Parents’ Informed and Voluntary Consent to Haematopoietic Stem Cell Transplantation

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Declaration

‘I, Mary Bartlett, 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

This sociological study offers new insights on the topic of informed and voluntary consent, and how it is negotiated in haematopoietic stem cell transplantations. The study explores the experiences of parents of children under the age of 18 years old who received stem cell and/or bone marrow treatments on Blood and Marrow Transplant (BMT) units within the United Kingdom. The goal of this study is to contribute to the ways clinicians can support families to become involved in the treatment decision-making processes for major medical treatments, whilst ensuring that parents' consent to treatments on paediatric wards is informed and voluntary.

Previous research focused on family medical experiences has found that communication throughout a child's illness changes over time within the physician-family relationship. Clinicians have also reported that they are seeing a shift in decision making authority within paediatrics, where the parents are gaining more authority within the shared decision-making relationship. This study builds on this by drawing on Bourdieu's theoretical framework of the habitus, field and capital, to show that the notion of habitus provides a way of tracking changes in the relative power of medical practitioners and parents. Thus exploring communication becomes a key factor in showing how the dispositions of parents change over time to allow for a shift in the decision-making authority.

This study draws on in-depth narrative interviews with parents about their experiences of the BMT consent process and the ways in which decisions for children's (patients and donors) treatments are negotiated. The data shows that consenting in BMTs is an iterative process that goes beyond the 'event' of signing a consent form. As a result, this study provides a framework based on illness narratives that can be used to assess and support family participation in the BMT consent process. The study also proposes a potential assessment tool, yet to be developed, aimed at clinicians, for supporting families through consent processes.

Impact Statement

This research into the bone marrow and stem cell transplant consent process explores the ways in which parents engage with medical practitioners in the decision-making process. It is intended to support further research which focuses on medical decision-making processes, particularly from the child's perspective in major medical treatments. Currently other research explores heart surgery as a major medical treatment that children go through. This research explores another major treatment area, bone marrow and stem cell transplants. These transplants are considered as major because they are often viewed as the last resort for keeping children alive, especially when other treatments have failed. They also require other major procedures to be undertaken before the transplanting of bone marrow or stem cells can take place. Moreover, bone marrow transplants are also considered as major medical treatments because they can often require donations from healthy siblings, which raises further ethical questions around consent when the sibling donors are minors.

Therefore, this research highlights the challenges facing parents and children, which need to be considered when exploring legal issues about children's rights to consent to medical treatments. This research should support the debates around minor and major medical treatments; and who has the right to accept or refuse treatments, especially when the treatments are as complex as stem cell and bone marrow transplants.

In addition to supporting clinical, legal and research methodology debates, this research is intended as a resource for policy makers to use when making decisions from the results of the debates in the aforementioned fields. This research currently suggests for a change in hospital policies and consent processes for major medical treatment, and it offers further recommendations to help multidisciplinary teams add to this current contribution.

Contents

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Abbreviations

ALL: Acute Lymphoblastic Leukaemia

AML: Acute Myeloid Leukaemia

ATG: Anti-rejection medication

BMT: Bone Marrow Transplant

CNS: Clinical Nurse Specialist

CRS: Consent Ranking Scale

GvHD: Graft versus Host Disease

HLA: Human Leukocyte Antigen

HSCT: Haematopoietic Stem Cell Transplant

TIA: Transient ischaemic attack (mini stroke)

MDS: Myelodysplastic syndromes

NG tube: Nasal Gastric tube

PCA: patient-controlled anaesthesia

SCD: Sickle Cell disease

Preface

My BMT unit experience

Children often die during the BMT transplant process, and this was highlighted to me when I met a group of clinical psychologists who worked in a children's hospital. I was looking for a research site and a team of clinicians who could supervise me on a BMT unit during the data collection phase of the project. The team of psychologists I had a meeting with revealed to me that a high number of children die during the transplant process, either through the disease returning after a transplant, drug toxicity during the transplant or from other secondary causes. They were also concerned that I had decided to take on such a sensitive piece of research, because from their perspectives they felt that few people would want to talk about their experiences of consenting for a bone marrow transplant for their children.

While considering death as the possible end result from transplants, it is also essential to mention that the transplant process can often be traumatic for families. During the early planning stages of this research, it was very clear to see that parents and their children suffer a great deal of psychological distress from the effects of both the illness and the possible treatments.

Although I was a participant observer in many situations where families were visibly distressed, I am bound by confidentiality, legal and ethical obligations; and this limits the information that I can report here to corroborate what I saw. I cannot report specific details in this thesis, and I can only make general observations and comments. But it is important to make these observations as they may assist future researchers in their studies.

Firstly, I saw distress from parents during the BMT consent consultations. Fathers and mothers were reduced to tears by the prospect of a transplant. I saw a range of psychological distress factors that went beyond the possible death of a child. Would a successful treatment allow the child to eventually lead a normal adult life? I heard of children's fears of becoming donors and their subsequent behaviour that showed signs of psychological trauma.

Moreover, I heard from parents who participated in the interviews not only of their trauma but of the trauma experienced by other parents. But the most traumatic experience I came across in this study was the death of a child.

The BMT unit is packed full of emotions, even the doctors cry. I myself was not immune to the distress of the BMT unit. I cried many times after attending the BMT consent consultations. The emotional toll was ever present, and I was just an observer! I held back tears to maintain a level of professionalism as the parents often assumed that I was a member of the clinical team. And I cried the most, on the long drive home, after an interview with a bereaved parent. I later saw a picture of her son, James. He was in hospital and there was another image of him before he became very ill. I had not seen a picture of him on the day of the interview with his mum. I had been so immersed in the conversation that I forgot to ask. Maybe I was being too polite, avoiding the possibility of causing her more distress.

Chapter 1: Introduction

> What are the major issues for publics and the key troubles of private individuals in our time? To formulate issues and troubles, we must ask what values are cherished yet threatened, and what values are cherished and supported, by the characterizing trends of our period. In the case both of threat and of support we must ask what salient contradictions of structure may be involved.
> (Mills, 1959, p.11)

The Thesis

This thesis explores parents' experiences of making decisions and negotiating consent for their children in bone marrow transplants (BMTs) and stem cell transplants, collectively known under the umbrella term of haematopoietic stem cell transplantation (HSCT). It advocates for further research to be conducted into how treatment decisions can be shared by families during the transplant process on paediatric BMT units. This thesis also recommends a new assessment tool which came out of the study's findings, to be used during illness and treatment for the purposes of supporting shared decision making in BMTs. This recommended tool is intended to provide support to parents in welcoming their children into the consent process with the guidance of the hospital clinical teams. For clarity, BMTs will be the dominant term used throughout the thesis, but where necessary HSCT will be used depending on the type of transplant or infusion being discussed.

Over the course of the thesis I will address the following four research questions:

1. What are parents' experiences of the HSCT/BMT consent process for their children?
2. How informed and voluntary were their decisions for HSCT/BMT treatments?
3. How can parents support their children in sharing decisions about bone marrow and stem cell treatments?
4. How can the HSCT/BMT consent process be modified to support parents in shared decision-making?

The rationale and justification for these questions will be addressed throughout the following chapters, starting with how I began my journey into exploring the world of bone marrow transplants.

The Journey into BMTs

My research journey into bone marrow transplants happened incidentally as I was starting to explore doctoral study in the final term of my master's research at Goldsmiths, University of London. I was initially in talks with another university to develop my masters dissertation which at the time focused on the intersections of race, class, and gender within ballet and how the varied pedagogical approaches have an impact on national and international elite ballet dancers. However, as I had conducted previous research on health outcomes for children I applied to the advert for this studentship. Thus I was employed to conduct this project as part of a joint effort to increase research collaboration between University College London's Social Research Unit and Birkbeck university's Philosophy department, under a Bloomsbury Colleges studentship. The aim was to add to a wider portfolio of studies at UCL's Social Research Unit which explored consent and shared decision making in healthcare. The studies that I was adding to were heart surgery (Alderson et al., 2022; Alderson 1990 & 1993), neonatal care (Mendizabal-Espinosa, R.M. (2017), diabetes (Alderson, Sutcliffe, and Curtis, 2006), and mental health, which all encompass broader views from children, young people, parents, and professionals on the topic of medical consent.

As a social researcher I knew from experience in conducting primary research how difficult it can be when it comes to securing research sites and finding potential participants for studies. So I started the scoping process as soon I was awarded a place at University College London to undertake this doctoral study on consent to major medical treatment. In relation to the topic of parents, children and informed consent to major medical treatment, I slowly started to explore what treatments could be considered major for children and I followed some initial leads into a blood disorder known as sickle cell anaemia (SCD) (Khemani *et al.*, 2017).

The initial intentions for this Bloomsbury funded study protocol were to explore how children with SCD make decisions to have their spleens removed, have BMTs and other types of surgery that they may require for the management and treatment of their illness. Brierley and Larcher's 2016 paper informed this protocol as they argued that there are confusions when it comes to how children consent to medical treatments. They also argued about the difficulties that clinicians face when it comes to making decisions to override the decisions of teenagers (Brierley and Larcher, 2016). Therefore in proposing a medical speciality, I began with SCD.

There are around 15,000 people in the UK with sickle cell disease (Sickle Cell Society, 2021). However, after meeting and talking to a specialist SCD consultant at Kings College Hospital, London, I found out that there was a lack of children having their spleens removed on a non-emergency basis, and a lack of children having BMTs for SCD disease in the UK. I had previously conducted research into the differences of the lived experiences between children with SCD in the UK and USA, in the sociology department at Goldsmiths, and I was quite familiar with the treatments available. But that was a second-year undergraduate qualitative study which combined ethnography with semi-structured interviews (my unpublished undergraduate project). The results from that study showed major differences in the children’s experiences based upon the healthcare systems in both countries. And I thoroughly enjoyed that project as it gave me an insight into how healthcare can be experienced differently by those with the same illness, so I was ready to revisit this particular hemoglobinopathy. On my journey of trying to find a research site which focused on SCD, I was told about a few BMT units in London and their work for non SCD related illnesses, which would open the study up to a wider range of illnesses.

Therefore, I contacted one of the suggested BMT units in the summer of 2017 and secured a meeting with the director of their children’s BMT unit which is situated in England. After we met and discussed the research project at length, under the unit director’s instructions, the unit’s team started to prepare for my arrival as an observer. And through the provision of an NHS non-medical honorary observer contract, I was granted observer access into the world of stem cell and bone marrow transplants. The director of the unit stressed the high importance of me knowing exactly how the BMT unit functioned on a day-to-day basis so that the study could be informed by my experience on a unit. Thus the goal of the observer contract was for me to first see and understand how a BMT unit worked for three months, before starting my research into the consenting process for parents, which would lead into further research with children as participants. However, as I was following some families through the entire consent process (see figure 1), my observer contract was extended, and I spent six months on the unit in total, making on average 2-3 visits a week, with the pre-outpatient clinic meeting being the most important and informative session of the week. In my search for a starting point to the topic of consent in major medical treatment, I ultimately ended up with the most major and complicated treatment children could possibly consent to if given the option (Ladd, 2018). So if the decisions are considered major for children, I first wanted to see how parents experience making these decisions so that further research could involve the children themselves.

I found that BMT units are very complicated and challenging places to work on, and they are also very challenging when it comes to the social science researcher trying to situate themselves within the space of the unit, because of the extremely varied day-to-day situations that the families and doctors find themselves in (Oppenheim *et al.*, 2002; Packman *et al.*, 2010) . Needless to say, I was delighted to have the opportunity to explore this particular field of medicine, especially as an outsider looking in with the beneficial provision of the NHS observer contract. I quickly realised during my days on the unit that BMT units can become overwhelming for staff and patients as well as observers. In order to get a grasp of the medical procedure and explore the dimensions and different factors, such as family dynamics, histories of illness/type of illness and treatment options involved in the choices that parents make towards their children's treatments. I argue that it is important to situate all these factors within both medical and sociological works alongside my own observer's insight. Although I would like to note that my personal insights into

BMTs will not form any part of the data or analysis in this thesis. The parents' experiences are the central focus of this thesis.

Bone Marrow and Stem Cell Transplants

A bone marrow transplant (BMT), often referred to as haematopoietic stem cell transplantation (HSCT) in literature and practice (hospital units), is a procedure where a person's blood producing cells are replaced with their own cells (autologous transplant) or with those from a donor (allogeneic transplant), (Roberts and Hann, 2020; Bauk MSN *et al.*, 2013) following an often major illness. At times people refer to HSCT as a stem cell or bone marrow transplant/BMT depending on the types of blood products that are being transfused, and often these treatments are administered on a bone marrow transplant unit, so patients and healthcare professionals call these BMT units. Over a decade ago, haemopoietic stem cell transplantation (HSCT) or bone marrow transplant (BMT) was "the only curative therapy for a range of inherited and acquired disorders of the bone marrow and immune systems in children, including high-risk haematological malignancies, bone marrow failure syndromes, metabolic disorders and primary immunodeficiencies. The preferred human leucocyte antigen (HLA)-matched sibling donor is available for around only 25% of such children" (Hough, Cooper and Veys, 2009, p.593). For most, having a bone marrow transplant may also involve transfusions of other vital cells such as cord blood or peripheral blood; and in other cases, cells involved in clinical trials such as CAR T cells (Sheykhhasan and Manoochehri, 2022, Qasim *et al.*, 2017) which have been enabled by new methods of gene therapy.

The HSCT procedure can be a lengthy one, as patients go through multiple medical processes, such as conditioning and preparing the body for the transfusions, and then the transfusions of the cells, right through to recovery. The patients a stay in hospital for long periods of time and spend the minimum of a few months in isolation because their bodies are more prone to infections and side effects once treatment has started (Biagioli *et al.*, 2016). The other transfusions mentioned above explain why bone marrow transplants also come under the term haemopoietic stem cell transplantation. But the term one chooses to use is often based upon individual treatments, though in general I can only assume that 'BMT' is the general consensus. At this early stage I can assure the reader that both terms HSCT and BMT involve the same medical procedure but with varying cells in the intravenous line.

One of the main side effects that can arise from the transplant, which forms an important aspect of the consultation phase of the treatment, is graft versus host disease, also referred to by most as GvHD (Lier *et al.*, 2023). The procedures involved in BMTs and HSCTs, such as chemotherapy and total body irradiation (TBI), cause children to become immunocompromised for a long time, and that is the reason that they have to be isolated. Once they reach day 0 and they receive the new marrow or cells, they are then faced with the complication of graft-versus-host disease (GvHD). It is "the major cause of short-term (day 100) mortality after HSCT (*BMT).* GvHD is caused by several factors that trigger the activation of donor T-cells. The donor T-cells recognize the patient as a foreign body host and therefore attack various organs. The main target organs for acute GvHD are the skin (varying degrees of skin rash), gastrointestinal tract (diarrhoea) and liver (increased liver values, particularly bilirubin). Acute GvHD occurs in 30-50% of all HSCTs, usually within 100 days after the transplantation and is graded from 1 to 4, where 1 is mild and 4 is life-threatening "(Kisch, 2015, p.25).

In addition to the complexity of the treatment, families are often faced with difficult decisions about donor selection, especially when they must consent to healthy HLA matched siblings becoming donors. Again, these complexities make hematopoietic stem cell transplantations a major treatment which deserves further exploration in relation to how parents make decisions for their children to undergo treatments on BMT units (Khemani, et al., 2017; Raj et al., 2018).

Why study consent in Bone Marrow and Stem Cell Transplants?

The research problem for this study originates from what appears to be a paradigm shift over authority and power within medical decision-making (du Pre and Brierley, 2018). The clinicians du Pre and Brierley note that,

> As healthcare decisions become undoubtedly tougher the values and beliefs of the patient are of increasing importance in determining the course of action, not just clinical facts. This has been mandated by the UK courts, who have determined that the welfare of a patient or what is in their best interests – of which more later – cannot be based on medical best interests alone (du Pre and Brierley, 2018, p.17).

This means that decisions made in medical spaces are no longer centred solely on the clinician’s overall judgement. Medical sociologists have explored the type of paradigm shift that du Pre and Brierley mention, where medical decisions were based on a patient’s judgement before moving to clinician focused judgements. However, their studies examined the changes in knowledge production within the field of medicine rather than the shift of power within complex decision-making. This latter topic is studied in the historical research conducted by sociologist Nicholas Jewson (1976), who took inspiration from the work of historian Erwin Ackerknecht (1955/2016). They both studied how, through the course of medical advancements, knowledge of illness shifted. A person-centred approach, where the patient held the knowledge of their ailments and it was the doctors who sought to understand illness directly from how a patient was feeling, gave way to an approach where the patient’s narrative was no longer of relevance for the doctor to carry out their job. Of course, their analysis of the patient and patient-doctor relationship was quite a deterministic way of looking at this major shift within knowledge production in medicine. It separated, and almost ruled out the possibility that doctor and patients might work together in sharing medical decisions through the course of illness. Nevertheless, the concepts these authors used allowed readers to see how there was a shift within the modes of knowledge production in medical spaces (Jewson (1976)

Similarly in relation to my research problem, there has been a shift from a paternalistic model (Snelling, 2016) of consent to an individualised person-centred model, as du Pre and Brierley continue to argue in their paper:

> "the overdue end of paternalism noted earlier has occurred throughout healthcare and has been associated with the loss of physician/healthcare-team autonomy, with a paradigm of shared decision making now dominant" (du Pre and Brierley, 2018, p.18).

Aubugeau-Williams and Brierley (2020) also relate this shift to cases within the UK courts, the most cited cases being, Montgomery v Lanarkshire Health Board 2015, and Rogers v Whitaker 1993 and Sidaway v Bethlem 1985. It appears that within the medical realm there is an increasing shift as to whose voices hold weight within the medical conversation. This shift has not gone unnoticed by other clinicians (Brierley and Larcher, 2016) or other common law jurisdictions (Wik, 2014), arguably because it is a cause of conflict within medical spaces (Wilkinson and Savulescu, 2019). When considering this shift to more negotiated forms of medical decision-making or shared decision-making, I want to see how this happens in the context of BMTs by asking how informed the parents are, and how voluntarily they give or withdraw their consent for their children's treatments on BMT units.

Brierley and Larcher's (2016) paper about adolescent autonomy in medical decision making is one of the catalysts for exploring consent within BMTs, and again, the foundation of the original Bloomsbury proposal for this study. Brierley and Larcher (2016) explore the legal conditions that, on the one hand allow young people to make decisions about their medical care, but on the other hand can also override these decisions if they do not align with what is believed to be in the 'best interests' of the young person. It is evident that clinicians sometimes seek more guidance about when they can override the choices of young people. "As healthcare practitioners, we do need clarity over the circumstances in which society expects that autonomous choices of adolescents can be overridden" (Brierley and Larcher, 2016, p.484).

Similarly du Pre and Brierley (2018) continue to discuss the clinical challenges that clinicians face when considering who is best suited to decide for children. These arguments are again presented against the backdrop of the legal system which formulates the problem in terms of the ‘best interests’ of the children (Birchley, 2021), and they explore how the ‘best interests’ idea of medical decision-making impacts everyone involved in the decision-making process. It is not clear from these studies whether clinicians want the parents to be the main decision makers or not. But what is clear is that legal cases of disputes and disagreements are causing harm to family relationships through media portrayals of conflict around consent. Again, this is quite interesting, and the most recent case in public memory is that of Charlie Gard (Wilkinson and Savulescu, 2019). However, in the case of bone marrow transplants, the consent process has been shown in a little more detail in the case of Jaymee Bowen, otherwise known as Child B (Ham, 1999a; Ham, 1999b).

I say more in the thesis about how Child B’s case also fits into a discussion about multiple transplants, but Jaymee Bowen’s case is arguably a very good example that shows how consent in bone marrow transplants does not rest on the decisions of a doctor or parent alone. It also shows how the child’s best interests are protected by more than one institution. But in this thesis, I focus on the institution of the family. The Jaymee Bowen and Charlie Gard cases show that legal institutions can step in when things go wrong and override all other decisions (Wilkinson and Savulescu, 2019). But I also want to consider how family decisions are made, and more specifically how parents make decisions when they are faced with limited choices when it comes to bone marrow and stem cell transplants. These are my central questions.

Thus my research problem centres on two main types of conflict concerning consent within the changing environment of medical decision making. The first is consenting to have a transplant, and the second is consenting to end treatment. I ask how parents’ consent may become problematic at these two polar ends of the consent process (Ham 1999a; Wilkinson and Savulescu, 2018). These issues are often the reason why the courts become involved in dispute resolutions.

There are also other factors that make the process of consenting to haemopoietic stem cell transplantations particularly interesting to study. First, the legal disputes to which they sometimes give rise can be made more intense by the fact that transplants can be funded either by the state (NHS) or independently. This creates scope for disagreements about treatment, as can be seen in the case of child B (McIver and Ham, 2000). In some cases, families have crowd funded for their children, presumably due to the cost of multiple transplants or disputes about treatment options within their medical teams. By contrast, other treatments such as heart transplants or novel clinal trials, such as nucleoside therapy in Charlie Gard's case, cannot be crowd funded, and parents rarely have the option to move their ill children from one medical team to another without some form of legal battle (Wilkinson and Savulescu, 2018). The various ways in which haemopoietic stem cell transplantations can be funded therefore raises distinctive problems around the issue of consent. This thesis aims to follow the line of communication for eliciting consent for bone marrow transplants, in order to understand parental medical decision making within this particular field of medicine.

A second distinctive feature of haemopoietic stem cell transplantation that makes it particularly interesting to study is that, unlike other medical interventions on which research has been done (Alderson 1990, 1993), they are not surgical treatments. Haematopoietic stem cell transplantation (HSCT) or bone marrow transplant (BMT) is a transfusion-based treatment and differs from conventional surgical treatment in a number of significant ways. Conventional non-donor surgical treatments usually involve a patient and their medical team, whereas in BMTs there is a patient and a donor (who may sometimes be abroad). For some families the donor is a sibling (HLA matched) (see HTA 2021) or another family member. Where this family member is a parent, the donor is called a haploidentical match (Veys, Amrolia and Rao, 2003). This dimension makes BMTs a particularly complex and interesting treatment to explore in relation to the consent process, partly because some families consider the treatment a last resort (D'Souza, Pasquini and Spellecy, 2015), and partly because, depending on the donor, the whole process can be an immersive family experience (West et al., 2020).

