the care of their baby and adjusting care according to patients' and family's needs. They also think they can benefit from parents' opinions.

In order to being able to work together with parents, as results from both questionnaire and meeting with nurses show, staff members wish and need to have more training. In addition to this, during conversations staff members say that there is a need to raise consciousness in order to be aware of infants' needs to be with their parents. This is supported by some comments in the survey:

“All neonates are fragile, however not only training is important for a better care, but also the interest in their condition and simply because of being indefensible, bonding with their parents but above all with their mother is important”

On the other hand, staff members also seem to believe that a quiet and peaceful environment is necessary for them, moreover adjusting levels of light and noise is one of the aspects they choose as wanting to change or improve. Paradoxically, during the morning the radio is normally on with pop music. There is another need that staff identify in regard to the physical environment in the unit: having appropriate spaces for them to eat and rest. And in regard to the social environment, they express the need of feeling supported by managers.

There are some fears identified by staff members when working together with parents, probably the most relevant one is the idea that parents require too much support from them. This is in contrast with aforementioned necessary attitudes such as taking time to teach parents or adjusting care according to their needs. Other important fears are that parents might be distressed by some procedures or that they can upset other parents. During the reunion, nurses mentioned that

“When parents come into the unit they are just looking at what happens with other babies, and when they leave they accuse us with other parents”

This suggests staff sometimes see the parents' presence in the unit as a threat. Even though some staff members think that parents could increase the risk of infection in the unit, this did not come as the biggest threat perceived contrary to what was expected.

In regard to the five things that staff would like to change or improve in the unit, three of refer: modifying light and noise levels, more in-service training and improving interactions between babies and parents. Nevertheless this project will also inform managers about staff members' feelings in relation to support and facilities for them to eat and rest.

Conclusions

There seems to be good windows of opportunity in order to develop strategies to involve parents more actively with their children. For example, results suggest that staff members are aware of the benefits of bringing parents and babies together and the importance of their role in doing so, therefore next steps should include researching more on the reasons for not doing this. Apparently one of these could be the lack of staff or at least the perception of it.

New questions arose from these results for example: all the participants in this survey agreed that fragile babies need very gentle care, however many procedures in this unit could be considered as aggressive (at least for the researcher), also most of the respondents believe that babies respond if we talk to them, however during observations I have noticed very few staff members talk to the babies when they approach them, contrary to what parents do during visiting hours. Most of the participants also agree that they find it easy to read babies' cues, but during observations I have noticed staff members tend not to look at the baby or not to watch or listen to the baby's cues because they have to finish a procedure. So this makes me think that many answers to this survey have a component of social desirability, where people tend to give the correct answer more than the real one. During conversations with the team members about survey results they mentioned

“it looks like you are talking about people from a different unit”

Hence these results need to be complemented with interviews to participants and more observations.

Based on the results, the most accessible way to start making changes in the unit seems to be the physical environment, more specifically light and noise levels.

Appendix 10: Interview guide staff

Introducing myself, summary of the research project and thanking for participating.

Would you like to tell me about your role in the unit?

What do you like/don't like about working here?

What are the challenges of looking after very sick babies?

What do babies need the most when they are here?

How do babies feel when they are here? How do they let you know?

How do parents feel?

What is it like when parents come to see babies?

Can parents contribute a little? How could they help (if at all)? (basic care, stressful events, decision-making)

How would you describe your relationship with the parents?

What do parents need when they are here?

What do parents need when they take their baby home?

What can you tell me about your relationship with colleagues? (If prompt needed communication, support, environment, multi-disciplinary work)

If you could change something what would it be?

Are there any other things you would like to talk about?

Appendix 11: Interview guide parents

Introducing myself, summary of the research project and thanking for participating.

How did your baby come to need special/intensive care?

What was the first time that you saw your baby in the unit like?

How did the staff support and inform you?

How much were you able to care for your baby in the unit? (Prompts feeding, touching, holding, changing, other)

Can you tell me about your best time in the unit?

Can you tell me about your worst/hardest time in the unit?

How do you believe your baby felt while in the unit, can you describe some of the experiences?

How would you describe your relationship with the staff?

Were you able/did you want to share in making decisions? For example?

How did you find the other parents?

What help did you have about going home and after your baby left the unit?

On the whole, how do you think being in the unit affected your relationship with your baby?

And your partner's relationship with your baby?

Are there any other things you would like to talk about?

Then general evaluation if not already covered and some of your closing the interview questions.

Appendix 12: Guide to observing babies

Type of intervention

Babies' behaviour before and during intervention **

How baby was approached (talked to, pace, visual contact)

Environment: number of people, light, noise.