Society’s understanding of HSCT/BMT has also been stimulated and in some ways confused by popular novels such as Jodi Picoult’s ‘My Sister’s Keeper’ and Ian McEwan’s ‘The Children Act’. These fictions raise a number of questions: concerning the extent to which families participate in decisions regarding children’s medical care, and how far their decisions are accepted by those involved in the decision-making process. The authors bring to life the idea of consent to blood transfusions and bone marrow transplants, and their works form part of the media portrayals of these processes identified by du Pre and Brierley (2018). These fictions are undoubtedly valuable. They offer vivid accounts of what it is like for families to go through the processes of consent, illustrating the complexities of the process and the many characters involved in decision-making. However, while their narratives are not completely unlike the findings discussed here, this thesis offers a more systematic account of the same issues. By studying them in an academic vein, it aims to view them from a social scientific perspective.

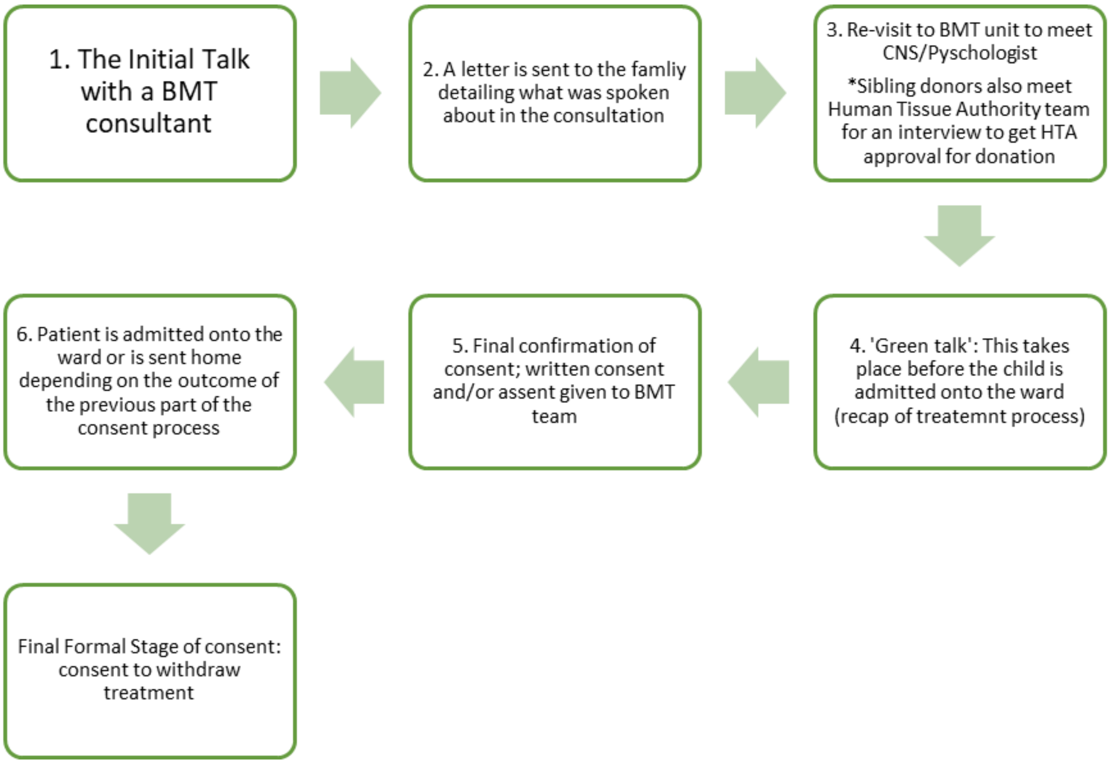
Contextualising the Study

This sociological research study therefore offers an in-depth exploration of the (BMT/HSCT) consent process, including the two distinctive features mentioned above, from the perspective of parents. It highlights the ways in which decisions for children’s (patients and donors) treatments are negotiated by those involved in their care. By initially giving a voice to the parents before expanding the study further to healthcare professionals and children, this research suggests a novel strategy for improving the ways families are involved in the consent processes for major treatment decisions. On the strength of its investigation of the parents’ experiences of the medical treatments that their children undergo for malignant or non-malignant illnesses before they reach a BMT unit, and the decisions they make about whether to approve a stem cell or bone marrow transplant, this research is able to recommend some changes to the BMT consent process. To support these recommendations, the thesis sets out the basis of a consent assessment tool, which I propose from an informed analysis of the data. This sample tool is aimed at supporting parents when it comes to sharing decisions and entering the formal consenting process with their families (see figure 1 of the observed BMT consent process). Once developed further by other specialists, it is intended to be used by clinicians to consult with parents, so that all parties can sensitively manage and make decisions during the transplant process.

Again this is why I believe that it is important to understand the parents' experiences of BMT/HSCT consent, so that an idea of where children are positioned within medical decision making can work as a guide for putting the clinically perceived SDM paradigm shift into context. Thus, it is useful for primary research to be conducted into the current experiences of parents in regard to major medical decision making, especially within the BMT/HSCT consent process. Understanding the decision-making process may fill in the gaps as to how the decision-making priorities are shifting away from clinicians, as previously mentioned (du Pre and Brierley, 2018).

This research is of course indebted to previous studies, which have explored parents', patients' and donors' experiences of giving consent to bone marrow transplants. None of them, however, have focused on the questions and the research problem considered in this thesis. Some have focused on the information that patients recall being given in consent consultations (Lesko *et al.*, 1989), clinicians' perceptions of their patients (Patenaude, Rappeport and Smith, 1986), or donors experiences of bone marrow transplants (Kisch *et al.*, 2015). Some have used philosophically based approaches to discussing the ethics of sibling donor consent (Wik, 2014; Lyons, 2011a; Pereira *et al.*, 2017, Bendorf and Kerridge, 2011)). Other authors have produced quantitative studies, mainly using quantitative methods for data collection (Jacoby *et al.*, 1999; Miller *et al.*, 2011; Raj *et al.*, 2017). This study fills in some of the gaps not covered by previous studies of the same field of medicine, by focusing on the parents' experiences of the consent process through their stories of consenting to treatments on BMT units throughout the entire course of their children's treatments. It uses a mixed method research approach to explore the entire BMT consent process from the beginning of treatment right up until the patient is discharged from the BMT unit. Figure 1 below shows the different stages of the process for seeking consent from parents. The flowchart was constructed during the initial scoping exercise of a BMT unit.

Figure 1: Flow diagram of the consent process and the ideal methods to be employed at each stage of research



The social scientific, mainly abductive strategy (Blaikie and Priest, 2019) for conducting this study stems from the many perspectives within the topic of informed consent (Beauchamp and Childress, 1994; Gillick v West Norfolk and Wisbech HA 1985; Mason and Laurie 2023), especially in relation to children. And this is where I propose that an understanding of what informed consent means in paediatric stem cell and bone marrow transplants is needed, through a sociological analysis into parents' experiences about the consent that they give for their children on BMT units (Lyons, 2011b).

Thesis Overview

With the existing literature in mind, this thesis aims to address the four questions listed at the beginning, using a combination of in-depth interviews and an online survey. To repeat, the four questions are:

1. What are parents' experiences of the HSCT/BMT consent process for their children?
2. How informed and voluntary were their decisions for HSCT/BMT treatments?
3. How can parents support their children in sharing decisions about bone marrow and stem cell treatments?
4. How can the HSCT/BMT consent process be modified to support parents in shared decision-making?

Since this is a sociological study of a diverse population, a combination of social scientific methods is most appropriate. The social sciences, as opposed to the natural sciences, allow for more subjectivity within the tasks of researching and analysing the social world, and as mentioned above, the world of BMT units can be extraordinarily complex.

By using a mixed method approach to data collection and analysis (Creswell, 2014; Bazeley, 2018), the research considers the varying social contexts in which medical encounters occur (Silverman, 1987). Through the use of an online survey, in-depth semi structured interviews and reflections on previous observations of a BMT unit (throughout the research process), the different dimensions of the consent process are disentangled, to understand how parents experience the treatment decision making process for their children on BMT units.

The other benefit of using mixed methods for this study was that they made it possible for families to participate in relatively loosely structured ways, enabling them to contribute to the study as naturally and as freely as their medical circumstances allowed. In a way, qualitative methods can be seen as a more family friendly choice, and, by contrast with the tightly structured methods used by positivist methodologies (Silverman, 2022; Alderson and

Morrow, 2011), this reflexive approach enables researchers to pay due diligence to the individual differences of each participant.

The interpretivist methodological approach which is dominant throughout this thesis also allows the themes and ideas within the work to stand out. The idea of informed and voluntary consent has multiple meanings, and throughout this thesis I guide readers deeper into the world of transplants, and the role of stakeholders within the consenting process.

Introducing the Process of Consent

In explaining the methods I have used, I shall start with a clinical definition of informed consent.

> Informed consent is the communication between the physician and patient that leads to the patient agreeing to undergo a medical intervention. A valid informed consent involves a patient with sound decision-making capacity, an intentional decision by the patient with understanding free from undue influence by the medical staff and an ability to communicate the acceptance of treatment to the treating physician. The ideal informed consent thus requires that the patient appreciates his clinical situation, understands the consequences of the proposed treatment and alternative therapy options, appreciates the specific implications of this information into his future and integrates this information into his decision. (D'Souza, Pasquini and Spellecy, 2015, pp.2-3).

This is the main definition of consent on which I shall rely, as it comes from a study which theoretically discussed the consent process for adults receiving HSCT transplants from an oncology perspective (D'Souza, Pasquini and Spellecy, 2015). Thus it is a useful definition for my exploration of informed consent from a parental stance. In this study the patient is a child and does not do the consenting, rather, the parents consent on the child's behalf. This immediately raises the question of whether the conditions specified in the definition (decision-making capacity etc.) apply to the parents. This standard definition of consent may not fit the parents' experiences in this study, and that is one reason why the analysis of consent needs to be refined in BMTs.

With this main definition of consent in mind, the results section will delve a little deeper into what consent looks like, on the basis of the data collected from the parents. Briefly, I found that everyone involved in the treatment process, and not just the consenting process, had some limitations when it came to decision making. The idea of informed consent was certainly not how I imagined it to be, and everyone in the BMT context grapples with the idea quite differently. Choice does not mean choice when it comes to BMTs (Schaefer et al., 2022; Benedict, Simpson and Fernandez, 2007). What will be seen is that the spaces of BMT clinics and wards bring to life a whole new meaning to what it means to give informed and voluntary medical consent.

The parents in this study expressed how they felt that their children just wanted to feel better and be comfortable in the treatment process, whether it is via a bone marrow transplant or a stem cell transplant. The parents become enlightened throughout the treatment process and eventually move from the narrative of a cure to the desire for a better quality of life for their children. The results also imply that the doctors have the job of saving the lives of their patients subject to a myriad of restrictions; some deriving from the prognosis of individual cases and some from the institutional demands of the hospital (McIver and Ham, 2000; Linney *et al.*, 2019). The nurses and the other healthcare professionals continue to do their jobs around these complications of illness, as the parents' testimonies suggest. And as for social scientists- they are just in the way, as I discovered whilst scoping the BMT unit! The best they can do is recognise that everyone in this situation is limited in their knowledge when it comes to the BMT process. I wanted to understand what it was like for the parents concerned, without causing any harm to the process of consent. I wanted to know what they thought beyond just consenting to a treatment protocol. I wanted to know what it was like to make informed decisions when chemotherapy was one of the unavoidable toxins involved (van der Plas *et al.*, 2017). What was it like for parents to make decisions on units where most of the children died?

The challenge of writing a thesis like this one is that there are many factors involved within the whole idea of asking parents to consent to complicated procedures, which I and my readers have to be considerate of. Ideally, a study should aim to take into consideration the trajectory and lifeline of illness, and how the experiences of illness can be difficult for all those involved (Frank, 1995). It is difficult for parents because they must adjust their lives when a child is ill. As well as that, they must also come to terms with the possibility of their child dying. Family structures are tested in these situations, where a family is faced with an ill child and then has to re-shuffle the whole family dynamic around the hospital setting (Beckmann et al., 2021; West et al., 2020).

For the child patient, there is a whole new angle to illness, and only they can give a subjective and meaningful account for their experiences of illness. Their parents can see their longing for the feeling of being content, not only in their bodies but also in their surroundings. And the parents are often seen as the ones who can facilitate and support them in making their views heard.

Siblings also play a role in the illness journey, especially when they are identified as donors for the transplant (D ’auria *et al.*, 2015). They bring their own intentions to the imagined ideals of informed consent and initiate a further process of consent in which parents play a major role. Thus, consent is a multifaceted process, to which many individuals contribute their own points of view. I aim to guide the reader through this web as clearly as possible, and I hope I can shine a little light into the world of haematopoietic stem cell transplantation and parents’ experiences of consenting to the treatments involved.

My findings have a number of potential audiences. They may be useful to social scientists who are either interested in the topic of BMTs or want to explore research methods for healthcare research. They can assist doctors aiming to improve the consultation experiences of patients and families. They may also be valuable to ethicists discussing paediatric shared decision making, and professionals working in social services whose service users are going through major treatments. The findings may also be a valuable resource for parents with an interest in the BMT process. But most importantly, I hope that it will be an enlightening resource for those who went through a BMT unit as children and may wish to understand a little more about the consenting process.

Summary of thesis layout

This thesis is structured into eight chapters, each focusing on one aspect of the research process. Chapter two is a review of the literature which introduces the theorists that I have chosen as the foundations of my explorations into narratives of consent on BMT units. This chapter also explores what is currently relevant to the topic of informed consent in BMTs and it identifies the gaps which need more work to support families and clinicians with making decisions about major medical treatments. Chapter three focuses on the methodology and logic behind the chosen research strategy. It also offers a rationale for the methods employed throughout the data collection phase and gives an account of how the methods developed, how the data was collected, and the analytic approach to the analysis. This chapter also offers reflections on these methods. Additionally, it includes an in-depth description of the participants of the study and the themes that came out of the analysis. The following three chapters are centred on the analysis of the data. In chapter four I begin to unpack the BMT consent process as an event where the consent form is signed, and this begins with the ‘initial consultation’ where families are told what to expect during the treatment process. I also touch on the expectations of the parents and what they thought about the information that was given to them before their children’s transplants and the realities of that information. In chapter five I continue to show that consenting continues throughout BMT treatments, after the event of signing the initial transplant consent form. I show that consent in BMTs is an iterative process that stops once the treatment process is complete. I also explore how parents become familiar with the BMT unit and start to adjust their identities according to their experiences of the unit. Finally, I finish the analysis with chapter six, where I explore how parents interact with their children and make decisions for them on the BMT unit. I also justify my reasons for using parents as witnesses of illness, and how their experiences can support further study on topic of the thesis. Chapter seven then continues with a discussion of the narratives that are presented in the previous analysis chapters and explores their significance to the aims of the study. Moving on from that, Chapter eight is divided into two parts. The first half includes some limitations of the study design and process, and it offers recommendations for further study into the topic of this thesis. The second half of the chapter provides a summary of the study's findings and their potential for clinical impact, concluding with my final remarks.

Chapter 2: Literature Review

> I see a footnote and before I read it, I guess what book or article will be cited. I am usually wrong, at least about what the author cites. I am correct in that what I guessed makes the same argument and could have been cited, but the author has learned the same thing from a book or article I have not read. But then I seem to have read something that the author has not. The point of the footnote game is not only to prove that no one has read everything; it is to demonstrate that no one needs to read everything (Frank, 2010, p.17)

Literature Review Strategy

I started conducting a review of the literature during the first year of my PhD studies so that I could find a suitable project. I continued to review the literature in depth, right up to the start of the data collection phase. This was to ensure that I had covered all the angles of my research aims. I also returned to the literature during my analysis of my findings and used it to guide my discussion of them. I relied a great deal on literature that was linked to suitable research methods for the study, and my search strategy was informed by discussions with my supervisory team, sociologists and other experts in the medical field. I also wanted to make sure that the theoretical framework I relied upon could be applied in practice, and much of the chosen texts linked theory with practice. The key texts that I chose will be discussed further, but my initial strategy was to find literature on the topic of consent, informed consent, major medical treatment, haemopoietic stem cell transplantation, family experiences, family structures, parents' consent. These were the key words that I started with, and I used a number of databases such as PubMed, Cochrane Library and SCOPUS, alongside Google scholar and books from my university's library collection. Moreover during my survey of the literature I sought and selected literature that was in 'conversation' with my research questions (Branley, Seale, Zacharias, 2018).

During the entire project I used Mendeley, a reference managing tool to store the literature that I found, and I organised selected texts into themed files (BMT, Consent, Shared decision making, Ethics, Legal, Agency, Social Research Methods & Analysis). From there I started to filter through the materials to select literature that was driven by my research questions, and literature that was ideal and relevant for the data collection phase. I returned to literature that I stored in Mendeley and continued to add to it throughout the entire research process and during the write up of this thesis.

Introduction

The literature reviewed in this chapter has been selected for its relevance to the four research questions introduced in Chapter 1. As will become evident, the bodies of work that I outline here bear on the central themes of my study, the methodology of the thesis as a whole, and the methods of data collection and analysis on which I rely. Because my use of the existing literature is tailored to my specific research problem, there is some work that might be thought relevant, but which I do not discuss or touch on in great detail. For example, my study of the consent process focuses on parents whose children are under the age of 18. It is also important to stress that my study focuses on families. I have been guided by the literature on family formations and structures.

My survey of the literature falls into two main parts. In the first, I consider a sequence of theoretical outlooks and show how they can provide tools for my own research. I start with the sociologist Pierre Bourdieu, whose social analyses provide the overarching framework for my project. Bourdieu’s ideas are in turn taken up by Arthur Frank, in his account of how the concept of the patient has evolved within medical and sociological inquiry. But most importantly, I use Frank’s account of how stories of illness can be of assistance in trying to understand the experiences of those within what he calls ‘the remission society. At each stage, I show how these, theoretical approaches can support my research aims.

In the second part of the survey I explore the literature on communication and consent, and on shared decision making in medicine. My aim in this part of the discussion is to provide a theoretical context for my analysis of the extent to which consent on BMT units is informed and voluntary, and what the BMT consenting process looks like from the perspectives of parents.

Bourdieu's Theoretical Framework

There is a great need for a sociological understanding of the medical field in which stem cell and bone marrow transplants, and the donations on which they depend, take place. This area of specialism is unique in using donations from living minors in order to help other minors, especially siblings (HTA, 2021). Thus, informed consent comes both from those suffering from illness and from those who are healthy and do not require treatment, the research participants in this study (parents). Understanding the lived experiences of parents who go through these processes is vital for informing communication within BMT medical spaces. To provide a theoretical framework for such an understanding, I first draw upon the model of society developed by the French sociologist, Pierre Bourdieu. I focus on his notions of the habitus, the field, and his different forms of capital (cultural, social and economic) (Bourdieu, 1979/2010). Bourdieu's sociological work provides a framework that can be built upon, not only for understanding family structures, but also for grasping how these structures shape communication between families and those with institutional authority (medical professionals). For Bourdieu, different behaviours are shared by those who inhabit particular spaces; for example, doctors and nurses occupy the space of a hospital and they behave in certain ways within it. These behaviours in turn form, and are formed by the habitus, a set of implicit norms (LeGrow et al., 2014). This idea of habitus offers a helpful way of thinking about BMTs because of how long families have to spend on BMT units during the transplant process. During this process, identities are bound to be changed and the dispositions of those in the hospital are contingent on the shared space of the BMT unit and/or other units that they are part of. The sharing of a space plays a vital role in one's habitus.

A habitus, as Bourdieu understands it, is

> … a subjective but not individual system of internalized structures, schemes of perception, conception, and action common to all members of the same group or class and constituting the precondition for all objectification and apperception. (Bourdieu, 1977, p. 86)

A group of people who share a habitus therefore share a way of life.

> One of the fundamental effects of the orchestration of habitus is the production of a commonsense world endowed with the objectivity secured by consensus on the meaning (sense) of practices and the world, in other words the harmonization of agents' experiences and the continuous reinforcement that each of them receives from the expression, individual or collective (in festivals, for example), improvised or programmed (commonplaces, sayings), of similar or identical experiences. The homogeneity of habitus is what - within the limits of the group of agents possessing the schemes (of production and interpretation) implied in their production - causes practices and works to be immediately intelligible and foreseeable, and hence taken for granted (Bourdieu, 1977, p.80)

But while the notion of habitus is helpful for distinguishing the structures of meaning that people create, one needs to be careful not to think of these as static. A habitus is always located in, and contributes to, what Bourdieu calls a field, in the sense of a field of forces . As he explains, a field is,

> a structured social space, a field of forces, a force field. It contains people who dominate and people who are dominated. Constant, permanent relationships of inequality operate inside this space, which at the same time becomes a space in which various actors struggle for the transformation or preservation of the field. All the individuals in this universe bring to the competition all the (relative) power at their disposal. It is this power that defines their position in the field and, as a result, their strategies. (Bourdieu, 1998, pp.40–41)

A hospital belongs to a field in which doctors, nurses and so forth possess different kinds and levels of power. And as Grenfell points out, this way of analysing society has implications for the way researchers study social phenomena. As Bourdieu saw it,

> It was necessary to examine the social space in which interactions, transactions and events occurred…an analysis of social space meant not only locating the object of investigation in its specific historical and local/national/international and relational context, but also interrogating the ways in which previous knowledge about the object under investigation had been generated, by whom, and whose interests were served by those knowledge-generation practices (Grenfell, 2008, p.67).

Knowledge can be thought of as being produced within a field, by individuals who have a habitus, which in turn gives them certain interests. Turning now to the subject of this study, Bourdieu provides a helpful framework for analysing the process of BMT transplants and the forms of consent on which it depends. First, the parents on whom I am focusing pass through a medical habitus which possesses its own norms. As they interact with the hospital, and specifically with the BMT unit, they internalise these norms. They come to understand how the hospital works and enter into a new habitus (LeGrow et al., 2014). In addition, as Grenfell highlights, the way they interact with the unit is shaped by the other spaces in which they live, and by their individual family histories.

The parents' understanding of the unit's norms, and their place within it, is not the same as that of their children, though both groups are part of the habitus. The hospital becomes a family's new 'bubble', given that they have to spend long periods of time in it, and they equally but individually work out how to live in this new space whilst they go through the treatment process with the patient. For Bourdieu, the habitus works within a given field and is a determinant of how actors behave in a familiar setting. Only when one does not know the space one enters does it become apparent that one is an outsider.

> When habitus encounters a social world of which it is the product, it is like a 'fish' in water…it takes the world about itself for granted (Bourdieu and Wacquant, 1992, p.127).

To enter a habitus is at the same time to enter a field – a field of powers where what one can do is related to one's structural position. As families learn how a hospital works, they develop different relationships with medical teams and their members and acquire greater or lesser powers to determine what happens to them. For parents, this may affect the way consent is given and understood. Again, this is a further point at which Bourdieu's framework becomes relevant for conceptualising these interactions. Bourdieu noted how the habitus contains groups who may disagree about what is possible or permissible.

> …practices are always liable to incur negative sanctions when the environment with which they are actually confronted is too distant from that to which they are objectively fitted. This is why generation conflicts oppose not age-classes separated by natural properties, but habitus which have been produced by different modes of generation, that is, by conditions of existence which, in imposing different definitions of the impossible, the possible, and the probable, cause one group to experience as natural or reasonable practices or aspirations which another group finds unthinkable or scandalous, and vice versa (Bourdieu, 1977, p.78).

The equivalent of this kind of generational conflict can occur within a medical setting such as a BMT unit. As Bourdieu repeatedly makes clear, the norms that exist within a habitus are largely unconscious. They are only noticed when they cease to hold. This aspect of his view is taken up in David Silverman's longitudinal study on communication within clinics (1987), which illustrates the shifts of power that occur within a habitus. Silverman identifies the way the power dynamics between doctors and families change as families become familiar with the clinic space and gain more knowledge of it. Thus my research concerns the process through which families, and more specifically how parents enter the habitus of the BMT unit and develop relationships with the clinical teams.

Silverman (1987), who used Bourdieu's framework to explore communication in paediatric clinics, also appealed to Bourdieu's notion of cultural capital. He found that power relationships changed as parents began to accumulate this type of capital (Bourdieu, 1984) in the form of medical knowledge. Although the parents in Silverman's study did not have the artefacts of certificates and degrees to show that their medical knowledge and hospital knowledge had advanced during the period of illness, they were able to demonstrate this change in the way they communicated with doctors. To put it in Bourdieu's terms, there are different types of capital at play within society, and these forms of capital can be gained, exchanged, and symbolised (Bourdieu, 1987; Skeggs, 2004; LeGrow et al., 2014). Of his forms of capital, cultural capital is in my view the one most relevant for exploring the interactions on the BMT unit. "Cultural capital can exist in three forms: in an embodied state, i.e. in the form of long-lasting dispositions of the mind and the body; in the objectified state, in the form of cultural goods; and in the institutionalized state, resulting in such things as educational qualifications" (Skeggs, 2004, p.17). Some readers would argue that all forms of capital are relevant, particularly since transplants may either be received on the NHS or paid for privately, and I shall therefore discuss economic capital in later chapters.

These changes in cultural capital are what Bourdieu describes as forms of power at work within a field based on the habitus of the people within it. And this illuminates the complexity of the relationships within medical spaces. Within these spaces, doctors are often perceived as holding more power than others, especially when it comes to decision making (Snelling, 2017). And to examine this assumption, it is vital to map out the BMT illness journey whilst observing the consent process as it unfolds for each family in this study. As noted in the opening chapter, the research issue for this study takes account of the changing power dynamics within medical decision-making, thus clarity on how the illness journey affects the consenting process is important.

By using Bourdieu's concept of habitus as an epistemological tool for exploring the BMT consent process, I can look at how families are involved in the consent process, and what role they play in decision making, depending on their place in the habitus, and the cultural capital they acquire during their medical journeys and experiences of illness. For when people spend lengthy periods of time in new spaces that are initially unfamiliar to them, they may learn how others behave in those spaces and they may also learn the language of those spaces, leading themselves through a process of habituation and comfort. By exploring the meaning of habitus in medical spaces, one can start to see the clinical interactions between medical professionals and families in ways that would not be visible to an outsider. As families acquire a knowledge of the field and the hospital habitus, their relationships with healthcare professionals will become qualitatively different (LeGrow et al., 2014: Silverman, 1987). Their position in the field will alter as they acquire cultural capital. For parents, the hospital habitus has already been described "through their ability to play the valued rules of the game – in the language, non-verbal communication, perceptions, and behaviours they exhibit. This habitus often predisposes parents to behave in ways that they consider most likely to maintain or enhance their roles as parents based on the resources available to them and past experiences in healthcare fields" (LeGrow et al., 2014, p.330)

Dixon-Woods, Williams, Jackson, Akkad, Kenyon and Habiba (2006) conducted a study on women's consent to surgery where they also used Bourdieu's work for their theoretical framework. They considered the field, the habitus, and the individual agents' capital. For example, healthcare professionals were regarded as more authoritative because of their medical knowledge, itself a form of cultural capital. The authors described the role of cultural capital in making decisions and the ways in which this capital had an effect on how women made decisions regarding surgery (Dixon-Woods et al., 2006). The use of Bourdieu's theory of the field and habitus demonstrates that there are structures already set in place as to how individuals of all positions interact within medical settings, whether or not they are consciously aware of this.

This current study adopts the same theoretical framework as Dixon-Woods et al.,(2006) to show how the habitus developed by parents in a hospital interacts and evolves through long term treatment, and the role the habitus plays in the decision-making process. In a way this is an aspect that requires further analysis, given that du Pre and Brierley (2018) neglect to mention that long term stays in hospital may be a contributing factor in the changing dynamics of decision-making authority from a clinical perspective.

My study also contributes to a further issue discussed by Dixon-Woods et al., (2006): the issue of marginalisation. Dixon- Woods et al., studied women, who were once openly marginalised within society (Skeggs, 1997). Some of the parents I discuss are, of course, also women, including mothers who have been identified as having the most involvement in the upbringing of children (Lareau, 2011; Reay, 1998; Mayall, 2002; Nelson, Miles, and Belyea, 1997). It might seem that I should follow Dixon Wood et al., (2006) by also focusing on sex roles. In fact, however, both mothers and fathers are involved in the treatment processes with which I am concerned, and I aim to take both into account (Hochschild, 2012). The views of all those involved in the study are given the same analytical weight in contributing to the understanding of how informed parents are when it comes to consenting to treatments on BMT units for their children.

A further aspect of the consent process with which Bourdieu can help, concerns an unease experienced by some health care professionals. du Pre and Brierley (2018) discuss a type of unease that some professionals feel about sharing the process of decision making with parents. According to du Pre and Brierley, they express concern about the extent to which families gain information from the internet, particularly about new treatment options that are said to reduce mortality rates. In paediatrics, they note, “a third party routinely makes decisions for our patients, their parents!” (du Pre and Brierley, 2018, p.18). Drawing on Bourdieu, one may see this as a reflection of an evolving shift of power within a field, and as Charles Wright Mills (1959) suggests, as an issue that requires the need for further exploration into consent, and most importantly informed and voluntary consent. After all, it can be argued that the voluntary nature of consent from the parents may be a physician’s primary concern, as they are the ones treating the patients. And the general connotations behind the term ‘third party’ as used by du Pre and Brierley implies that parents may not be viewed as equal decision makers within the medical space. To examine these points, one also needs to consider the lived experiences of parents, as I do in this study.

To capture these experiences I take a narrative approach. Medical sociologists Arthur Frank (1995) and Rita Charon (2006) are avid proponents of illness narratives, and they argue for the use of stories within medical settings. They see these stories of illness experiences as ways of engaging with moral and compassionate care within the physician-patient relationship (Frank, 2010; Charon, 2017). This is one of the reasons why their work is useful for guiding the exploration into parents' experiences of their children's illnesses and of consenting to transplants for them. This narrative approach can contribute to the ways in which the BMT consent process can be re-imagined for supporting family-physician communication further.

In his own historical work on illness narratives, Arthur Frank also draws on Bourdieu's theoretical framework, particularly his study of how medicine and medical thinking advanced for one community in North Africa (Bourdieu, 1977). Taking up some of Bourdieu's ideas Frank examines how illness, and the way people think about illness, has changed since the 1950s, and suggests that this change is a part of postmodernism (Frank, 1995). In the postmodern era, he argues, illness becomes a state that he categorises under the term 'remission'. People who are in this state are in the 'remission society' (Frank, 1995). For Frank, this is where stories are more pertinent to forming an understanding of the sick person beyond illness and treatment. He explains that,

> Members of the remission society include those who have had almost any cancer, those living in cardiac recovery programs, diabetics, those whose allergies and environmental sensitivities require dietary and other self-monitoring, those whose prostheses and mechanical body regulators, the chronically ill, the disabled, those "recovering" from abuses and addictions, and for all these people, the families that share the worries and daily triumph of staying well (Frank, 1995,p.8)

The illnesses that come under the treatment list of a BMT unit fit this profile. They often involve a period of remission, especially of malignant illnesses. For example a child might undergo a period of remission from AML (Acute Myelogenous Leukaemia) or ALL (Acute Lymphoblastic Leukaemia). But a child might simultaneously suffer from other severe illnesses such as Severe Combined Immunodeficiency (SCID), Wiskott-Aldrich syndrome (WAS), or bone marrow diseases like severe aplastic anaemia or Fanconi anaemia (Dietz *et al.*, 2017). And in this study, their parent's experiences become a central focus for the aim of the thesis. Such children on paediatric BMT units are part of the remission society. Moreover, as Frank argues, it is not only the patient that is within the remission society, but also their family. This study therefore looks at parents as members of the 'remission society', and also, to borrow from Bourdieu as 'witnesses' of illness (Bourdieu 1977). Therefore, their stories offer value to the understanding of their own positions within paediatric medicine, and within the overall decision-making process for their children's treatments.

In his popular work Frank (1995) elaborates his claim that the outlook of current medicine is postmodern, and here again his discussion is relevant to this study. When thinking about the voices of those in the decision-making process and the current changes taking place as to whose decisions hold the most weight (du Pre and Brierley, 2018), it can be argued that society is dealing with an early stage of postmodern medical thinking, where the patient's voice is returning into medicine.

> "The physical existence of the remission society is modern; the technical achievements of modernist medicine make these lives possible. But people's self-consciousness of what it means to live in the wake of illness is postmodern" (Frank, 1995, p.9)

This idea of the remission society can also be thought of as extending to those living with chronic illnesses, as illness is a constant part of their biography, whether present or dominant (De Clerq, Elger, Wangmo, 2016). Frank argues their narratives enable other members of society to understand how they navigate the world and also enable them to make sense of their own worlds. My rationale for exploring Frank’s notions of the importance of telling illness stories for those who are part of the long-term remission society is because as he says, it is a society. There are multiple perspectives within this society and for me the focus starts with the parents. As BMT unit patients remain patients for many months, and sometimes years, after they have been discharged, considering families as belonging to the ‘remission society’ allows a focus on the narrative exploration of illness and recovery from a sociological perspective.

I will now move onto the research that has been previously conducted into family and patient communication with physicians in the hospital. This literature will support the study when it comes to research questions one and two (What are the parents’ experiences of the BMT consent process and how informed, and voluntary were their decisions for treatments?

Communication, Consent and Shared Decision Making

Research into parents’ and children’s experiences of consenting to surgery in sociology began around the late 1980’s with the work of David Silverman (1987), published in his book *‘Communication and Medical Practice: Social Relations in the Clinic’.* Research in this domain came from the ideas for shifting from paternalism to shared decision making which started in the 1970s in medical ethics (Veatch, 1972). Silverman's work followed the trajectory of these ideas of medical communication between the patient and the physician. His work was a longitudinal study which spanned nine years, exploring consultations in a range of clinics. Through the use of qualitative research methods such as observations and interviews, he explored how patients and their families communicated with healthcare staff, and how these encounters influenced decisions made about treatments in the patient-parent and physician relationship (Silverman,1987). The heart of his research was focused on the communication that takes place in paediatric clinics, which would today inform ideas about decision making and how information is shared amongst all those involved in treatments that involve the family, and in particular parents. The majority of the clinic observations in his study were for conditions which required follow up appointments and which lasted approximately 24 months, such as cleft-lip, heart disease and diabetes. These illnesses would now fall into Frank's category of the 'remission society' as I noted before. As patients remain part of the BMT unit outpatient clinic for around 2 years post-transplant, they too would be considered as belonging to the remission society as so would their parents.

Silverman's conclusion was that consultations change a great deal through the life span of illness and treatments, and that as parents and doctors come to understand their positions in the setting of the hospital, their interactions change. His data showed that the decision-making powers shift accordingly within the physician and parent-patient relationships, and in line with the child's illness and the treatments available, whether curative or palliative (Silverman, 1987).

Silverman's research into the communication between physicians and families lends support to the view defended in this thesis, that the power relations between parents and medical professionals in a BMT unit alter as treatment progresses, and vindicates the theoretical framework so far described. Bourdieu's theory of habitus encompasses the possibilities of identity formation, reformulation, and capital growth. As the knowledge of a child's illness expands for caregivers, and more time is spent within the hospital setting, so too their understanding of the treatment processes grows. Silverman was able to identify this growth in parental knowledge through the dynamic shifts in the decision-making power of families in relation to physicians. This growth in medical knowledge was also reported in Dixon-Woods's study (2006) as previously mentioned.

This thesis will use Silverman's conclusions as a basis for examining how the interactions of all parties within a BMT unit develop over the course of the consent process. The longitudinal nature of Silverman's study adds weight to his conclusions and is another reason for adopting his ideas. Of course, at the time when Silverman conducted his study, access to hospitals was arguably considerably easier to gain, so that it is now harder to gather data ethnographically, as he did. However, retrospective, and reflexive accounts in the form of participant recall of pre-BMT consultations and experiences of being part of the remission society are still valid ways for examining these interactions, and I use the contents of a research diary to support my own interpretations of the research process. In BMTs the consent process can be gradual before the signing of the legal consent form (see figure 1 in chapter 1), and this gives the study the advantage of looking at consent in its many stages.

As a doctoral student of David Silverman, Priscilla Alderson continued to research parents’ experiences of consenting to their children’s heart surgery. Her doctoral research published in 1990; and other follow up work published in 1993, found that clinics were not ideally suited to informing families about treatments and treatment procedures. Her research began with a qualitative analysis of parents’ experiences and then moved on to children’s experiences of giving consent to heart surgery, with the aim of adding to the shared decision-making literature. Like Silverman’s work, Alderson’s research followed up on the experiences of these families within medical encounters, but she focused on heart surgery in particular as it was a major treatment decision for families at the time the research was conducted. She aimed to find ways of ensuring that families were willing to undergo complicated procedures and trusted their doctors. When focusing on parents’ decisions to consent to surgery and their experiences of the decision-making process, Alderson (1990) found that “not all essential information for consent can possibly be covered in clinics, and this stage can seem too early to discuss consent. However, after a child has been admitted for surgery, suddenly it can seem too late to demur” (Alderson, 1990, p.61).

Although Alderson highlights the issue of the timing of consent, she refrains from providing an indication of when the right time could be and thus leaves a gap in the period between the first consent consultation and the child being admitted onto the ward for treatment. This raises questions as to when and how information should be relayed to families, but it also supports the need to explore how parents qualitatively experience the entire BMT consent process from beginning to end, especially given that treatment can last a long time. One advantage of BMTs is that the consent process can be iterative, as

Silverman (1987) found, and it can also be ‘individualised’, to quote the head of a BMT unit. Therefore there is scope to extrapolate rich data about consent from the narratives of the parents, to fill in our understanding of what occurs between the initial consultation and the hospital ward admission.

In exploring consent from the perspective of parents, one can better understand the types of information given, the types of questions asked at each stage, and how parents navigate treatment decisions during the entire treatment and consenting process. This will allow for a more detailed picture of the role of parents to emerge and it will contribute to the final research question of the study; how can the BMT consent process be modified to support parents in shared decision-making?

Alderson and her research team have recently expanded on her earlier research by exploring the views of professionals, parents and children when it comes to consenting to non-urgent heart surgery and shared decision making during these treatments (Alderson et al., 2022, Alderson et al., 2024). In their study conducted between 2019-2021 they interviewed 45 professionals, 12 parents across 2 hospital units and six children to find out their views of taking children’s consent seriously for heart surgery, and how to respect these views through shared decision making. However, the literature generated from this research is currently focused on the professionals’ views about when they think that they should discuss consent with minor patients. The data on parents’ experiences is yet to be published from their study. I hope to add the views of parents within the BMT consent process for BMTs/HSCTs as this is still a gap in the current literature when it comes to exploring parents’ informed consent experiences in specific medical contexts.

In their recent research on shared decision-making Alderson and her team take a critical realist approach to their advocacy for children’s consent, and in thinking about this, they take a retroductive approach (Mukumbang, 2023) to their analysis of shared decision-making, and the need for children’s involvement in the consenting process (Alderson et al., 2022). As I shall elaborate on this in more detail within the methods chapter, the retroductive approach is focused on explaining mechanisms in society, which neglects to explain the structures within which these mechanisms work (Alderson 2013, Blaikie and Priest 2019). But in this research, I take a constructionist approach (Silverman, 2018) that has the ability to broaden the public understanding of complex consent experiences through the narratives of the parents. I argue that before one embarks on advocating for children to make medical decisions for life-saving treatments (Alderson et al., 2024), there needs to be a broader understanding of the spaces that these decisions take place in. Moreover, it may be helpful to know how parents can be supported in shared decision making so that they can support their children if appropriate.

As Alderson's original and current research (1990 &1993; Alderson, et al., 2022) concentrates on conventional theatre-based surgery procedures, there is another gap here for exploring procedures that fall under the term 'surgery' but are beyond the scope of the operating table and may not be universally viewed as surgery. Except for the extraction of bone marrow from patients, donors, and sibling donors, BMTs, and again HSCTs as mentioned in the previous chapter, can be thought of as non-surgical procedures. The actual process of the transfusion of cells happens through the inserted Hickman line, hence the term HSCT (as transfusions can be with bone marrow or stem cells, and sometimes both during the treatment), so the process varies from person-person (Feivelson, 2006).

Alderson's work nevertheless remains a relevant point of reference for those who go through the bone marrow donation process, which *is* a surgical procedure. It is necessary to offer clarity in that the transfusion of blood products and bone marrow need not be branched under the umbrella term of 'surgery' per se, as this would diminish the contribution that this study can offer on major medical procedures. Therefore I believe that the term 'procedure' may be better suited for referring to BMTs and HSCTs rather than the term 'surgery'. Moreover, during the scoping phase for the study, when I spent time on a BMT unit, I found that the healthcare professionals did not think of BMTs as major surgery and some even frowned at my use of the term surgery. Therefore, the use of the term 'procedure' may be more appropriate.

Nevertheless, Alderson's work on surgery clearly provides a context for understanding the development of research focused on parents' consent to complex medical procedures. The distinction in the language used here in my work and in Alderson's work may also help other researchers to explore the topic of conventional surgery and procedures involving elements of surgery with minimal confusions when it comes to family consent in medicine.

Following on from Alderson's work, and staying on the topic of experiences of consent, additional research focused on consent relates to older children, teenagers, and young adults receiving oncology treatment (Day, 2017; Hart et al., 2020). Emma Day's thesis '*Principles and Practices for Involving Teenagers in Decision-Making about their Care and Treatment: A prospective participant-observation study to inform policy and practice',* focused on models of decision making amongst young teens who were having cancer treatment. Her participants were aged between 13 and 19 years old and she focused on six decisions that they faced throughout their cancer treatment. These decisions were feeding, the place of care, participation in clinical trials, phase three trials, stem cell transplants system controls, and end of life care and treatment (Day, 2017). Additionally, she looked at how parents and healthcare professionals allowed teens to be part of these decisions over the course of their illness. Like this study, Day's study (2017) considered the long process of treatment, and the decisions made by families throughout the course of treatments . An in-depth qualitative analysis of everyone's experiences during the treatments led Day to conclude that the decision-making process is not static and that each individual involved had a role to play.

Day concluded that the teenagers in her study were comfortable with not being told too much information about their care once diagnosed. "Teenagers themselves voiced their views that they do not have the experience or knowledge to be that main decision maker for decisions of consequences. Instead teenagers and their families acknowledged that consultants were the principle, decision-makers" (Day, 2017, p.342). She also highlighted some recommendations on how healthcare professionals can increase participation from teenagers.

Aside from children being autonomous decision makers in treatment consent, Day uses her data to show that there is trust on the part of children when it comes to decisions about their care and treatment. This study will also take an in-depth look at that assertion about the trust in the family relationship, and how this trust is bestowed upon parents and healthcare teams when it comes to making treatment decisions. In a way, it can be argued straight off that trust plays a pivotal role in the communication process, but the data from this study is essential for corroborating this idea. The parents' narratives will be important when it comes to analysing how they make decisions and how consent starts from them in the first instance as the parents of sick children. Day's study shows how Alderson's research on shared decision making has been developed by others. These studies also show how children may rely on their parents to make decisions on their behalf, and thus how central parents are in the process of shared decision making

If Day found that the children in her study relied heavily on the adults involved in their care to make the best decisions, it can be inferred that this is where the clinicians are seeing this shift in decision-making responsibilities. Could it be that the parents are stepping in more and more in current times, creating the medical communication paradigm shift that du Pre and Brierley (2018) describe? Discussing the question of who can make the best decision for the child, Lynn Gillam refers to what she calls the zone of parental discretion (Gillam, 2016). This is the area in which clinicians accept parents' decisions in medicine.