Who was with baby?

Positioning (nest, head alignment, arms and legs)

Self-soothing strategies

External strategies to help baby sooth (talking, touch, positioning, rolls)

Signs of pain or discomfort (facial gestures, hands, feet, vital signs)

What happened after intervention? (Comforting strategies, babies' reactions)

How did it feel over all?

What went well?

** Some behavioural cues to remember

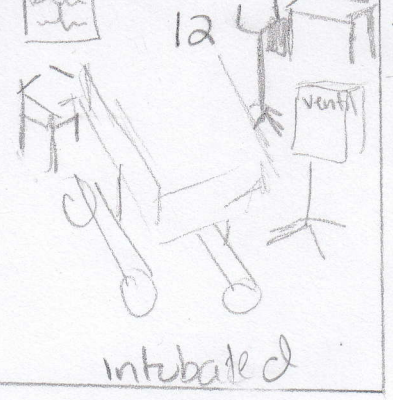
Physiological	<ul style="list-style-type: none">• Breathing pattern; gagging, hiccough, gasps.• Skin colour• Oxygen saturation• Digestive movements.• Tremors
Motor	<ul style="list-style-type: none">• Muscle tone• Position of extremities (flexed, extended)• Quality of movements (smooth/sudden)• Arching, squirming• Facial expressions• Hand movement: fisting, splaying fingers, bringing hands together.
States	<ul style="list-style-type: none">• Deep sleep, light sleep, drowsy, quietly awake, actively awake, fussing or crying (quality, definition and transition)
Attentional	<ul style="list-style-type: none">• Yawns, sneezes, cooing, looking in, looking away, mouth movements.
Regulatory	<ul style="list-style-type: none">• Looking in, cooing, hands together, hand to mouth/face, clasping feet, grasping, sleeping/quietly awake, smooth movements, modulated muscle tone, stability in vital signs.