Gillam's idea of the zone of parental discretion starts to bring the parent back in as a central contributor to the conversations of consent within the physician-paediatric patient relationship. As my initial definition of consent illustrated, the literature on shared decision making is often associated with the physician-patient dyadic relationship (Charles et al., 1997), with the recognition of the triadic patient-parent-physician relationship if the child is too young (Wijngaarde et al., 2024). Gillam focuses on the triadic relationship and uses the term "'Zone of Parental Discretion' to refer to the ethically protected space where parents may legitimately make decisions for their children, even if the decisions are sub-optimal for those children (i.e. not absolutely the best for them)" (Gillam, 2016, p.2). This can be a challenging thing for parents, as clinical decisions are centred around information related to the disease and thus the parents, as not the sufferers of illness must decide on behalf of their children, what they believe to be the best solutions (Ruccione, et al., 1991).

When it comes to paediatrics and shared decision-making, Charles et al., (1997) also put the parents back into the physician-patient conversation as third parties within this relationship. du Pre and Brierley note the 'third party, the parents,' in a negative connotation, and almost seem reluctant to acknowledge the participation of parents in medical decision making (du Pre & Brierley 2018). By contrast, Charles and her team (1997) see third parties as essential to shared decision making in medicine. Although they do not write about parents, they note that such a medical SDM relationship can be seen as a coalition rather than a hindrance to the physician-patient relationship (Charles et al.,1997). This is where Gillam sees the discretion lying in SDM. The clinicians are aware of how important the role of parents is in decision making and thus allow them a discretionary zone as the advocates for their children in the paediatric context.

It is within these debates that I have been able to situate the parents as the starting point for exploring BMT consent. Hierarchically they are the stakeholders who stand between the clinicians and children. Parents are by law assumed to be the first decision makers for minors (Mason and Laurie, 2023). Therefore, focusing on their experiences of the consent process can support further research to piece together what the entire decision-making process looks like in BMTs. Moreover, this can support an understanding of what shared decision making looks like in BMTs. In a way I begin at the opposite end of the spectrum from the existing literature, by exploring how far the decisions made by parents are informed and voluntary, as opposed to how decisions are shared by stakeholders on BMT units, as Alderson aims to do in her current work (Alderson, et al., 2022). I believe it is important to make this distinction quite early on in this thesis, because the two can easily become conflated. Shared decision making in medicine focuses on the relationship of information giving and sharing between the physician and the patient (Stiggelbout et al., 2023), whereas informed consent focuses on how much that information is understood and competently accepted by the patient or the person who gives proxy consent for the patient (parent/guardian) (Katz et al., 2014). In this thesis my main focus is on informed consent and the decisions parents make on paediatric BMT units. This is a starting point to support further research with other stakeholders on BMT units to build an overall picture of how everyone involved in the consenting process can share the decisions on paediatric BMT units. This is also the trajectory that Alderson's research (1990 & 1993) took in relation to heart surgery, where informed consent was explored first through family experiences. That research is now being extended to understand and improve shared decision making in paediatric heart surgery (Alderson, et al., 2022).

With the parents in mind, I now return to Bourdieu. I argue that the relationship between habitus, field and capital is important for examining how the parents give consent on BMT units. Studies focused on parenting choices have shown that Bourdieu's theoretical framework plays a role within social practices. The habitus is developed within fields and within these fields there is capital accumulation and there are capital exchanges. Parents make use of their capital within particular fields, and this is made possible by the constitution of their habitus within these fields (Lareau, 2011). Parenting studies also show that there is a relationship of exchange when parents make decisions in relation to their children, whether it is everyday decisions or medical decisions (Vincent & Ball 2007, Vincent & Maxwell 2015). Sociologist Annette Lareau is a fitting example here for demonstrating how parenting strategies and family structures can support a Bourdieusian understanding of decisions made by parents on BMT units.

In Lareau's qualitative study on childhoods she identifies two main ways that parents raise their children. In this thesis, I argue that these childrearing strategies play a role in how parents make decisions and how parents may experience the BMT consent process. Lareau's first type of parenting style is the 'development by natural growth'. This is where parents let the child grow up accordingly to their environment and what is around them, with little input into the activities that the children take part in. The second parenting style she identifies from her data is the ‘concerted cultivation’ parenting style, where children are raised in a way that the parents think will benefit them. This type of parenting approach includes the careful selection of schools, planning organised activities for children, extracurricular activities outside of school hours and being involved in the child’s schoolwork and their schooling in general. In addition, Lareau touches on the importance of family communication and how the data in her study captures the communication linked to each of her identified parenting strategies. She found that each type of parenting style involves its own way of communicating, ranging from minimal interactions (development by natural growth) to in-depth conversations (concerted cultivation) (Lareau, 2011). For Lareau, these two types of parenting styles reflect different class-based experiences (Vincent and Maxwell 2015; Lareau, 2011; Vincent and Ball, 2007). She associates the “natural growth” group with working class families and the “concerted cultivation” with middle class and higher upper-class families. Comparisons for this class-based analysis could be made using socio-economic demographics, but my data set in this study is too small to make generalisations in relation to that part of her analysis. However, Lareau’s idea that parenting styles are linked to communication styles is helpful for this study, as I am not only seeking to understand the parent’s experiences of the BMT consent process, but I am also interested in how communication works within the consent process. Though I am not looking to impose Lareau’s parenting styles on my data. I take the broader point that ways of communicating and parenting differ, and they shape and inform power relations in my field of study.

Silverman (1987) and Alderson’s research (1990, 1993, 2022) that I have touched on, has shown that communication in clinical interactions is a key factor for ensuring that consent from families is informed and voluntary. One study that has attempted to explore parents’ perceptions of voluntary consent to BMTs post consent will be discussed in the following section, and I link this back to the factor of communication. So far, I have discussed the theoretical framework I am using and explained how the notions of habitus and illness narratives are relevant to my concerns. I have also discussed the existing literature that shapes and supports my aims and research questions in relation to parents' medical experiences. However, the ideas surrounding medical consent have yet to be discussed in detail. My next task is to introduce them.

Situating the meaning of consent in the study

There are many definitions of consent in the literature and many views of how it can be obtained, how it can be explained, and how it can be identified. For example, theorists distinguish written consent, verbal consent, or implied consent (Beauchamp and Childress, 1994; Mason and Laurie 2023). In exploring consent within this thesis, I will consider how far consent is informed within HSCTs, and how voluntarily it is obtained from parents.

One study which has explored BMT consent from the parents' perspective is Miller et al.,(2011)'s. In contrast to Day's study (2017), Miller and her team (Miller et al., 2011) explored parents' perceptions of voluntariness when consenting to bone marrow and stem cell transplants for their children. They tested a new instrument which explored how parents perceived their experiences of consenting for their children to have bone marrow transplants. Their sample included 219 parents who were recruited on a BMT unit and from this research they developed a tool called the Decision-Making Control Instrument (DMCI) to understand parents' consent decisions. They identified a 9-item scale after conducting a factor analysis to note the level of voluntariness that was involved in each parent's decision to undergo BMT treatment protocols for their children (Miller et al.,2011). This control instrument which uses a 6-point Likert scale is useful for this study on consent because it covers the voluntary aspect of the second research question (*How informed and voluntary were their (parents) decisions for HSCT/BMT treatments*). Moreover, using the DMCI as part of the data collection process will allow the study to test the tool with parents who have also experienced HSCTs/BMTs alongside supporting qualitative data in the form of interviews. I have implemented the DMCI in the data collection methods for this thesis as it will be useful during the analysis to see whether or not it would have an effect on the overall results of the parents' reflections of the BMT consent process.

Miller and her team argued that "although voluntary action cannot be measured, a person's perception of whether his or her action is voluntary can be measured by testing for perception of intentionality and non-control" (Miller et al., 2011, p.731). This is the reason why the DMCI tool is employed in this study. Miller et al., (2011) continue to argue that the DMCI "provides insight into the individual's perception of the degree to which the decision was self-controlled vs. controlled by others. When used alongside an assessment of situational factors, the DMCI may be useful in identifying external conditions that lead to decreased perceived voluntariness" (Miller et al., 2011, p.738). Thus, in this study, the DMCI is integrated into the survey and is used alongside the interviews, which will be important in establishing how the participants' decisions were perceived at the time of treatment and afterwards. I will also be able to fill a gap that Miller's study identified. This gap is about the need for additional methods that relate to assessing situational factors when providing medical consent. The DMCI in itself does not produce qualitative data and it is through qualitative data that I will be able to assess perceptions to voluntariness in consent. Moreover, Miller (2011) and her team only explored voluntariness in consent and not the entire BMT consent process, and this is where I hope to fill in the gap by also exploring how informed and not just voluntary consent is in BMTs. The interviews will allow me to explore the 'informed' aspect of consent by learning more about how the parents in this study perceived their experiences of consenting to transplants.

The aim of this thesis is to consider the entire haematopoietic consent process and touch upon how the major treatments that a patient may undergo before being transferred onto a BMT unit, may impact parental consent and paediatric shared decision making. I also aim to explore and illustrate the possible paths which lead into the confusions surrounding the arguments around consent (Brierley and Larcher, 2016). Given that Larcher and Brierley's 2016 paper titled 'Adolescent autonomy revisited: clinicians need clearer guidance' was the catalyst to initiating this research, it would be useful to make reference to any supporting data on this.

Principles of Informed Consent

Consent can be thought of in multiple ways, such as consent in the broader terms of the word and informed consent. The broader use of the term does not specify a particular type of consent or way of consenting. By contrast, the notion of Informed consent highlights a particular type of consent. In medicine, the imagined ideal is informed and voluntary consent as is also supported by law (Mason and Laurie, 2023). Beauchamp and Childress (1994) point out that informed consent has five defining factors and discuss these in more depth in their work. As they explain

> Legal, regulatory, philosophical, medical and psychological literatures tend to favour the following elements as the analytical components of informed consent; (1) competence, (2) disclosure, (3) understanding, (4) voluntariness, and (5) consent. These elements are then presented as the building blocks for a definition of informed consent…one gives an informed consent to an intervention if (and perhaps only if) one is competent to act, receives a thorough disclosure, comprehends the disclosure, acts voluntarily, and consents to the intervention (Beauchamp and Childress, 1994:145)

The identified components of informed consent show that these features are of importance in ensuring that consent is at the optimum capacity of being informed. These components can also be tracked back to D'Souza, Pasquini and Spellecy's (2015) definition of informed consent for patients that I mentioned in chapter one. These components also fit into the main objectives of shared decision making, where those who are giving consent must understand what they are consenting to and be able to voice their preferences where possible (Katz et al.,(2014). Thus the rationale for this thesis is to construct a theoretical framework of what consent means in the context of BMTs/HSCTs; and explore what consent in the legal framework might mean for parents when consenting to medical treatments on BMT units. Hence a legal standpoint of exploring consent is the most ideal in this situation of paediatric BMT units. This is clearly because when it comes to transplants on BMT units, minor children can also be involved as donors, and they are often referred to as sibling donors. However, their participation in the process of donating their bone marrow or stem cells is legally overseen by the Human Tissue Authority (HTA) and not just their parents or medical professionals. This is an important aspect to consider in BMTs because the parents' experiences of the consenting process can be impacted by whether or not they have an HLA donor match within the family.

As I have just introduced, the Human Tissue Authority's role on a BMT unit is to oversee the consent process when it comes to sibling donors, and they have a legal framework and guidance which healthcare professionals must follow alongside parental decisions (HTA 2021). Thus consent to BMTs/HSCTs in the legal context is a prerequisite to understanding what the problem is in relation to family involvement in the consent process for complicated procedures. Especially if I relate back to the research problem of decision-making and autonomy within medicine, it makes logical sense to have an overall focus on the legal framework, given that when it comes to biological donations this is one of the limited medical fields that minors can donate within whilst still alive, but where their parents' rights as co-fiduciaries are affected.

However, I will not delve into the jurisprudential aspects of the law because, although they are important, there is no scope to cover the debates within them (Bingham, 2010; Adams and Brownsword, 2006), until there is a clearer definition of what consent means and what consent is in BMTs/HSCTs, which this thesis aims to address. When thinking about law in society, one often thinks of the legally binding artefacts which remind citizens that they are bound by the law and in this case, the consent form. So, when I refer to the law, I am in no way scrutinizing it but illuminating its role within the consent process as the main signifying feature of consent (evidenced with signed documents).

As Beauchamp and Childress (1994) identified a number of elements involved in informed consent, it is vital to engage with the parents' experiences to explore how each of these elements was present as their children went through the transplant process. The first of these elements of informed consent is competence. Competence to consent to treatment is arguably the most important element needed for any person to legally be able to fulfil the requirements of the idea of informed consent (Weithorn, Campbell and Wemorn, 1982; Hunter and Pierscionek, 2007; Hein *et al.*, 2015). The element of competence is based upon a person being able to comprehend the information that is being given to them. Arguably this is crucial when it comes to medical decision-making and the default ‘competent’ adults in the family are the parents. As seen in the earlier consent process diagram (fig.1), the written part is the final element of the BMT consent process (before consent to withdraw treatment). But to get to that, there is a level of competence needed by those who are part of the consenting process.

My decision to put aside Beauchamp and Childress’ other elements of informed consent is because disclosure, understanding and voluntariness, plus consent will be focused on within the collected data and the analysis chapters. Competence in this instance is what welcomes children into this debate on the shift of decision-making authority and Beauchamp and Childress’ other elements naturally follow. To start a conversation about consent, one must be clear about the competence of the person they are going to seek the consent from. There is an automatic assumption that adults are competent and thus children are not automatically welcomed into the conversation of consent (Turnham, Binik and Wilkinson, 2020). In a way, this is a small gap that I intend to defend in this thesis. And the parents’ narratives about their children’s illness journeys are significant for understanding the family experience of consent on a BMT unit. Especially when parents enter a shared decision-making process with the HTA when minor siblings are identified as potential donors for the child who is a patient on the BMT unit.

Therefore, in this thesis, through the parents’ narratives, I aim to highlight the elements of the transplant consent process, so that one can begin to see where the child is positioned in the medical interactions to act autonomously or as a co-signatory of the legal written consent part of the consenting process. After all, that is what is assumed to be the important part of the consenting process, as that is what shifts the responsibility from the patient to the medical professionals in all medical encounters (Cave and Purshouse, 2020). It is also the proof that lasts long after treatment protocols, long after examinations and long after illness has passed, or the postponement of death has run its course. And in this case, I will be specifically exploring how the parents reach the stage of signing the consent form for transplants. Though for children there is a level of competence that is required. In this study, I only make this reference to children in relation to child donors as this is where consent for parents becomes complicated. I also refer to children's agency as a starting point for further research into the topic of BMT consent because of how child donors and child patients present different consent experiences for their parents, especially within the same family.

Decision makers for HLA minor donors

Parent's consent for HLA matched sibling donors is a little different in BMTs. An insight into how consent works for child donors is very useful here as it can be a little more complicated for their parents. I also reference children here because of Brierley and Larcher's paper which I have mentioned as playing a role in why parent's experiences of the consent process are important for exploring communication and avenues for shared decision making on BMT units (Brierley and Larcher, 2016). For the child donors, the legal path to consent differs from the sick child. They have the HTA oversee part of their consenting process and this part of the BMT consenting process for families requires children who are selected as donors to show the HTA team that they are 'Gillick' competent.

The case which first brought about the term 'Gillick' in the medical field pertained to a teenage girl who wanted to be prescribed contraception without the knowledge of her parents (Gillick v West Norfolk and Wisbech HA 1985). Her mother did not agree to doctors allowing her to seek contraceptive advice and treatment without her knowledge as the parent, and in turn she filed a case against her local health service. In summary, the judge concluded that if an older child were of sound mind and was deemed competent to make decisions regarding their healthcare choices, then they could be termed as ‘Gillick’ competent. Once Gillick is applied to the BMT situations that I am concerned with, the extent of parents’ authority to make consent decisions for their children becomes very complicated. The HTA requires sibling donors to show that they are ‘Gillick’ competent when they are giving consent to donate stem cell or bone marrow to their siblings

Legal scholar Lisa Cherkassky identified three legal pathways for the sibling donor consent process and these pathways are as thus.

> (i) Gillick consent may be applicable to non-therapeutic medical procedures; (ii) a parental consent may override a teenage refusal to validate the procedure (subjective), or (iii) the High Court may decide what is in the best interests of the child (objective) (Cherkassky, 2015, p.1).

She also found that there have been no actual child donor cases within the UK which have accepted Gillick competent decisions for a refusal of donation from sibling donors, and any such cases have been overruled by the courts (Cherkassky, 2015). The fact that the common law can be applied on an ad hoc basis demonstrates that the provision of Gillick may not always be a recognized one, let alone one that is exercised under a framework which gives children (patients or donors) agentic opportunities to consent to treatments. This is why I also chose to focus on the legal framework as it plays a role in how parents can experience the BMT consent process for sibling donors who are minors. Cherkassky has found that even when children are Gillick competent, the courts can still override their decisions to refuse to become donors which can present an issue for parents.

So I argue that when it comes to child donors, the idea of agency, rather than competence may be the main factor when it comes to their consent on the BMT unit. Here it may appear that I am conflating the two terms, competence, and agency, but I can assure the reader that I am not. Rather I am separating the two, and possibly not in a binary way where one is used just for adults and the other for children. But in a way, I specifically want to reserve the word ‘agency’ for children because the literature on childhood places more significance on agency than examining competence (Wyness, 2018; Prout, 2000). This may be because the notion of agency is strongly swayed towards actions whereas the idea of competence requires a little more measure to be accepted by those who are looking out for it in children.

There are a few debates in childhood studies about the meaning and idea of children's agency (James and Prout, 2015) but for clarity of argument, Oswell's theory of agency is ideally the most fluid and productive for this research. In his analysis of childhood agency, Oswell (2013) identifies four key questions that childhood studies scholars focus on, and this study is slightly swayed by the fourth question; "what freedoms or controls are appropriate to be placed on the child" (Oswell, 2013, p.5). For transparency the other three questions that he mentions are "what is a child; in what ways is childhood differentiated from adulthood? how do we understand the growth of a child?" (Oswell, 2013, p.5). Question four (above) in this instance aligns better with Bourdieu's theoretical framework, and arguably it is an insightful way of exploring agency when it comes to the question on how parents can involve their children in the shared decision-making process. Once there is an outline of how the BMT unit consent process may be experienced by families, it may become easier to explore which freedoms and controls can be placed on children in these situations. Or even how parents may expect to be sidelined when it comes to their children's consent process when the child is a donor.

Therefore when it comes to agency, Oswell notes that "children's agency is not defined in terms of children or adult spaces, but rather through highly entangled social relations" (Oswell, 2013, p.267). For Oswell, children's agency is not just one thing that defines the child's ability to instigate change within their lives and their lived experiences. Rather, agency is relational to the situations that it becomes relevant for exercising. An attempt therefore to situate 'children with agency' in the realm of childhood cannot work as a blanket term for all children who are currently passing through the current conceptual ideas of childhood (Prout, 2000). Rather, Oswell argues, it is more realistic to evidence children's agency within particular contexts. Thus he concludes his analysis of the intersectionality of childhood and different spaces as;

> …agency is always relational and never a property; it is always in-between and interstitial; and the capacity to do and to make a difference is necessarily dispersed across an arrangement. Moreover, children's agency constitutes a problem space, which is composed of questions, investigations, and methods of analysis, but which also invites further questions, investigations and analyses. It is not constituted as a solution. It does not indicate a model that can then be deployed as a form of explanation of different kinds of social conduct. The different spaces of experience, experimentation, and power that I consider-concerning the family, schooling, crime, health, play and consumer culture, children's labour and children's rights-constitute particular complexes of arrangements in which 'agency' is a significant factor, but equally it makes little sense to consider these spaces in terms of agency residing within individual children in the context of pre-existing social structures (Oswell, 2013, pp.270-271)

Oswell's ideas also have a place within Bourdieu's notions of the habitus, and how the habitus can be situational, but on the other hand also relational to the people and structures it is observed in. For one's embodied habitus is unconscious but also ever at play within social interactions, and this is the point which Oswell makes. For Oswell when it comes to children, agency is relational and is not stagnantly based on structures but is ever available to express its presence as a mechanism for children's participation through their spaces. Thus in thinking of children's agency being relational to the structures that they are in, I move back to consent and how children's agency falls into the medical idea of the 'Gillick competent' child. I consider how it becomes relevant to the parent's experiences of consenting for treatments on BMT units for sibling donors, and for child patients when further research is conducted on this topic.

The adult centric notion of the 'Gillick competent' child also brings back the idea of the law and how the law is ever present when it comes to children's agency within medicine.

> In medical treatment, children’s ability to consent is assumed by law at 16 years, and can be applied to those under 16 years of age who can demonstrate their capacity to understand (fully) the nature and purpose of the proposed treatment and its consequences for themselves and their family (Brierley and Larcher, 2016, p.482).

However, there are no clear guidelines as to how children’s and young people’s capacity to consent can be assessed (Barsky et al., 2021). This is another reason why I have taken this approach of agency with children and not competence as a significant factor to their participation in consenting to medical treatments. And as Brierley and Larcher (2016) note, there are no clear protocols for clinicians to follow when it comes to putting a pause on the child’s agency and reigning back the clinician’s power to make the final decision, unless it goes to court as Cherkassky (2015) found. Beauchamp and Childress state that “in medicine, the motive for determining incompetence is to protect patients against decisions they might make that are not in their interests. Many therefore believe that standards of competence should be closely connected to levels of experience, maturity, responsibility and welfare” (Beauchamp and Childress, 1994, p.138). Hence, quite often children’s abilities to consent are challenged by those with the legal rights to protect them (Brierley and Larcher 2016, UNCRC 1989, England and Wales Mental Capacity Act 2005, Human Tissue Authority 2017). This is the other end of the ‘Gillick’ idea, where decisions are made for children under the ‘best interests’ principle (Birchley, 2021). Again, it may seem that this issue has no place here, where I am exploring the parent’s experiences of BMT consent. However, I have to address this point, because for some parents, the ability to voluntarily consent for their children is temporarily paused when their child is a donor. The questions of where children stand within the medical arena as individual persons with agency (Cave and Purshouse, 2020), and how the structures in healthcare allow them to exercise their agency within their given societies, therefore arise. These questions fall into the last two research questions of my study. To explore them further and situate them in this thesis, I have briefly explored children’s rights to consent to medical treatment, using the English legal system which is governed by common law principles. It may differ for jurisdictions governed by civil law principles (Wik, 2014).

> The usual distinction to be made between the two systems is that the common law system tends to be case-centred and hence judge-centred, allowing scope for a discretionary, ad hoc, pragmatic approach to the particular problems that appear before the courts, whereas the civil law system tends to be a codified body of general abstract principles which control the exercise of judicial discretion (Slapper and Kelly, 2012, pp.4-5).

As the United Kingdom is part of the common law system territories, the aim is to refer to the common law and the case of Gillick in a demonstrative manner. This will allow me to show why there are ongoing confusions about children's participation rights within medicine, and in particular why there seems to be a shift in decision making authority from a clinical perspective.

Slapper and Kelly (2012) note above that the common law is case based and relies on previous judicial decisions when addressing legal matters. Thus common law uses 'Gillick' as one of the most referred to provisions for ensuring that children under the age of 16 years are eligible to exercise their agency, although not always successfully as I have mentioned in relation to sibling donors. But currently 'Gillick' is the most suitable concept that can be used to demonstrate children's agency in healthcare.

Going back to Oswell (2013) and his stance of relational agency, Gillick demonstrates that his idea of relational agency as the provision (Gillick) only becomes available to children when they enter medical spaces. Outside of medical spaces, most decisions that children and those under the age of 18 can make are pretty much set in stone. Gillick allows some room to manoeuvre when making decisions that affect children's lives. In BMTs it allows donors to exercise autonomy only as much as the system allows. However, it removes the parent's ability to voluntarily consent to non-therapeutic treatments for their children. So on the one hand parents can make decisions for the sick child, but on the other hand cannot in essence share the decisions for their donor children.

In the case of sick children going through BMT units, it may be difficult to consent to treatment, as the options are complex and there are two other parties involved in the decision-making process (Day, 2017; Dixon-Woods et al., 2003), the doctors and the parents (Birchley, 2016). Children who are having bone marrow and stem cell transplants require a group of decision makers, each with their own individual skills and knowledge to support the consenting process. Moreover, legal scholars Mason and Lauire note that in law,

> It can be taken as being now accepted that a doctor treating a child should always attempt to obtain parental authority but that, provided the patient is capable of understanding what is proposed and of expressing his or her wishes, the doctor may provide treatment on the basis of the minor's consent alone. The decision to do so must be taken on clinical grounds and, clearly, must depend heavily on the severity and permanence of the proposed therapy (Mason and Laurie, 2013, p.94)

Therefore, in the case of BMTs/HSCTs, Gillick as a measure for competency to consent becomes more complicated. However, when it comes to sibling donors it becomes even more complex as others have found in their research (MacLeod et al., 2003: Bauk MSN et al., 2013: Pentz et al., 2014). When the sibling donor is a minor, their autonomy bounces back to the State under the body of the Human Tissue Authority (HTA) (Cherkassky, 2017). Thus what can be seen here is a web of decision-makers and a web of decision possibilities. Although clinicians are at the top of this, as they suggest the treatments options, it is clear that the relationships between the shared decision makers give each individual scope to exercise their agency. But again it is situational and relational, and that is why I have begun this research with the perspectives of the parents first.

Summary

In this review I introduced Bourdieu's theoretical framework of the habitus and identified its importance for gaining an understanding of the consent process on BMT units. I also explored other studies that have identified how his framework has worked for similar topics and how it can offer support to this study. I also returned to the research problem to show how Bourdieu's idea of the habitus can support how one can understand how voluntary and informed consent is in haematopoietic stem cell transplantations alongside the use of narrative inquiry. Frank's theories on the impactful nature of storytelling and illness narratives further support the parents as participants in this study as they are classed as 'witnesses' within the remission society. Although I have also touched upon children's agency to show how the parents' experiences of consent can be effected when they have minor sibling donors within the family. I have also discussed how an understanding of the consenting process on BMT units can support further studies that can have the children as the main participants.

While I have not touched upon all the literature which falls into the field of BMTs, this survey review has been for the purpose of highlighting the gaps that I aim to fill under the scope of literature in medical sociology and medical consent for major treatments. This review is a starting point for understanding what the BMT consenting process is like for families and how communication in this process can support tools for enhancing shared decision making for treatments in this field.

Chapter 3: Methodology

> The social scientist cannot begin to describe any social activity without knowing what social actors know, either what they can report or what they tacitly assume while engaging in social activity” (Blaikie, 2010, pp.89-90)

Introduction

Throughout this section I offer the rationale behind the methods I use and explain how I settled for a convergent parallel mixed methods design by using both qualitative and quantitative methods (Creswell, 2014) to complement the abductive research logic of this thesis (Blaikie and Priest, 2019). The survey of relevant literature for this research played a role in the epistemological approach that I have taken towards the methods and data analysis. Identifying a key issue for the study and narrowing the focus onto one group of stakeholders, the parents, added to my ideas of how I was going to effectively try to capture their experiences of the consent process, whilst also following the line of communication throughout their experiences. To do this, I was torn between research strategies because I had to reflect on what knowledge was important and what tools were going to be the most effective for answering the research questions.

Blaikie and Priest offer guidance as to what type of questions different logics of inquiry can answer. I found that the research questions for this study are suited to the abductive logic on the premise that it can strongly offer answers to what and why questions, but most importantly like the other logics it can answer why questions, fitting in well with this study’s questions. Thus,

> The abductive “logic of inquiry involves constructing theories that are derived from social actors’ language, meanings, and accounts in the context of everyday activities. Such research begins by describing these activities and meanings and then deriving from them categories and concepts that can form the basis of an understanding of the problem at hand” (Blaikie and Priest, 2019, p.99).

I also present an overview of the methodological schools of thought that guide the research, which was also influenced by my abductive approach. My previous research designing experiences also helped me quite a lot when it came to selecting my research approach. Again Blaikie and Priest (2019) note that “the choice of a logic of inquiry, or combination of them, constitutes the second most important research design decision. The reason for this is that knowledge can only be advanced in the social sciences by using one or a combination of four logics: Inductive, Deductive, Retroductive and Abductive.” (Blaikie and Priest, 2019, p.21)

In this chapter I will also discuss the ethical issues of the project, the patient and public involvement (PPI) that resulted in the final drafts of the data collection materials and the steps taken to ensure that others could attempt to replicate the study in the future. Moreover, I discuss the chosen analytical approaches that suited the collected data, and I offer some insight into the process of analysis. I also offer a brief overview of the participants involved in the in-depth interviews, to ensure that the interactions that we had are best understood with the ‘set scene’ of our meetings (Alleyne, 2015). This will lead into the outline of the themes that will follow into the findings segment of the thesis in chapters 4-6.

The literature review in the previous chapter identified the methods used in the existing literature on the topic of parents consenting to major medical treatments, and this chapter will highlight how my research will cover the gaps identified. To recap, the research questions that were generated throughout the planning process and during my time on the children’s BMT unit in London are centred on exploring the parents’ experiences of the BMT/HSCT consent process through a cross-sectional mixed methods design study (Creswell, 2014). These questions reflect the aims of the research, and they offer a narrow pathway for illuminating what the consent process is like on BMT units. The questions are:

1. What are parents’ experiences of the BMT/HSCT consent process for their children?

2. How informed and voluntary were their decisions for BMT/HSCT treatments?
3. How can parents support their children in sharing decisions about bone marrow and stem cell treatments?
4. How can the HSCT/BMT consent process be modified to support parents in shared decision-making?

Here is a brief outline of the study design.

Study Research Design Table	
Study design	Mixed methods convergent parallel design
Data collection methods	Online survey, qualitative in-depth interviews (both available to participants)
Recruitment strategy	Charities sending a call for participants through newsletters, support groups and social media advertisements (purposive snowball sampling)
Inclusion criteria	Parent/carer/guardian of BMT unit patient (in or out-patient) Out-patient of the BMT clinic Relative living with patient of BMT unit (in or out-patient)
Exclusion criteria	Those who had not signed a consent form for BMT treatment to start
Sample size	7 participants (8 fully completed online surveys, 1 partially completed survey, 4 in-depth interviews), total= 9 children responded for.
Ethical approval	UCL Institute of Education approved April 2019 (Study Internally peer reviewed August 2018)
Data analysis	Narrative Analysis and Descriptive Statistics

Research Design

A successful sociological study begins by identifying a research problem. As mentioned at the start of this thesis, my problem can be located within the way medical decisions are changing. They are evolving towards the path of being more shared than purely accepted because of the perspective of the clinicians (du Pre and Brierley, 2018). Thus, in considering what the best research design would be, not only for the study, but to address the research questions and add to the existing literature, it became clear that the abductive approach as opposed to the other approaches was better suited (Blaikie and Priest, 2019).

In assisting with the rationale for this particular chosen logic of inquiry, Blaikie and Priest (2019) go on to argue that the abductive logic covers ground that all the other research strategies (Inductive, Deductive and Retroductive) tend to miss out. They argue that the purpose of the abductive strategy is "to discover why people do what they do by uncovering the largely tacit, mutual knowledge, the symbolic meanings, intentions, and rules, which provide the orientations for their actions. Mutual knowledge is background knowledge that is largely unarticulated, but which is constantly used and modified by social actors as they interact with each other" (Blaikie and Priest, 2019, p.99). In a way, their assertion about this research strategy fits in with the theoretical framework of Bourdieu's concept of the habitus (Bourdieu, 1977), his account of the development and knowledge exchange of different forms of capital (social, cultural, economic) and how these play a role within medical spaces.

I argue that there is utility in marrying the research logic with one's overarching theoretical framework for optimum knowledge production. The abductive strategy of social inquiry places an emphasis on the significance of the characteristics within a group, and how these characteristics play a role in the formation of the social norms and actions within it. The group that this research focuses on was quite specific in nature and although they were all hospital users, they were specific to the BMT unit which means that on a micro scale, their actions are completely different to those of the wider hospital community. Thus the abductive strategy's focus seemed more ideal as a methodological approach. I found that the other research logics were not suitable for my study as;

> Inductive logic starts with the collection of data and then proceeds to derive generalizations…Deductive logic cannot answer 'what' questions but is used exclusively for answering 'why' questions…and is concerned with explaining some social regularity that has been discovered and which is not understood. Retroductive logic also starts with an observed regularity, but it seeks a different type of explanation…Retroduction uses creative imagination to work back from data to a causal explanation.
> (Blaikie and Priest, 2019, pp.21-22)

Therefore, the idea of the possibilities of data that can be extrapolated from social actors with the abductive logic in mind, fits in well with my research aims for eliciting stories that can offer so many perspectives to understanding the experiences of illness (Frank, 1995 & 2010). Blaikie and Priest continue to note that, the "abductive logic produces understanding based on 'thick' descriptions and social scientific concepts that have been derived from everyday concepts and accounts"(Blaikie and Priest, 2019, p.112). Therefore the data collected is more than likely to fit the archetype of stories which can further support Bourdieu's framework of habitus, field and capital (Bourdieu, 1984).

By starting with descriptions of the parents' experiences and working up towards a theory on consent in paediatric major medical treatment, this study can further add to the developing literature on family consent. Whilst also focusing on the research dilemma of the shifting paradigm of medical consent hierarchies as highlighted chapter 1 of this thesis, this study can support strategies for improving shared decision making. As Frank identified, many stakeholders are part of the 'remission society', as seen in the literature review. The parents' accounts are the first to be explored in relation to my research problem and the issue of informed and voluntary consent. Thus this study is quite similar to Alderson's research that I mentioned earlier, which explored parents consenting to children's heart surgery (1990). Alderson too started with the experiences of parents and then moved on to researching children, and then most recently, other stakeholders in paediatric cardiology major decision making (Alderson et al., 2022)

Epistemology

The main epistemological approach which holds this research together is the interpretivist approach.(Bryman, 2004; Silverman, 2022). "In interpretivism social reality is regarded as the product of its inhabitants; it is a world that is constituted from the meanings participants produce and reproduce as a necessary part of their everyday activities together" (Blaikie and Priest, 2019). Thus this approach also links with the abductive research strategy and its purposes for understanding the social world. Interpretivists seek to compile knowledge about the world in a way that considers the impact of social interactions and how societies are developed and maintained on the foundations of their actions. Again, the pattern of 'no man is an island' is evident here. I am aware that my actions have an effect on those who I wish to research. Each individual actor not living within a vacuum plays a part within their social realities, and interpretivism offers the possibilities for understanding the mechanisms at work within different spaces.

I would also like to note here the strong link between the abductive logic of inquiry and constructionism, which recognises that reality is constructed and co-created by the actors within it (Berger and Luckmann, 1966/1991). As mentioned in the literature review, Bourdieu's concept of the habitus is also being heavily relied upon as an epistemological tool for this study (Bourdieu,1990). His in-depth analysis of how the habitus permeates social practice and plays an important yet often unconscious role in social interactions, offers guidance as to how to make interpretations of the knowledge to be gained from this study. In relation to the habitus and understanding the social world, he argued that,

> Unlike scientific estimations, which are corrected after each experiment in accordance with rigorous rules of calculation,

> practical estimates give disproportionate weight to early experiences: the structures characteristic of a determinate type of conditions of existence, through the economic and social necessity which they bring to bear on the relatively autonomous universe of family relationships, or more precisely, through the mediation of the specifically familial manifestations of this external necessity (sexual division of labour, domestic morality, cares, strife, tastes, etc.), produce the structures of the habitus which become in turn the basis of perception and appreciation of all subsequent experience. (Bourdieu, 1977, p.78)

Others also note that interpretivism places great emphasis on understanding individuals and their actions within a larger view of society and interpreting how their actions give meaning to their lives (Gerth and Mills, 2009). Therefore, within the context of haemopoietic stem cell transplantation this approach to gaining knowledge about the consent process is ideal for constructing a theory of how families witness and experience the nature of the consenting process. Bourdieu also notes that it is ideal for researchers to have knowledge of the people and spaces that they wish to research before they begin the research process (Bourdieu, 1999). I mentioned in the opening chapter that I had to immerse myself within the life of the BMT unit before I could begin this study, and my experiences on the BMT unit helped to inform the way this study was designed and constructed. I had to situate myself and my personal experience of the BMT unit within each stage of the research process before I decided the next steps. My experiences played a major role in developing the epistemological position that I have taken thus far, and I offer reflexive commentary on my position at various points in the thesis.

The interpretivist epistemological approach also fits in with the abductive logic of inquiry as it allows for the collection of qualitative data, which forms the base of interpretivism's ideas of generating knowledge about the social world. The search for narratives from the parents' experiences of their child's illness journeys and consenting to their child's treatments is the main rationale for choosing this approach.

The literature so far has shown that multiple methods of data collection, such as observations, semi-structured interviews and questionnaires have already been used to explore the research topic when it comes to consenting to bone marrow and stem cell transplant treatments (Lyons, 2011b; Wik, 2014; Patenaude, Rappeport and Smith, 1986; Lesko et al., 1989; Jacoby et al., 1999; Miller and Nelson, 2012; Wyatt et al., 2015; Raj et al., 2017). For these reasons, I remain reflexive with how I approach the entire research process in this thesis

Understanding that the consent process is likely to change or be experienced differently by others throughout the course of this research and thereafter is a key task for this study. According to Gerard Delanty, “a reflexive social science is one in which the social researcher must question their own role in the research process since they are part of the object” (Delanty, 2005, p.121). Moreover, in narrative seeking research, the presence of the researcher does not remain in a vacuum, because for narratives to be successfully collected, there must be dialogue (Frank, 2012). For one the researcher has been driven to seek out the participant due to an identification of an issue, and thus the research process begins with a laden (conscious or unconscious) perception of the issue at hand (Mills, 1959; Back, 2007). So, to be reflexive as a researcher is important when it comes to data collection and data analysis.

To achieve a reflexive style of method within the thesis, a research diary was kept throughout the entire project. This diary was important in reflecting on the idea of reflexivity within research and how the researcher plays a silent and seldom considered effect on the methods of data collection and the data collected (Berger, 2015). However, the research diary is used to corroborate the findings during the data analysis phase, where needed, rather than for collecting data (Mosurska, 2022). Moreover, when researchers collect records within research diaries, these records have not been put under the scrutiny of research ethics committees, and thus some accounts cannot be used in the presentation of findings. That is not to say that diary entries do not help the research process, they do. They assist the process by adding context that may not be recorded within the interview transcripts. They take the researcher back to a point in time, and this adds context to the accounts of the social actors who are involved in the research process (Alleyne, 2015). Research diaries also assist in the design process, and they offer reflections on lines of inquiry to follow and notes on how to conduct an ethical study, at least as I found throughout this and previous research projects.

In a way, a reflexive sociological approach opens the way for employing an approach that mirrors standpoint theory. “Standpoint theory does not rule out the insights of any group or person. Each group contributes the distinctive knowledge emerging from its particular social situations and social structures” (Swigonski, 1994, p.392). Frank also argues for the importance of standpoints when he discusses his form of narrative analysis that he refers to as dialogical narrative analysis. However, although recognizing the importance of reporting multiple standpoints, he also argues that this is not possible in research studies, nor is it fair to report multiple standpoints (see Frank, 2012). Therefore, I understand that although I am only seeking the experiences of the parents, I know that the other stakeholders also have their standpoints which will not be reported in this study. Frank’s argument for this is that,

> What justifies this apparent one-sidedness is the recognition that the reports present stories not as transparently accurate descriptions of what is—not as having some privileged understanding—but rather as storytellers’ representations of what they perceive. People’s stories report their reality as they need to tell it, as well as reporting what they believe their listeners are prepared to hear (Frank, 2012, p.38)

Epistemologically, this interpretive and reflexive project can be closely related to standpoint theory and the sociology of knowledge (Skeggs, 1997), in that the only way to comprehend the interactions of parents and their children with healthcare professionals within the decision-making process is by bearing in mind that each will have a different experience within the same medical interaction. As Frank notes above, these standpoints cannot all be conveyed in one report, but nonetheless they can still be collated. Berger and Luckmann (1966/1991) note that, “the world of everyday life is not only taken for granted as reality by the ordinary members of society in the subjectively meaningful conduct of their lives. It is a world that originates in their thoughts and actions and is maintained as real by these" (Berger and Luckmann,1991, p.33). Thus, individual experiences alongside wider experiences are important in understanding the consent process on a whole. These scholars all agree to the same point; in that reality for individuals is based upon interactions with other members within their spaces. And their knowledge reflects these interactions, without knowing what they know, the social researcher cannot say anything about their knowledge or their realities (Blaikie and Priest, 2019).

Contemporary standpoint theorists mainly focus on the oppressed (Intemann, 2019). Here I want to rotate the standpoint idea of oppression by using standpoint theory as a way of knowing those realities in closed off spaces. I want to think about standpoints in a positively neutral way and not so much as knowing about those in positions of perceived lower power, as traditionally thought of in standpoint theory (Intemann, 2019). In standpoint theory, a standpoint is a position in society, involving a level of awareness about an individual's social location, from which certain features of reality come into prominence and from which others are obscured. "Standpoint theory begins with the idea that the less powerful members of society experience a different reality, as a consequence of their oppression" (Swigonski, 1994, p.390). However, it should be noted that I do not believe that the word oppression is appropriate in the BMT/HSCT context, because medical spaces already have knowledge hierarchies. To assert that medical spaces are oppressive could misguide others into assuming that medical experts are oppressive, which is the opposite of their role and vocation. And it is certainly not a message I want to endorse in this study. Though the message of knowing that individuals in shared spaces have multiple differing standpoints is why I note the importance of standpoint theory in this study.

Methods

The development of the methods

The methods used to collect the data for this study were developed over the course of the first term of the doctorate degree in the autumn of 2017, and they are contingent upon developing an in-depth understanding of the trajectory of the consent process in bone marrow and stem cell transplants. Much of the planning process involved being a participant-observer (Frank, 2012) on the BMT unit that I had access to through the provision of an NHS observer contract between 2017-2018. Gaining access to the BMT unit was the easiest part, but the observations were the hardest because they involved watching families go through difficult processes. As an observer I had the privilege of sitting beside the medical teams, facing the patients. And this was the recommendation from the director of the unit. He suggested that the only way I could positively conduct the research was to see what life was like on the BMT unit before moving further into the design and data collection phases. He advised that those phases of the research process should be informed by my understanding of what happens daily on a BMT unit.

As I began to understand the BMT unit and the timetabling of the key interactions and appointments that the healthcare professionals had with the families, it became clear that each group/stakeholder in the process had their limitations when it came to consent throughout the trajectory of the child's illness journey. One stakeholder's role could not be understood without understanding the role of the other. Though, I was also mindful about how my position as a researcher within the space of the BMT unit may have had an effect on the interactions that people were having around me, as these interactions were forming my views of the unit. At times they may have known my purpose for being on the unit (clinical teams) and at other times they may not have known who I was (healthcare staff, families) so I was aware of how this may have effected interactions where I was present.

Originally the research was intended to gain the perspectives of all stakeholders (Doctors, Patients, Parents, other healthcare professionals on

BMT units) involved in transplants, and the plan was to capture these different experiences by using a variety of methods. However, this was challenged by some of the institutional rules of social research within medical settings, even before the research challenges that were presented by the COVID 19 pandemic in 2020. One of these challenges was the restrictions placed on public access to medical buildings.

In the case of this study, the biggest barrier to involving all the relevant stakeholders was gaining UCL research sponsorship and NHS ethical approval (Lee et al., 2021), both of which were time consuming processes that can take a minimum of 3-6 months to complete once started. In terms of preparation, the majority of the key steps for conducting hospital-based research were in place at the beginning of the second year of the PhD programme. I had a hospital site which was willing to participate in the research. I had received occupational health clearance from UCL, I had also received a full and enhanced DBS check from the hospital, so the only thing I needed was sponsorship and NHS ethical approval, the former being the prerequisite to the latter. However, this process did not come without complications, and it became clear in the middle of the second year of the PhD that in order for the research to continue under the Bloomsbury funding guidelines and without delay, that I had to look for potential participants outside of the hospital, so that I could complete the research in my given 3-year timeframe.