Appendix 13: NICU lay-out

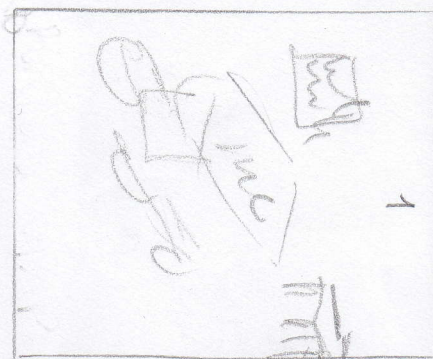
24 NOV 14
2/2/2



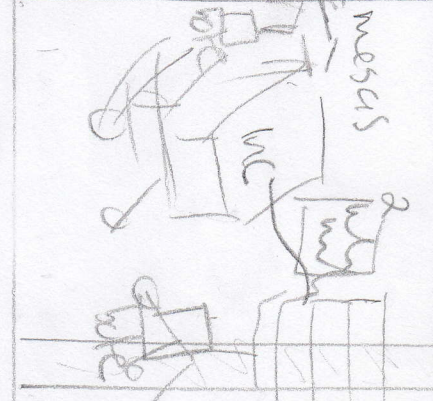
To storage room



intubated



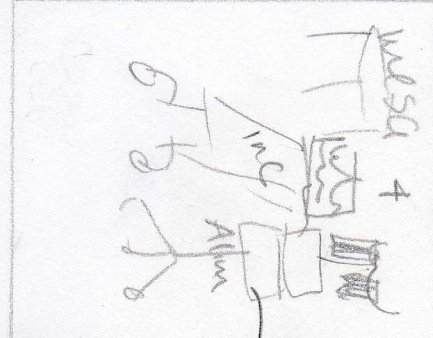
1



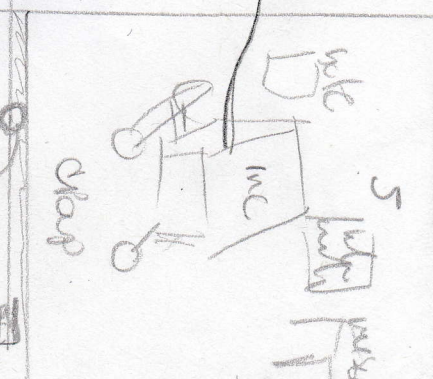
2



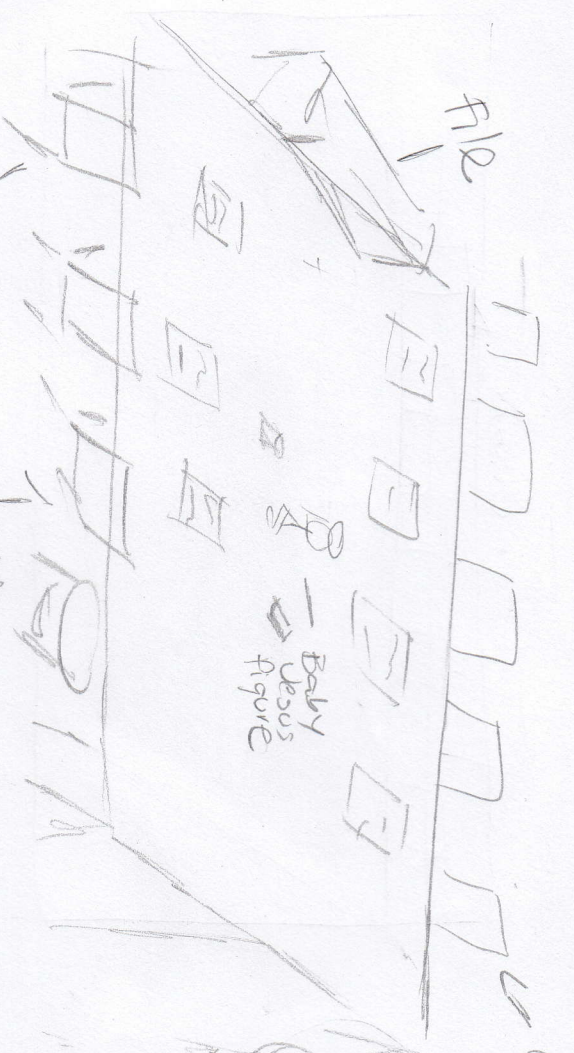
3



4



5



FILE

chairs

staff table

Baby Jesus figure

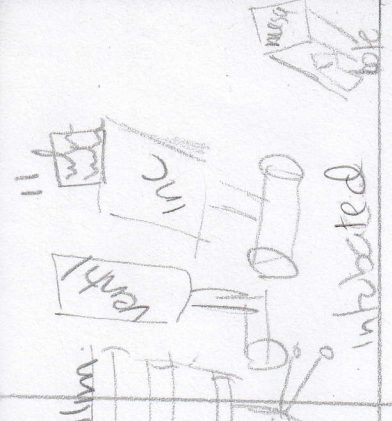
chairs wrap

paper towels

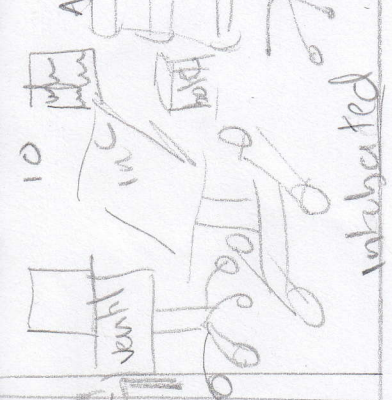
radio

washing area

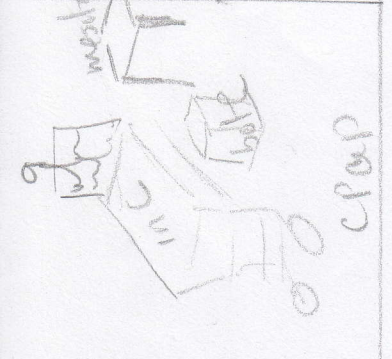
to tap



intubated



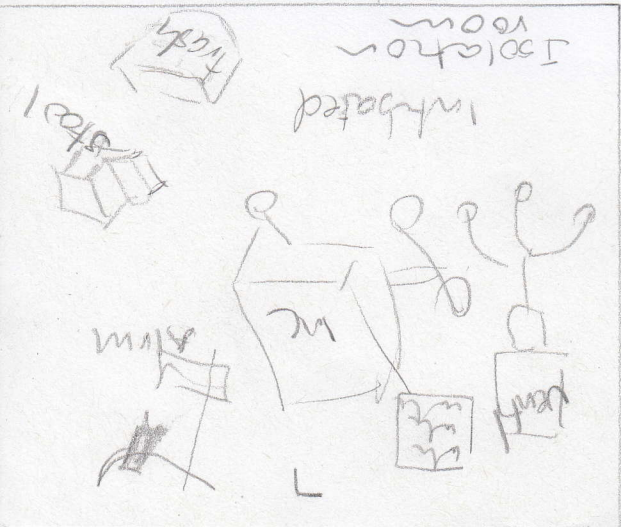
intubated



intubated



intubated



intubated

isolation room

Appendix 14: NICU square footage