Fortunately as the parents of the children from the target population were not the ones receiving NHS treatment, they were the only ethically viable stakeholders to recruit for the study without the need for NHS ethical approval. Gaining institutional approval from my university to conduct the study did not present the same challenges as gaining NHS ethical approval, so I made the decision to get institutional approval first. Once my observer contract ended on the BMT unit and it was clear through the planning stages that access back onto the unit as an ethically approved researcher was proving difficult (pre-covid), the parents became the connection between the outside world, the patients (their children) and the hospital setting. The nurses and doctors could no longer be interviewed as imagined without UCL sponsorship and NHS ethical approval as this would affect their employment contracts.

As discussed in chapter 2, the process of a stem cell or bone marrow transplant is not identical to that of ordinary surgery, and technically it does not involve any major surgery. Instead, it involves a transfusion of either bone marrow or stem cells through an intravenous line (Hickman line) located in the central part of the upper body of the recipient (Feivelson, 2006). So, it was only through the observations of the BMT unit that the following methods were considered and chosen, and they are outlined in more depth throughout this next section. These methods were centred around a convergent parallel mixed methods design using an online survey and in-depth qualitative interviews (Creswell, 2014).

> Convergent parallel mixed methods is a form of mixed methods design in which the researcher converges or merges quantitative or qualitative data in order to provide a comprehensive analysis of the research problem. In this design, the investigator typically collects both forms of data at roughly the same time and then integrates the information in the interpretation of the overall results. Contradictions or incongruent findings are explained or further probed in this design. (Creswell, 2014, p.15)

The questions used in the survey and in the interviews were developed in accordance with my experiences of the BMT unit. As I spent more time on the unit, I began to draft questions that were key for the research. Admittedly the survey is what some researchers would call a questionnaire as it seeks both quantitative and qualitative forms of data (Seale, 2018)

In regard to the sample size, it was anticipated that around 20 families, would participate in the study, either through completing the online survey or participating in the in-depth interviews. Although it can be hard to estimate numbers in qualitative research (Sandelowski, 1995; Baker and Edwards, 2012) so sample sizes are usually dependent on the populations in question. From speaking to the consultants on the BMT unit, I learnt that bone marrow and stem cell transplants were not as frequent as other treatments and on average only 20 new patient transplants were performed each year on the children's unit that I was observing. However, the unit's patients were also part of the outpatient clinic post-transplant for an average time of two years, so the sample size estimation also took these numbers into consideration. I used the same sample estimation whether the participants were going to be recruited from a hospital or not. Again, before moving to outside participant recruitment, this BMT unit was intended to be used as a case study because of the age of the patients that it cared for. So, my sampling ideas were centered on this one unit as a starting point for my research topic (Creswell, 2014).

Nonetheless, the study also had an inclusion and exclusion criteria which meant that only those who had started treatment could participate, thus allowing the sample estimation to fall into both the in-patient and out-patient categories. In this case, as the study was not on a hospital site, most of the participants fell into the out-patient category.

In addition, the sample was also intended to be a purposive one (Flick, 2014) where there would have been a range of malignant and non-malignant illnesses and an even spread of male and female participants involved depending on who volunteered. These volunteers were eventually recruited from two charities that advertised the research to their support groups. The charities were the Anthony Nolan Trust and Fanconi Hope. Once it was clear that a different participant recruitment direction needed to be taken (public and not hospital), I contacted the managers of these support groups to ask for their support in helping to recruit volunteers for the study. I had heard of the Anthony Nolan Trust through my observations of the pre-outpatient clinic meetings, and I had been told about Fanconi Hope by a family I spoke to on the BMT unit. So, I followed these leads to support the project through what ended up being purposive snowball sampling (Seale, 2018).

The Anthony Nolan charity is a popular source of information for those who require stem cell and/or bone marrow transplants. They help medical professionals in finding donors, and they have volunteers who support families that are having treatment for cancer. They also collect stem cells, cord blood and bone marrow from volunteers, and they also conduct scientific research amongst other outreach programmes (see anthonynolan.org).

Fanconi Hope is a charity that supports those with Fanconi anaemia. “Fanconi anaemia (FA) is a rare hereditary disease characterized by bone marrow failure and developmental anomalies; a high incidence of myelodysplasia (MDS), acute nonlymphocytic leukaemia (AML), and solid tumours; and cellular hypersensitivity to cross-linking agents.” (Bagby and Alter, 2006, p.147). These two charities worked with me to ensure that the information given to their members was clear and concise through consultations of the study materials, a form of Patient Public Involvement (PPI) as I will also discuss in this chapter.

I also contacted other BMT units in the country prior to the research moving from being based within an NHS hospital. Some of these units treated particular illnesses and others were for different age groups. The aim was to collect experiences from families with patients/donors between 0-16 years old where possible. In addition to NHS BMT units I also contacted other organisations for their support such as The Sickle Cell Society and CLIC Sargent, a charity that works with young people who have cancer. However, the final collaboration was with Anthony Nolan and Fanconi Hope. And from these two charities the sample consisted of only parents, which was ideal given that during the scoping exercise it became clear that each stakeholder’s role in the consenting process should be understood individually, to critically inform follow up research on the topic.

Once the research received ethical approval from the Institute of Education, UCL (see appendix 6), I started to distribute research posters, information sheets and study information sheets to the gatekeepers of the study, Anthony Nolan and Fanconi Hope, (see appendices 1-4). They used an invitation letter (appendix 3) which they distributed to their members via email accounts, and they also posted the study recruitment poster on their social media pages. The patient age range within these groups varied, but there was no age limit for the parents of children who had been through or were currently going through the transplant process. Although the research protocol did have the following inclusion and exclusion criteria (see following table). A research protocol was also important for planning the research and it was used to receive a peer review before the data collection phase.

Study inclusion and exclusion criteria table.	
Inclusion	**Exclusion**
• Parent/carer/guardian of BMT unit patient (in or out-patient)	• Those who have not formally started the BMT process (this is signified by a signed treatment consent form)
Out-patient of the BMT clinic	• People with no direct connection to a patient of a BMT unit.
• Relative living with patient of BMT unit (in or out-patient)	

Method Designs

I will now discuss the designs of my data collection methods. I have experience of employing both the methods that I used, and I was aware that careful consideration was needed when it came to the layout of the survey and its contents. I had to ensure that the questions on the survey were going to be effective for both the survey and the interviews. Moreover, I referred back to what the abductive approach aimed to do as a logic for inquiry and thought about how the sociological problem could be resolved during this crucial stage of the project. Given the change in approach to participant recruitment, I had to ensure that if the survey was the most favourable data collection tool by potential participants, it had to collect a high calibre of data. Although, as I was using both methods at the same time, the interview guide also had to reflect the contents of the survey.

To recap, the research problem is focused on the paradigm shift of decision-making power in medical spaces. And I want to explore communication within the BMT consent process to understand medical decision making in this field of medicine, and to see how informed and voluntary parents give consent on paediatric BMT units.

The Survey

The main rationale for using a survey to collect quantitative data was so that a different kind of perspective could be given in relation to the research aims (Stiff et al., 2006). Of course this approach is closely linked to the positivist epistemology. One of the key advantages of this approach is that phenomena can be grouped according to similarities or differences and operationalised into ‘social facts’ (Durkheim, 1982). These facts can act as variables which in this case can be used to empirically assess the usefulness of the consent process (Duncan and Cramer, 2001) and can be analysed to determine the expectations of the participants alongside the outcomes pertaining to their experiences of the BMT process on a whole (Field, 2016).

The main difference between the dichotomous methodological schools of thought mentioned in this chapter, is that the interpretivist methodological assumption favours subjective means when exploring the social world , while the positivist assumptions of objectivity favour objective data derived from an assumed objective reality (Silverman, 2022). Of course, it is debatable which approach is more useful in helping one to understand our social realities. However, it is important to leverage both approaches for building on the knowledge already available about bone marrow and stem cell transplants, and how consent is sought for treatments involving children who are patients and donors.

The survey for this study was designed using open and closed questions to gather both qualitative and quantitative data, and it also included the Decision-Making Control Instrument (DMCI) which was used at the end. The DMCI is used to look at perceived voluntariness when parents make treatment decisions. The higher the total score using reversed scoring of the 9-point scale, the more voluntary the decisions are. The DMCI was initially used in a hospital setting 10 days post consent, but in this case the variable of ‘days post consent' was not used (Miller *et al.*, 2011). Therefore, the DMCI was used as an additional exploratory tool embedded within the survey for the thesis topic. It also seeks to support the research question on voluntariness.

Careful attention was also given to what types of questions the survey should seek and what types of data the questions would generate. But the overall survey design was guided by my experiences of spending time on a BMT unit.

The survey design was standardized for reliability, and it was to be used alongside the interview schedule. If the participants opted for the interview only, then the same questions used in the survey were to be asked, albeit modified for a conversational approach (de Vaus, 2013). This was to ensure that all participants were to be asked about the same topics. Alternatively, where participants volunteered for the interview after the survey, then they were asked to elaborate on some of their answers to add more clarity to those already given on the survey

The survey and the interview both sought reflections from the participants but on various levels where the latter was more in-depth, however that is not to suggest that the former lost its exploratory power. People reflect differently and others prefer different modes of reflection in terms of social research methods (Seale, 2018). Moreover, the survey questions (see appendix 6) were phrased to align with the narrative inducing question (NIQ) (Flick, 2014) of the interview schedule (see appendix 5). Within the survey there were also nine open ended questions which focused on the thesis aims, making the survey a strong tool within this study for generating meaningful data for this thesis. Overall all the questions related in some way to two narrative inducing questions that were part of the interview schedule. These were,

Can you tell me a little about your/your child's illness, how it started and how you decided to first visit the doctor?

Can you tell me a little bit about (child's name) before he/she was diagnosed? How were they as a character?

These narrative inducing questions were the prompts for the parents to tell their stories of their children's illnesses and their experiences of the BMT consent process (see appendix A for their responses to the NIQ). The survey like the interviews also followed a strict eligibility criterion and those who had not started their BMT journey were not able to participate. As the survey was online, those who had not started treatment were not able to continue beyond the study information page. I designed the survey using the online survey platform Qualtrics, and I had programmed it to end automatically for those who were not eligible or chose not to consent to continue beyond the study information page.

The final design of the survey was based on the idea of giving parents and carers the opportunity to answer questions that were relevant to their own situations, and unless they made some errors, they were not asked questions which were not applicable to them. A Word version of the survey can be found in appendix 5 and this indicates the material within the online survey. The version in appendix 5 is also based on a final peer reviewed recommendation from a BMT support group manager who offered feedback on earlier drafts and checked the quality of the questions I planned to ask (see appendix 5a). The review from the support manager highlighted questions which needed to be changed and considered more carefully to account for the sensitive nature of the topic. This review was also important for ensuring that the material in the survey was appropriate for gathering the information the study required and formed part of the study's patient and public involvement (PPI) goals (Renedo, Komporozos-Athanasiou, Marston, 2017).

There were also number of advantages for having the survey available online. The online platform Qualtrics allows participants to provide an email address so that they can be sent the survey to complete at a time that better suits them, and this is ideal in a society where the use of technological gadgets is ubiquitous. The Qualtrics programme allows administrators to check those who have completed the survey, and it also allows them to send reminders to those who have not completed it. In the case of this research it also provided data on the traffic flow to the survey, and it showed how many people had attempted to complete the survey, and where they stopped. However, the data presented will only reference those who completed the survey to the end. Moreover, the online availability of the survey allowed data collection to be more secure than using online forums on a website where the participants' accounts could be more vulnerable to unwanted advice or abuse. So the online survey ensured increased privacy and anonymity for the participants.

I will now discuss the interview method and what I did for this study. This will lead into the patient and public involvement part of the design phase and the ethics process.

The Interviews

Throughout the study, the interview method was employed as a method for data collection alongside the survey. Firstly, the interview method in social research is favoured by qualitative researchers because it is viewed as a sufficient way to elicit meaning from individuals (Back, 2007; Blaikie and Priest, 2019, Kvale and Brinkmann, 2008; Silverman, 2022). The interview as a means of gathering rich data has also been considered a longstanding tool of advantage within qualitative research, and most particularly the long interview as it can generate a great deal of data from research participants, McCraken (1988) being its most cited proponent. The 'long' interview (McCraken,1988) is a primary source of data gathering as it is through having in-depth interactions with social actors that researchers can elicit and decipher meaning relating to their social realities.

However, the data derived from interviews is dependent on what a researcher asks the research participants and interviews are not always effective, especially if researchers are not reflexive as individual actors. After all, they are part of the same world as those they research. Therefore, Brinkmann and Kvale suggest that “a good interview question should contribute thematically to knowledge production and dynamically to promoting a good interaction” (Kvale and Brinkmann, 2008, p.131). This is a key point because researchers are part of the same world as those that they research, and the rapport created in an interview setting can come out of the questions being asked. In this case the benefits of the interview as a research tool for gathering data are contingent upon the interview questions, and whether or not these are able to elicit knowledge which cannot be observed or collated through one of the other research methods that have been used in this project. To avoid reader confusion here, I appreciate that the research diary is a method in itself governed by personal ethical guidelines (see Back, 2007 and Duneier, 1999)

In addition, interviews allow for probing of answers which makes them useful for gaining clarity on the language and meaning that research participants are trying to convey in their answers. An advantage that is difficult to apply to self-administered surveys hence the use of multiple methods in this study (Foddy, 2008). Of course, I would also argue that the long interview is very useful for this research because without a rich narrative on the BMT consent process, it would arguably be difficult to understand how parents are informed about the procedures and how voluntary their consent is. Again, these rich narratives are stories of family experiences of BMT units, and the consenting process on these units.

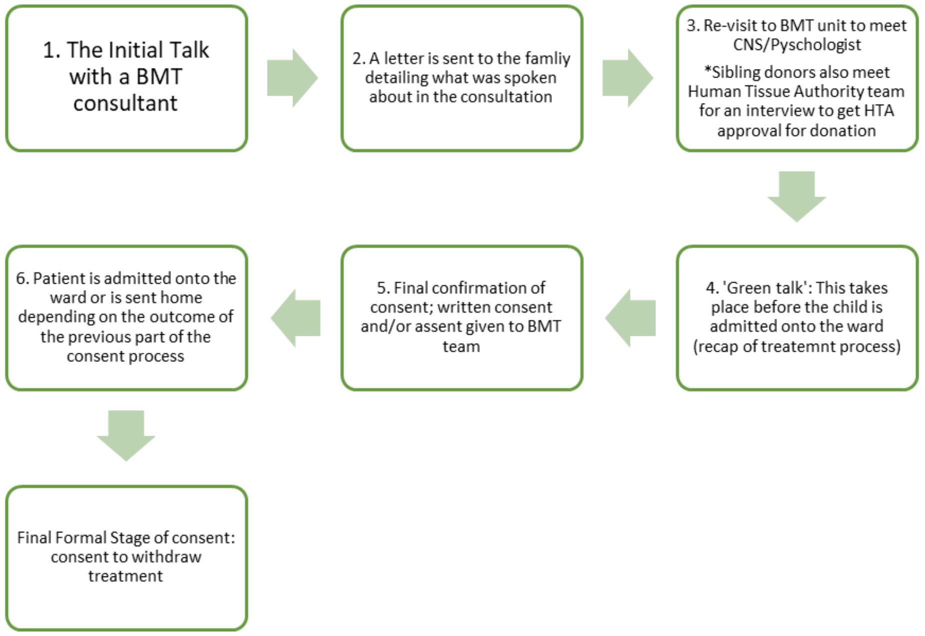
Thus, in consideration of ethical points, specifically the issue of psychological harm (BSA, 2017), the interviews followed a strict criterion for when and where they would be conducted with regard to the schedule of the children’s treatment. Firstly, it was anticipated that interviews were only to be conducted once patients had been admitted to hospital for their transplants, which would have been seven days post transfusion or later, to allow for the adjustments into hospital to take place. However, no participants fitted into this criterion at the time of volunteering to participate in the study. But this criterion was also relevant for a hospital-based study as this was to ensure that there were no conflicts of interest between participation in the study and treatment decision making. As a result, the interviews were to only be conducted with parents whose children had already started their BMT/HSCT treatment journey or had already been through it and had been discharged as in-patients from the hospital. These participants were also attending out-patient clinics at the time of the interviews, so they were still in contact with the hospital. I note that this had no impact on the study's ethical approval as the parents were not 'active' NHS patients or NHS service users at the time of data collection.

As previously mentioned, once children are discharged from the hospital, further transplant related check-ups are conducted in the outpatient clinic, and this continues for a number of years post-transplant. In relation to what was discussed in the literature chapter, the outpatient clinic enables those who are no longer in-patients to maintain the habitus of the hospital despite no longer being there. So the family (parents included) continues to be part of the 'remission society' and their illness narratives still play a role within their lives. And as they continue to embody the hospital habitus, it remains possible to analyse the changes in dynamics between the physician-family relationship, as Silverman (1987) observed in his study, a key point that will be returned to in the analysis.

The interview schedule that was used during the interviews was developed in line with what was observed in the initial stages of the research design phase. The consent process as I observed it, followed a certain ritual for those who have transplants but there were differences for those who have unrelated donors and those who have sibling donors (see figure 1). I believe that it is now also different for those who have gene therapy (Sheykhhasan and Manoochehri, 2022).

It would have been ideal to interview families during each stage of the consent process (see figure 1 below) to analyse the differences in experiences at and between each of these stages. However, this was not possible, and so the interview schedule had to reflect each point of the consent process to cover the disadvantage of not recording the participants' experiences at each stage within a hospital setting.

Figure 1: Flow diagram of the consent process



Ironically, the criteria that made the participants eligible to take part in the study such as "having started treatment" would not have allowed me to follow the families at each stage. And recording the participants' experiences at each stage of the consent process would only have been possible during observational field work. This is because the formal consent documents are not signed until the patient is admitted onto the ward, which is between stages 4 and 5 of the previously observed consent process. I say 'previously' as the consent process may have changed between then and the time of this publication.

Due to the nature of transplants and given the limited number of transplants within the UK each year, some of the participants were not local to my location in London. Therefore, some of the interviews were conducted via Skype. Ethically this did not cause concern for me as I have conducted Skype interviews in previous research projects, but I made this clear to the participants and ensured that I was in a private place when these interviews took place. Verbal and written consent was also given at the beginning of each interview, online and in-person.

Peer Review and Patient Public Involvement

Prior to commencing the data collection, the study was peer reviewed by an academic from the Institute of Education's Social Research Institute to ensure that the methods and the topic were suitable for doctoral research. The study was approved during this peer review process, and the suggested recommendations were addressed before the study began. This review was also important for forming parts of the UCL Sponsorship and NHS ethics approval processes. Following on from this review any changes that were relevant for the new participant recruitment direction were made, but again this review highlighted where each stakeholder fits, in a wider study on consent in BMTs/HSCTs.

Before the data collection began, it was important to get patient and public perspectives on the research project as a whole (Miles, Renedo and Marston, 2018). Initially patient and public involvement (PPI) sessions were going to be conducted at the hospital site, and I had a meeting with the PPI manager to learn more on how to do this. I was advised that this was an important aspect of conducting research about children and families, especially research that was intended to benefit the children's hospital experiences. However, as the NHS site was no longer going to be used for the data collection phase, I sought advice on the information sheets and consent forms from the charities Anthony Nolan and Fanconi Hope as they were going to assist in recruiting the participants. Copies of the study documents (information sheets, consent forms and interview schedule) were sent to the charity managers, and they forwarded these to their close contacts within their parent advisory groups. They gave detailed feedback on these documents, and I addressed their suggestions and recommendations before data collection began. The online survey was also given detailed feedback, and I made changes to ensure that this feedback was utilised within the final draft of the survey.

Moreover, through my own contacts with parents of children who suffered from chronic illnesses, I was able to get direct feedback on the consent forms and the information sheets. This was crucial in ensuring that the information was easy to understand before, during and after data collection. The language used in the study documents was also important. For example, I was advised that patients who worked with one of the charities received stem cells from a donor. The only difference was how the stem cells were collected from the donor. Through PPI it became clear that some stem cells received by patients would have been collected by peripheral blood stem cell collection (PBSC), known as stem cell transplant. Whereas a minority would have been collected via bone marrow, where the marrow is extracted by needle from the donor's pelvis under general anaesthetic, often known as a bone marrow transplant (BMT). Most people refer to both types as "stem cell transplant". This distinction was helpful, as previously the study documents were confusing for some of the people who reported feedback on the design, so changes were made for more clarity.

I believe this distinction between the ways stem cells are collected may also be confusing for the reader as in some places both medical terms bone marrow and stem cell transplant are used and in others either one or none or HSCT is used. However for absolute clarity, all the procedures take place on a BMT unit and that is the rationale for 'BMT' standing out more strongly as the term used most frequently in this thesis. It is also from my understanding and experience that everyone refers to BMT units the same (BMT units).

Ethics

This research study followed the British Sociological Association's 2017 *Statement of Ethical Practice*. The research also followed the guidelines of the Data protection Act 2018 and the General Data Protection Regulation (GDPR 2018), especially when it came to designing the participant information sheets and the consent forms.

I have been careful as far as possible to protect all interviewees' privacy, so that they cannot be identified in this thesis or in any reports by anyone, this includes the healthcare staff and families from the BMT unit I observed. All the research interactions were confidential, and I did not discuss anyone's views, whether given to me informally or during formal interviews, with anyone else during the planning stages, the data collection phase and the write up of this study.

The participants involved in the study were made aware that all participation was voluntary and that they reserved the rights: to withdraw from the study at any time before the thesis was submitted; to withdraw any data which has been collected from them before the thesis was submitted; to ask questions; to pause, ask for breaks and refuse to answer certain questions (see attached consent forms and information sheets in appendices 1 and 2).

The participants were also asked to signify their consent both verbally and in writing on the consent forms (Hammersley and Traianou 2012). The consent forms included opt-in or opt-out tick boxes beside each research method to comply with the GDPR requirements of consent documentation.

To ensure that the participants understood the study, the interview part of the research was explained to them orally and the information was also given to them in written form before and during the interviews. They were also given the opportunity to ask any questions about the study before commencing with the interviews. Unfortunately, there was no budget for interpreters, so the interviews could only be offered to families who did not require an interpreter.

However, those who were not fluent in English were still welcome to complete the survey. They had the option of completing it in the comfort of their own spaces where friends and families could interpret the questions for them.

To minimise risks of privacy breach, all of the data was collected within safe spaces, such as online from our own homes and in public cafes. The Interviews were recorded on an encrypted portable digital recorder, and all fieldwork notes were kept in a single diary separate from other research work and these were stored in a locked cabinet when data was not being collected. The raw data from the online surveys was stored on an encrypted laptop which was also kept at home. This laptop will remain in my home and be kept locked away during the course of the viva process when it is not in use, and all data will be deleted after I complete my studies. During the transcription phase, I verbatim transcribed all of the interviews, and they were anonymised during this process. The audio-recordings will also be deleted after the viva and submission of a successful thesis. Additional contact information about the participants, such as telephone numbers to arrange interviews or email addresses to forward the link of the survey were kept with a code sheet as part of the field work notes.

Reflection on the methods

Throughout the research process much consideration was given to the types of data collection methods that would best describe the transplant consent process. As previously mentioned, the reasons for transplants are not all the same and sometimes the process of treatment and recovery is beyond what doctors expect, so the aim was to simultaneously use a variety of methods which could capture the different elements of treatment (Bazeley, 2018). Initially, the idea was to conduct much of the research using participant observations, which rely heavily on the doctrines of ethnographic principles and anthropological history (Duneier, 1999). However, this was not possible, so the best available methods were the survey and interviews, but for me to recruit the participants, I had to make both methods available at the same time (convergent parallel design). Nonetheless, the survey method also allowed me to recruit participants for the interviews, even though I had a few setbacks from its online design features. In hindsight, I would argue that the participants who took part in both the survey and the interview were part of a longitudinal design process and not a cross-sectional design. However, this study is too small for me to make such a generalisation, but it is something for me to reflect on for further studies where I may employ a convergent parallel design (Bazeley, 2018).

The survey was initially designed using two platforms, REDCap and Qualtrics, and eventually Qualtrics was selected for the study as it was easier to navigate through and to manage. The first initial survey responses were able to highlight some technical design mistakes previously missed in the piloting stages. Even though the Qualtrics platform was used to collect responses, little details were missed on some of the multiple-choice questions (such as ‘My child passed away’). And I can only speculate that some potential participants may have felt dejected and chose not to continue with the survey because of the missing (‘my child passed away’), in hindsight this was due to my own naivety as I did not initially consider this as a possible option. However, one positive is that participants, were able to highlight these mistakes on the form, and this enabled me to make slight improvements to the format of the survey before others completed it. Any implications, albeit speculative, of this oversight will be discussed further in the analysis chapter.

However, the fact that I was able to recruit participants by using the survey shows how powerful it was as a tool in this research process; and that it should not be dismissed from consideration as a supporting method for qualitatively focused research projects (de Vaus, 2013). In this case, and in such a complicated field of transplants, it proved vital to make use of multiple methods to gather data. And, looking back, I believe that the data collection process would have been highly difficult outside of the hospital setting without a mixed methods approach.

Methods of Analysis

I will now finish this chapter with a discussion on the methods of analysis that I used to inform chapters 4-6. I will also introduce some of the participants and give details on our interviews to provide some context to the overall data presented in the following chapters. Lastly in this chapter, I will introduce the themes that came out of the analysis. This will set the foundation for the overall analysis of the data and the final chapters of the thesis.

Interviews: Narrative Analysis

The qualitative interview data was analysed using narrative analysis techniques, which move beyond just selecting themes at a single point of each interaction. Once I had transcribed the interviews verbatim, I imported them into NVivo to organise the data into the emerging themes. I began the coding with a collection of general themes and then I started to connect the data that was related across the interviews, and this process started to narrow down the codes into the main themes that I will work with in the analysis chapters. The themes that emerged during the early stage of the analysis were; family life, hospital life, first signs of illness, BMT decisions, risks in transplants, trust in consultants: dealing with consultants from different departments but working in the same team: drip feed process; Parents understanding treatment; consenting to chemotherapy; and total body Irradiation (everybody needs to consent to this). A final theme was long term health damage, the quality of life after a transplant. I arranged these themes into codes on NVivo and I selected evidence of these from the narratives that I had organised into cases (participants). Having identified these themes, I then moved on to sorting the data around the BMT consent process from the start to the end of treatment. As seen in table 4 the main themes that I found at this stage were, understanding information: choice and voluntariness; and supporting decision-making . These are the themes I shall use in this analysis.

The rationale behind choosing to analyse the data from the interviews using narrative analysis, a process which closely mirrors discourse analysis, was because of its approach to paying attention to detail through its iterative steps

(Bazeley, 2013). As with discourse analysis, narrative analysis pays close attention to the actors' words and the meaning they intend to disclose within the language they use. In particular, narrative analysis allows researchers to pay attention to the stories its subjects tell, and this is important for understanding the experiences of the parents in this study. The research problem at the start of the project was the driving factor for how the research was designed and conducted, and how the method of narrative analysis was decided upon. As there is a strong focus on the communication that takes place within the BMT consent process, analysing the experiences of the participants required an analytical approach that can make sense of the meanings behind the stories that they told.

Narrative analysis goes beyond the discovering of themes as is central to thematic analysis and it can also include a dialogical element to it, depending on the project aims. Brian Alleyne points out that; "it is important to keep in mind that an actual narrative research project will always see the researcher drawing on both analysis of narrative and narrative analysis" (Alleyne, 2015, p.49). Therefore, the analysis of the data in this study was twofold, and the process was an iterative one, moving from the identification and collection of abstract themes to a deeper engagement of them (Alleyne, 2015), which allowed me to concisely reduce them to what forms the contents of the following chapters. The first part being the analysis of narrative, closely engaging with the interview transcripts and familiarising myself with them to find the stories that the participants were telling me. During the transcription phase of my analysis, I did this by rewinding the tapes a lot and closely listening to what the participants were saying. The idea was to make sure that not only was I capturing every word of our interactions, but that I was also making sure that I understood what was being said. I also did this alongside reading my handwritten notes as there were times that more was said when the tape recorder was switched off. I wanted to take account for any notes that I may have made during these moments. This first part of the analytic process, the 'analysis of narrative' element of narrative analysis, I found for me personally, that it is a natural part of working with qualitative interview data. The process can feel immersive if it involves listening back again and again in an iterative process when the aim is to capture each person in the conversation's story. I believe this is what Alleyne argues about the need to draw upon both analysis of narrative and narrative analysis. I also recall this message as a student of his in the lectures on qualitative research. Thus this first step was where I coded the general themes that were coming out of the interviews.

After I worked on the first step of analysis of narrative, I moved onto the next stage of the narrative analysis where I focused on a detailed analysis of the dialogue between the speakers in the interview interaction. As the interviews were transcribed verbatim, the first part of the analysis as noted above was to find the stories (themes) within the transcripts.

> In narrative analysis we want to bring the concepts and language of the individual subject of the narrative to the foreground; the concepts and language of the individual narrating their story are what we call 'emic', and these are important for understanding the meanings given to events by that individual. So, analysis of narrative is a nomothetic approach that uses etic concepts, while narrative analysis is an ideographic approach that seeks to interpret the narrative in emic terms (Alleyne, 2015, p.47)

Alleyne points out that in narrative analysis the aim is to focus on the meaning of the story being told. What are the participants saying, and what do they mean to say? To which I would also add, in the case of research interviews, what is the interviewer trying to find out in the way that they question the interviewee to support the construction of the narrative. This part of the analysis phase encompasses a deeper exploration of the discourse between the actors in the dialogue. It considers the themes that have previously been extracted from the first part of analysis and then works with them to try and show the meaning behind the text. Narrative analysis allows researchers to search for meaning within the narratives of those they study, by paying in-depth attention to the meaning behind the language used in the narratives and stories of the actors they research (Wodak and Meyer, 2009).

For that reason, in this thesis I show that there is more to just knowing what the themes are; and that these themes needed a deeper analysis to understand what they meant to the study, and the aims of the study. As mentioned thus far, stem cell and bone marrow transplants are not simple procedures; they are complex procedures addressing complex medical conditions such as Severe combined immunodeficiency (SCID), bone marrow diseases like severe aplastic anaemia, Fanconi anaemia, Leukaemia, Sickle Cell Anaemia, and others. Therefore, the process of data analysis had to be one which goes beyond an accumulation of themes. It had to be geared to understanding the significance of the experiences that this small group of participants have to offer. Again, the rationale for relying on a narrative analysis of the data is partly because my study does not have a large enough number of participants for me to generalise across the entire context of BMT experiences (Silverman, 2022).

My selection of themes are geared to align with and make use of Bourdieu's theoretical framework of the habitus, field and capital. One of my objectives is to show how the parents' experiences through their stories of childhood illness journeys illuminate the habitus of not just life in hospital but life on the BMT unit. This method of narrative analysis will support the study by providing a clearer picture of how the habitus, as theorised by Bourdieu, plays a strong role in the communication relationships of those on BMT units, and how these relationships have an effect on the decision-making capacities of those involved in the treatment process. In a way I want to use stories as medium for showing how people become part of their surroundings and learn to live and construct their lives within the spaces they inhabit. This may support further understanding as to why clinicians are seeing a shift in the decision-making authority within the family, where parents appear to have more power in medical decision making (du Pre & Brierley, 2018).

Alongside using narrative analysis I have also used the quantitative data collected mainly from the survey, within the analysis chapters. Overall, the survey is what some would call a questionnaire as it contains a majority of open-ended questions that produced qualitative data, whilst other questions produced data which is suited to both qualitative and quantitative analysis techniques (Bazeley, 2018). Thus I will be drawing on two types of data where necessary in chapters 4-6, as both types of data offer their own particular insights into the research questions. In taking this approach I follow other researchers, who have noted that, “narrative analysis draws on a range of theories and in fact contains within it several different varieties of analysis, so it is hard to specify overall rules about what kind of data ought to be analysed, or even how any one narrative analysis should proceed” (Griffin and May, 2018, p.512).

Survey: Mixed analysis

The survey in this study was quite unique as it contained a mixture of qualitative and quantitative measures. The data from this was analysed using descriptive statistics for the quantitative measures and these will be individually touched upon throughout the analysis chapters. As the survey was used alongside the interview method at the same time through what I mentioned earlier as a convergent parallel design, the survey data are analysed alongside the interview data (Bazeley, 2018). The survey also included questions that were directly in line with the main research questions (see table A). These open-ended questions were analysed using the narrative analysis approach. Table A also shows the questions that were covered in the narrative inducing question of the interview schedule. As noted earlier, the interview questions are very important for creating a rapport with participants and in a way, the survey attempted to mimic an interview interaction as much as possible within the questions that were used.

Table A: Survey Open Ended Questions

- There were 10 open ended questions with a focus on the thesis aims which offered the possibility for probing through the interviews.
- The 5 questions in right column of this table are all covered in the narrative inducing questions (NIQ) of the interview schedule.

Open Ended Questions in the survey	Questions within the NIQs of the interview schedule
1. Who talked to your child the most about what the treatment was going to be like?	6. Do you know what illness the treatment was for?
2. What did you find useful from the time you went for the first pre-treatment/BMT appointment, until you went onto the ward for treatment? (You can write in as much detail as you like)	7. What was the illness? (Please write as much as possible about it)
3. What did you NOT find useful from the time you went for the first pre-treatment/BMT appointment until you went onto the ward for treatment?	8. How long was your child unwell for before they went onto a BMT unit?
4. Was the treatment what you expected? Please write a little about your answer.	9. What was the reason for the treatment? Please write as much as possible about it.
5. Looking back at the whole experience of treatment, did you want your child to h**ave** the treatment, and why?	10. *_There is no right or wrong answer to the question below_ What age do you think that children are able to give written consent (signing a form) for treatment on a BMT unit? You can give a reason if you wish.

This survey, unlike the in-depth interviews was used as both a method of data collection and as a participant recruitment tool. The results of the survey highlighted some of the material which needed to be covered in the interviews. Therefore, throughout the analysis chapters both methods are referred to, considering the data that each tool was able to accumulate and contribute to the study.

The issue that stands with the approach that I have taken of using both the survey and interview data in the analysis is the one of methodological contentions between qualitative and quantitative data (Bazeley, 2018; Creswell, 2014). But my approach to a mixed methods design was one of pragmatism, flexibility and necessity to learn more about the BMT consent process. The abductive approach that I employed for the design of this study is centred on gaining new knowledge and thus I argue that if both qualitative and quantitative approaches to data generation support the purpose of this thesis, then I as a researcher must use both to report the relevant data. Bazeley also notes that “mixed methods researchers are typically open, also, to make use of “opportunistic data”, such as incidental comments and observations that are more usually regarded as noise and discarded” (Bazeley, 2018, p.29)

Whilst listening to the tapes and transcribing the interviews, it was clear that some of the questions asked were referring to answers previously given in the survey (see appendix 6). This shows that the survey as a method for data collection works well in helping to probe the answers that a participant has previously given (Bazeley, 2018). Both I, as the interviewer and the participants had a well built-up idea of what the interview was going to entail and maybe even what path it was going to take, as the interviewees had all completed the survey beforehand. The survey also prepared us (interviewer/interviewee) on how to handle and answer the questions that were going to come up based on the responses in the survey, given that some answers used bullet points. Moreover, the survey smoothed the transition of the narratives effectively through the ways that I was able to prepare and probe for in-depth answers based on the participants’ previous responses that they gave in the survey.

Participant Demographics

There is another important aspect to life that I want to highlight in this thesis, and it is one which causes variations in how families experience the transplant process, and that is the socio-economic statuses of families. Firstly, the following table B (participant demographics) below shows the demographics of the participants who completed the survey in this study, and this information was taken from the survey, table 3 (participant details) offers more data on the illnesses of the children. Though what can be seen in table B is that apart from Cathy, all the participants were married and either working full time or part time at the time of the interviews or in the most recent 12 months of completing the survey online.

The table (B) also shows that five out of six of the participants were in employment, one was in full time employment and four were in part time employment, and another was unemployed at the time of completing the survey (the seventh is not included). Although the data does not specifically allude to the type of cultural capital that the participants held, such as educational qualifications, it does give a description of the particular employment sectors that they were in. The table also shows that four of six participants were married, one was single, and the other was in a relationship. The rationale behind exploring the occupational status of these parents was so that one can better understand what their day to day lives were throughout the illnesses of their children and to get a picture on who may have been the main caregiver throughout the transplant process, given that it is a process which lasts a very long time. Parents are now working together to explore their lived experiences when their children are going through cancer treatments, and they are looking for ways that the government can support them when it comes to the economic impacts of childhood illness (itsneveryou.com). Therefore I believe that this data is useful to have as a base for further understanding of parents’ experiences of the consent process on BMT units. This data can also be used alongside more in-depth qualitative data when exploring family structures and parenting strategies (Lareau, 2011).

As previously mentioned, early in the research, bone marrow transplants and stem cell transplants usually require children to remain in isolation for a long time (Feivelson, 2006) where only their parents and carers can visit them within their isolation rooms (and healthcare staff). Most of these children can also end up being alone for long periods of time so understanding the occupational statuses of their parents was very important in trying to build a picture of the relationship these children had with their parents. It was also quite vital to get this information because it is through the parents' experiences and their stories of the experiences of their families and others, that one can get closer to understanding how, and when it could be useful to involve children or get them engaged in the conversation of consenting for transplants. This involvement covers research questions 3 and 4. Moreover, table B highlights the demographics of the people who took part in this research. Unfortunately, it is missing a wide variety of occupational statuses and marital statuses, which may not initially seem important, but may contribute to understanding that there are a wide range of disparities within the data that this lack of information may present, for now.

Table B Participant demographics

	Matt	Janet	Bev	Cathy	Zoe	Kate
Marital status	Married	Married	Married	Single	In a relationship	Married
Occupational status	Employed full time	Employed part time	Employed part time	Unemployed	Employed part time	Employed part time
Job description	High rank	Finance	HR	N/A	Education	Education
Age	Over 30	Over 40	Over 40	Over 30	Over 50	Over 40
Children at home	2	2	2	1	1	2

The other purpose of the demographics table and the other tables throughout the following chapters is to illustrate the data which came out of the survey, especially the data which supports the research questions.

The main themes from all the data are briefly presented in the following section after a brief overview of the participants in table 3, and a summary of the interviews that were conducted.

Data Summary

I will now introduce the participants and the main themes that will be discussed in the analysis chapters.

The Participants

The participants were all aged over 18 years old, and they were parents of children who had either had a bone marrow transplant, a stem cell transplant or both. The illnesses that their children needed treatment for were Fanconi Anaemia, MDS Refractory AML with mixed cytogenetic abnormalities, High Risk Refractory T Cell Acute Lymphoblastic Leukaemia, Sickle Cell Anaemia, Severe Aplastic Anaemia and Acute Myeloid Leukaemia. Two of the parents had other children who were bone marrow donors for their siblings; whilst two other parents, a mother and a father were haplo-identical donors for their children. A child of one participant was deceased at the time of interview but as I noted earlier, this option was missing from the survey, and they highlighted this to me when we met. One participant started the survey on two occasions, but they did not complete it, therefore I have accounted for them, but I have not included their data in the analysis. For transparency, I was going to invite them for an interview but after an online search of their name it became apparent that their child had died, according to the information on their bone marrow transplant ‘GoFundMe’ page. With this in mind, I believed that it was ethically more suitable for me to allow them to return to the study in their own time, but they did not. Nonetheless I have included them as a participant.

In total there were seven participants who contributed to this study using the survey and four of them were also interviewed. In retrospect, these participants can be viewed in the same light as those who take part in follow up interviews for longitudinal studies, given that the survey mirrored the interview schedule (Bazeley, 2018). In a way, taking part in the interviews was a follow up to their initial participation.

Parents are the only participants in this present study and for clarity they can be seen as ‘witnesses’ (De Clercq, Elger, Wangmo, 2016; Frank, 2012) of the accounts that they give in the data. As witnesses their accounts do not represent the views of their children, but rather their accounts are their thoughts about their children. The parents should not be seen as speaking on behalf of their children and the analysis does not intend for this to be the case. Although, one young adult enquired about taking part in the study as she had received a transplant as a child, but she did not participate in the end.

As the population for this type of research is quite hard to access outside of the NHS, my goal was to move towards a ‘methodologically oriented’ thesis; where I reflect on what I can and cannot say with different kinds of data. For clarity and transparency of methods, the term ‘methodologically oriented’ in relation to qualitative research comes directly from the renowned sociologist Professor David Silverman through the correspondence we had at the beginning of this research. He advised that this would be the best way to move forward with this type of study, especially from his experiences of his study on communication in clinics (1987) which I have so far touched upon throughout. In a way, this is similar to the reflexive research approach (Delanty, 2005). I therefore take extra care to reflect on the data presented and how this data informs the study’s questions. Although I do not use my own experiences of observing on a BMT unit as data.

Thus the goal for this type of research is to be mindful of my own reflections on the observations of the BMT unit, whilst analysing the online survey data, and the qualitative interview data together. This is to support the narrative analysis process when it comes to producing the overarching argument of this thesis. On reflection, the ability for me to be reflexive throughout the research process, not only as a researcher but also as a parent led to how the study was shaped and how the interviews were conducted. The interviews were formal in their sociological nature but not standardised, and I had to put myself in the parents’ positions as parents of ill children. This enabled me to think about how I would react in the circumstances which they experienced. This also allowed me to listen to their stories attentively and where possible I let them lead the conversations and at times I joined in with my own experiences. I was not an expert in their lives or in the conditions that their children were going through, thus I had to let them speak and follow up on what I needed clarification on. But I also understand the importance of my input in the dialogue that was constructed and without my input the dialogue may have been difficult to sustain for the production of stories.

My role as a social researcher was not to talk to them like I was a medical professional, instead I was there to open up a dialogue with them about what they thought about the consent process, and what they thought could have been more useful about it. As I was able to relate to them as a parent, I believe this helped in getting them to open up more and be as candid as they could be (with a complete stranger) about their children's transplant experiences[1]. This ease of openness from parents was also experienced during my observations in the clinic, especially as I followed one family through steps of the sibling donor consenting process. But again my experiences are not the data in this study. However, I noticed that once comfortable, the participants in this study and the people I met on the BMT unit were able to tell me their stories of illness.

The following table (3) gives more information about six of the seven participants in the study, their children, and the illnesses that they were getting treatment for. I do not include the seventh participant as they did not complete their survey, and it had a lot of missing data. This is followed by some more details about the interviews with the four participants who took part in the interview part of the study. I would also like to draw the reader's attention to the duration of the interviews and how varied the times are. In total the interviews lasted 7 hours and 33 minutes, combined.

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[1] *There are times where gender neutral pronouns (they/them) are used in the thesis to make the participants and those who they talk about less identifiable to the readers.*

Table 3: Participant Details

This table shows the names of the participants and the illnesses that their children had. They will be discussed using these pseudonyms throughout the rest of this thesis.

Participant's name (pseudonym)	Type of data	Interview duration	Childs' name (pseudonym)	Child's illness	Type of Transplant	Year of Transplant	Age at Transplant
Matt	Interview after survey	38 minutes	Emma	Fanconi Anaemia	Bone Marrow from dad Haploidentical	2018	5
Janet	Interview after survey	3 hrs 15 minutes	James (Deceased)	MDS, Refractory AML with mixed cytogenetic abnormalities	Bone Marrow and Stem Cells (Mismatched unrelated donor)	2017	8
Bev	Interview after survey	1 hr 15 minutes	Misty	High Risk Refractory T Cell Acute Lymphoblastic Leukaemia	Bone Marrow from brother HLA Matched sibling	2014	11

“ “	“ “		Jacob	“ “	Donor HLA Matched sibling	2014	9
Cathy	Interview after survey	2hrs 25 minutes	Troy	Sickle Cell Anaemia	Bone Marrow from mum Haploidentical	2014	11
Zoe	Survey		Henry	Severe Aplastic Anaemia	Bone Marrow (matched unrelated)	2017	16 (signed consent form)
Kate	Survey in May 2019	N/A	John (19 years old at the time of survey	Acute Myeloid Leukaemia	Bone Marrow from sister- HLA	2017	Not Known but signed own consent form
“ “	“ “	N/A	N/A	N/A	Donor- HLA	2017	11?

A brief and reflexive summary of the interviews

Below is a brief summary of each interview that was conducted. I offer more context on the families in the form of brief childhood histories in appendix A, where the participants describe their children before the transplants. This will hopefully add some imagery to the lives of these children as their parents talk about them throughout the interviews. Two of the interviews were conducted online and two were in person. I was quite nervous about the in-person interviews as I did not know what to expect from the parents that I was going to be meeting. Moreover, it was the first time that I had conducted interviews in very public spaces (the cafés), and I was aware that there were going to be many factors beyond my control. I was also mindful that there would be a lot of background noise and that this would affect what we spoke about and what I would pick up form the audio-recordings during the transcript phase. I was also particularly aware of how these spaces may make the participants feel and how they may effect what was spoken about in the interviews (what they told me, what they held back on). Therefore, as an interviewer I adopted an informal position where I presented myself more as a parent than as a researcher at times. I believed that showing how much I knew about transplants from the scoping phase of the research may have helped them to feel more comfortable to talk about their experiences with me. There are points in the presentation of the data where I show how this informal approach supported the conversations through the way I probed, gave my opinions or asked any follow up questions.

The Interviewees

Interview with "Matt" about "Emma": This interview was conducted with a father who donated bone marrow to his daughter who was 5 years old at the time of her transplant. As he lived in the North of England, the interview was conducted via Skype in the evening after he returned home from work. This was also very convenient for us both in terms of time and travel. It took us a while to get into the flow as he was settling down and had just returned home from work. I was patient with him because as a parent I understood what he was going through in terms of settling back into the house after coming in. Overall, the interview went well, and I was able to pick out points that I could improve on for further interviews. ***Interview pseudonyms: Matt and Emma***

Interview with "Janet" about "James": This interview took place early in the morning, in a beautiful café setting not far from the interviewee's home. I travelled there by car, and I was hoping to see her son with her as she had indicated on the survey that he was not at school. Unfortunately, when she arrived and I asked about him, she told me that her son had recently died. She wasn't sure whether she would have been able to participate in the study had she told me that beforehand. I was not prepared to interview a bereaved parent but as we talked, I quickly learned how to manage this unexpected interview situation. Moreover, although I had an interview schedule (see appendix 5), I chose not to follow it closely, instead I checked it every now and again to make sure nothing was missed out. I found that many of the questions were answered without me having to directly read them as they were written.

During the interview, near the point where we took bathroom breaks, Janet the interviewee asked me if I was going to ask her any of the questions on the paper. And I told her that everything was being answered as we talked, but I did give her the opportunity to go through the questions whilst I was away from the table.

Even though during parts of the interview the café did become very busy, it did not affect the conversation, and the staff were very accommodating of our privacy needs even though we took up quite a large table that other customers could otherwise have used. The staff kept our cups full of tea and coffee, and the interview lasted just over 3 hours in total. ***Interview pseudonyms: Janet, James, and Jack (James' brother)***

Interview with "Bev" about "Misty" and "Jacob": This third interview was conducted via Skype (participant's preference) with a mother whose young son had donated to her eldest daughter. Her daughter Misty had cancer and needed a transplant after the first treatment protocol had failed to work for her leukaemia. Bev's young son was a typical HLA sibling match, and he was asked to donate his marrow at the age of 9. Bev gave considerable background information about the chemotherapy treatment process and talked in detail about the medications which her daughter was currently taking after the whole transplant process. She also talked in depth about the impact the donation had on her son. I really enjoyed the conversation that we had about farm animals during the interview, and I was able to relate to one animal that they had started to keep as my mum also kept this same animal. I am mindful not to name it as it may be an obvious identifier. ***Interview pseudonyms: Bev, Misty and Jacob (Misty's brother and bone marrow donor)***

Interview with "Cathy" about "Troy": This interview was conducted in a quiet bistro in North-East London. The owners had allowed the interview to be conducted there at the request of the interviewee, and we were given access to an unopened space to avoid any disturbances. It was a very calm and relaxed atmosphere with background music coming from the venue, although at times it did get noisy as we were seated close to the busy kitchen. Cathy was very open and used her own diary that she had kept throughout the transplant process to help with recalling some of her experiences. As I have family members who suffer from sickle cell, I was very mindful not to assume that I knew everything that Cathy was talking about when it came to her son's SCD. I had to reflect on my position as a researcher and as a family member with a lived experience of sickle cell and hospitalisations from sickle cell, especially as a Godparent of a child with sickle cell too.

This was a very informative interview, and I had to turn the tape-recorder back on as we continued the conversation when we were leaving. It was one of those 'closing the door moments' where the interview starts afresh as soon as the recorder is turned off. ***Interview pseudonyms: Cathy and Troy***

The Main Themes

The analysis in the following chapters includes the main themes that were identified during the second stage of the analytic process. To clarify, the main themes that were identified as the most important using both the interview and the survey data were, understanding information, choice & voluntariness, and supporting decision-making. These themes also correspond with the research questions (Table 4). Once the themes were identified in relation to the research questions, it became easier to find the stories within them. Table 4 below shows the themes and their corresponding research questions. Both the methods of interviewing and collecting data through the survey supported the research questions.

Table 4: Main themes	Research question that the theme helps to answer
Understanding the information; Drip Feeding	1 & 2
Choice and Voluntariness; Limited Choices	2
Supporting decision-Making; 'We Know Best'	3 & 4

The transcription notation below gives context (Silverman, 2017) to some of the symbols that will be encountered throughout the findings. I have taken advantage of the small sample size, to provide longer quotations than usual, which is also in line with the narrative approach to qualitative data analysis. This should give depth and context to the key narratives selected and the results being discussed. It also helps to avoid decontextualising the interactions between myself as the interviewer and the interviewees, as the dialogue was a result of a reflexive approach to conversational interviewing (Rapley, 2018). My position as a researcher who had experienced many months on a BMT unit played a role in the development of the narratives. My knowledge of what happens on the unit meant that I was able to let the interviews flow with minimal interruptions of trying to clarify what the participants were saying. Therefore it was important that I avoided decontextualising the data in the presentation of the analysis for the reader. Thus the longer quotations will allow for the interactions of the interviewees and myself as the interviewer to be experienced better, as actors continually create meanings through their conversational interactions. In some extracts I have removed my interjecting responses which show that I am listening to the participants, such as “mmh”, “yeh” or “oh”, but this does not remove from the context of the stories being presented.

Transcription notation	
(( ))	Overlap in speech/talking over each other
…..	Long pause
______	Abrupt stop in speech

Summary

This chapter has introduced the methodology that underpins this study and the rationale for the chosen research strategy. The methods discussed were the most suited to exploring the research questions and the most suited to the aims of the project. These methods were developed using the most robust and up-to-date ethical guidelines and peer review process which included an internal review and a patient and public review before the data was collected. The remainder of this thesis is structured in the form of a conversation, where I seek to understand the consent process through the thoughts and views of those who have experienced it first-hand using a mixed methods approach.

In the following chapters I will look at stem cell and bone marrow transplants as processes, where consent is a matter of negotiation throughout. It is a medical journey that is built on expertise and immersion within the particular field, where parents learn about treatments and find their way through the process, and this is evident from all the interviews. I will show how the thread of Bourdieu’s theoretical stance on the habitus is at work within the experiences of the study’s participants, whether through the qualitative or the quantitative data collected in the study. I will explore how the parents become very tuned into the hospital setting and begin to assist the healthcare professionals in ways that go beyond the general day to day care that a parent provides. Through the stories extracted in the analysis process, it is evident that the parents develop an understanding of the medications that their children can tolerate, they help healthcare teams to understand their children, as they too become familiar with the individual needs of their patients during the transplant process. Again, this is where the parents as ‘witnesses’ offer insight into the treatment process as well as the consenting process. The following chapters show that consent in stem cell and bone marrow transplants is not as straight forward as one might think. Once the immediate legal issues have been addressed with the signing of the consent form, the trust in the physician relationship continues to be strengthened and built upon throughout the process of treatment. The transplant, although it is a single transfusion procedure characterised as ‘Day 0’ for all that go through it, is just the start. And that is where the elements of consent come into play within this complex process. The following chapters will analyse and discuss the themes identified in this complex process through the parents’ stories.

Chapter 4: The Consent Process as an Event

> so his disease returned again but in his bone marrow…umm yeh, so sometimes it can happen. But then let's face it, if they told us all these things that could happen ((yeh)) what do we do with that information....(Janet)

Introduction

This fourth part of the thesis will focus on the data and the results drawn from it, and I have divided it into three chapters which focus on following the parents through the treatment process from the beginning to the end. This will show what the entire BMT consenting process looks like for families, and it will shed light on how treatment decisions are made on paediatric BMT units. This chapter and the following two chapters will explore the data, following the trajectory of the aforementioned main themes (understanding information, choice & voluntariness, and supporting decision-making). I begin with the start of the BMT journey, following the narratives through the first stages of the consent process and I consider how parents understand the BMT/HSCT treatment process for their children. This is also the time where parents are to be given all the information about transplants, and it is the starting point for them to be informed about the decisions they have to make.

As I mentioned in chapter 2, the hospital is a field in which the parents must readjust their family lives in. In this chapter I will show how the parent's understanding of the hospital and its habitus starts to change once they go onto the BMT unit. These changes in the parents' dispositions are what I refer to when I talk about the 'BMT habitus'. This habitus is shaped by the structure of the hospital and is within the field of the hospital. The data in this study shows that the BMT habitus is characterised by the language used by the people on BMT units. It is communication based and is centred on the medical terminology used by parents and medical professionals. Moreover, the data will show that it is also characterised by the feeling of being comfortable to communicate with medical terminology in the interactions that the parents have with their child's clinical team.

In the presentation of the data I will also mirror the language that is used in the field of BMTs because it offers clarity as to how the people within the field understand the terms, phrases and expressions used within it. For example I start the analysis in this chapter by using the expression ‘the initial consultation’, but in reality, this is not the first consultation as one may think. On a BMT unit, the expression is used to describe a family’s first time coming onto the unit to formally speak to the BMT specialists. It does not mean that this is the first time families are being told about transplants. Rather, the expression is used in a performative way so that families and clinical teams understand where everyone is situated in the treatment process. Therefore in this chapter, I focus on parental narratives that are guided by their experiences of the ‘initial consultation’.

I will introduce consent as an event where the transplant begins after the consent form has been signed, moving the parents from a space of non-consent to having consented to their child’s transplant. Two main events take place here: the first time coming to the BMT unit and the signing of the consent form. Yet one of these is viewed as the most significant, and that is signing the consent form to begin the child’s transplant. But even as consent is presented as a singular event, using a variety of narrative devices to highlight the transition from unknowing to knowing necessary information to enable informed consent, a counter narrative runs alongside. The narrative of ‘drip feeding’ or the idea that information is not fully provided runs through the participants’ experiences and therefore the movement into informed consent is an event that never quite happens. The knowledge necessary for informed consent is always precarious and just around the corner. As the parents’ narratives will show; there are always gaps in the knowledge, and this is evident in the elements of uncertainty, unease and worry embedded within these narratives.

The initial consultation; Shared Uncertainty

The ‘initial consultation’ in the BMT context is when the parents first meet the clinical team on the BMT unit to discuss the treatment plans for their children. This chapter therefore focuses on my first research question: what are parents’ experiences of the BMT consent process for their children? For some parents, the initial consultation is the first time they are introduced to the idea of a bone marrow or stem cell transplant. Others, especially those whose children are suffering from cancer, may have visited the BMT unit during some time when they are in hospital for other treatments, as the topic can be introduced during the oncology treatment process.

The data indicates that the parents identify the initial consultation as the starting point of the process that culminates in consent, and thus I begin with it, focusing on the theme of understanding. This is in line with Beauchamp and Childress (1994)’s consent factor of ‘understanding’ as a part of what it means to give valid informed consent. All the participants in the study described this initial consultation part of the consent process as the most straining, as this was when they were told about their child’s prognosis, and this is where they started to understand the transplant process. During the analysis , this is where the counter narrative of the idea of ‘drip feeding information’ started to appear and float around as an important part of the participants’ consent experiences.

The narratives as a whole showed that parents felt there was a ‘drip feeding’ of information that began in the initial consultation and continued throughout the treatment process. This raised the question of how informed treatment consent decisions on BMTs are. I surmise that the issue here is not about parents giving consent. Rather, it is arguably about how much information medical professionals are willing to give at the initial pre-BMT consultation, so that family decisions can be as well informed as possible.

There are factors that contribute to making the treatment process uncertain for parents. Firstly, the consent process can appear uncertain because it is iterative. Whenever a treatment does not meet the expectations of the clinical teams, consent must be sought again for another treatment. Thus knowledge is constantly being generated within the BMT space, and this may be why the parents come to understand the information they are given as drip fed to them. Once the parents know something about the transplant process but are then presented with further information as their children's treatments progress, they may feel as though they have to re-evaluate previous knowledge to accommodate the new.

The 'drip feed' theme is thus central to my findings and again this is within the main theme of 'understanding'. The feeling of being drip fed came up often in the interviews and it was also evident in some of the survey responses to the open-ended questions, although the participants did not refer directly to the term (drip feed), and at times their references to it were discreet. The parents felt as though the information which was given to them at the initial consultation regarding a transplant for their children was either not enough at the time that they were receiving it, or that information was being held back. Here Janet, the mother of a child who passed away a few months before her interview with me, explains her observations of being drip fed information.

> Janet: I think you actually need to be honest sometimes, you need to be truthful, and at 'London1' they've got a thing which I've experienced now and I know so well, they do a drip feed process; you know where they tell you something today and in a week's time when they think you're ready for the next bit they give you the next bit and in a week's time you get the next bit. They knew all of that ages ago but they didn't tell you that ages ago because they are not sure that you could cope with it or if it's the right thing to do, or whatever if you'd been getting treated elsewhere you may have a different experience with that I think, I don't think the drip feed would have been done the same way, and personally I don't think I appreciated the drip feed process—
>
> Interviewer : I think they drip feed everybody don't they?
>
> Janet: Have you noticed that then?
>
> Interviewer: like they look at you and they know something is wrong, but they are not gonna tell you, you can see it on their faces, and they will just tell you a little bit ((but not knowing is so

> difficult)) like a consultant will say, "you'll have a little bit of pain in your mouth" and in my head I know that's mucositis and it's not just a little bit of pain, because another consultant explains what it is, and when you see a child with it, it's not a little bit of pain in the mouth…and I'm sure you know, it's a lot it's a lot of pain ((when you are given nothing to work with a child for pain relief)) but it's not how they give it to you-

Here I am probing how the information feels limited when it is given to the families, and I am helping to co-create the narrative. I know that a strong rapport with interviewees is important, and my probing techniques are based on my previous qualitative research into the experiences of children with sickle cell disease across two continents.

> Janet: and they do, they tell you that, they say to you we, we'll give pain relief it's gonna be okay, its only if you say "what pain relief do you give, are we talking paracetamol, are we talking something a bit stronger?" are we talking wipe-out you know it's only if they see that you've either got enough ability to cope with the truth, because some people haven't actually. There are people that can't cope, I think that's the other thing that you have to remember that actually, that approach does work with certain people, it's just that it doesn't work as a blanket-

Janet is accepting that the doctors cannot give her all the information that may be needed for an understanding of what the pain may be like for her child. However she does not agree with the approach, and she is aware that this is a general approach to giving information in clinical spaces. She perceives it from the perspective of being told the 'truth' and being able to 'cope' with the 'truth'. This awareness of how information is given to families in hospital spaces reflects Janet's hospital habitus. She understands the way things work, not because she poses a higher level of intelligence than other parents in the hospital, but because she embodies the unconscious state of being in the field. Like I mentioned in chapter 2, Bourdieu surmised that the habitus is "a subjective but not individual system of internalized structures, schemes of perception, conception, and action common to all members of the same group" (Bourdieu, 1977, p. 86). This means that whilst Janet has this awareness, it is not just limited to her experiences and is likely to be shared amongst the other parents in this study.

In this case, Janet understands the value of being told what to expect at an appropriate time, but she explains that others cannot cope, and she knows of parents who have not been able to cope with their children’s illnesses, and even those who have attempted suicide.

> Janet: I’ve known people that have tried to commit suicide, parents…

She also highlights the emotional aspects of being drip fed, which can be seen when she interjects in the interviewer speech above, “but not knowing is so difficult”. Research has also found that the transplant process can have significant psychosocial effects on parents (Kazak et al., 2020; Sands et al., 2017). Again this is retrospective and as Frank notes about illness stories, it is only after going through the experience that the narrator can come to understand what they have been through (Frank, 1995).

The role of an active interviewer makes the interviewer and interviewee active subjects of discourse and as such allowed the conversation to unpick some of the elements of the information giving stages. In my interview with Janet I remained an active interviewer to understand more about her personal experiences (Duneier, 1999). Janet is from another country and drip feeding for her is centred on the cultural aspects of an historically British way of being and acting; even though the act of being British involves holding back information in an effort to be polite. She is describing a cultural habitus that she has come to know and understand. She understands that there is a disparity between the medical professional’s habitus and that of the patients and she has picked up on the nuances in the communication between physicians and families because of this. Though in this case to be polite is to be dishonest and this is an interesting juxtaposition. As a practice, the trickling down of information is embedded in other cultural values (Skeggs, 2004). I was not exempt from the ‘politeness’ that Janet alludes to, as in my own efforts to be polite because she had caught me off guard with her revelation that her son had died, I did not ask her to show me a picture of him. But as a mother I know that this is something 'we' do, especially after talking about our children in great depth.

Janet also notes how, cultural differences also play a role in the drip feed process especially when people are not culturally 'English'. Here she addresses another communication issue when it comes to language, but she connects culture and language as one thing. Though I know that embodying the habitus of the culture does not necessarily have a connection with the language of the culture in question. However, in the BMT context and in relation to the drip feed process, Janet views the two as synonymous. She continues to give her thoughts on those families who do not understand English, and are therefore arguably not 'culturally British'

> Janet: I feel so sorry for those families, there's a lot of them I mean you must see it, I don't know where you, where you work, but in London, I'm sure because we are in the South East as well, there is a greater mix of people and, well yeh it is very global and umm, and umm cancer doesn't care who it affects, I don't think there is any kind of ethnicity that escapes or particularly is involved, so I think it's across the board. I've said that lots of times to the doctors actually that, culturally in the UK that we've got a thing where it's very English to hold back to people, like to say what you have to say but to ((inaudible)) but when you are talking about consenting and medical conditions, I don't think that's the time to be holding back and being polite.

Janet understands that London is very multicultural but, there is also the idea of being 'British' and embodying a British way of living. And she sees the drip feed process as being a 'British' way of providing information and that this is a cultural norm. She sympathises with families who do not share the cultural ways that she has experienced within the hospital settings. This idea of the hospital culture is another way of observing the hospital habitus. Bourdieu's theory of the habitus, as I mentioned in chapter 2 indicates that the culture of the hospital is deeply embedded within those who are familiar in its spaces, and it is subconscious as they move through the hospital as a field. Again this is where the habitus comes back into play in respect of being able to navigate the field. Although there is a dissonance with the cultural habitus of the BMT inhabitants, it does not mean that they do not share the same BMT habitus. As I introduced earlier, this BMT habitus is represented through the language (medical terminology) and how it is used between parents and medical professionals on BMT units. Thus what Janet is saying, is that when it comes to the way information is presented to families, some of them may not have an awareness of the wider cultural habitus of British life. There is an intersectionality of cultural communication practices in a space where communication is a vital aspect of the inhabitants' everyday lives.

Throughout the entire research process, it was evident that not all the relevant information regarding treatment is made available from the get-go. In my time as an observer on a Bone Marrow Transplant unit, I saw how selective information sharing played out in everyday life. It did not just involve the patients. It also involved most people who interacted with each other around me on the BMT Unit (especially during the initial consultations). As I understood a little bit about what happened in the initial consultation, it was easier to identify this theme of 'drip feeding' whilst analysing the data. The participants' stories, as they were conveyed in interviews and survey entries, made sense of the ways they experienced how treatment information was given to them, and how they understood this information.

Janet and I continue to discuss how the drip feeding of information works and come to an understanding that it is effective for some people and not for others (Herrmann et al., 2021). When talking to Janet I examined the 'drip feed' concept and found that it can be viewed as filtering and restricting information, but there is no evidence here whether this filtering is deliberate or only cultural.

On the other hand, another interviewee, Bev, did not experience drip-feeding like Janet, or to be fair, she did not recall it in the same was as Janet. For Bev, drip feeding was experienced as not being given enough information, rather than being given a little bit at a time. I asked Bev about the quality of the information her family were given during their illness journey, and the question I ask is very important for answering the study's research questions 3 and 4. I also included this question on the online survey as it was particularly important for the dialogue centred on feedback reflections.

> Interviewer: ……and, do you feel like, when you went in you were given enough information or do you feel like you should have been given more information-
>
> Bev: umm I think, my only, my only real concern that I have at the time, was looking back, she presented as what they call high risk umm so we were told 'don't worry, all children with ALL [Acute Lymphoblastic Leukaemia] go into remission' and we were prepared this two year protocol of…you know, chemo and hospital visits and you know, that's what they prepared us for, but actually, she wasn't responding like other children at that time, so she, so the mass in her chest which was basically the blood, the cancer was clumping in her chest area, umm that didn't go down as quickly as, as, it does in other people. Umm her bloods, her white blood cell counts didn't fall as quickly as, as they should have done once she started chemotherapy.

Here Bev's response to my question begins with a narrative of uncertainty; she must recall her earlier treatment experiences to consider the kind of information that was presented to her and her family. It appears that the only way that she can answer the questions is by looking back to the period of uncertainty so that she can frame the narrative in a way that portrays order and clarity to her experiences. Thus she must return to an uncertain time in her daughter's illness journey. This background story that she tells of her daughter's cancer gives context to her answer to my question. My particular question here does not specify who gave her the information and what part of her daughter's illness journey I am asking about. But what her answer shows is that that there is no distinction between clinicians/specific clinical teams for her when it comes to her family's consent experiences for Misty's treatments.

> Bev: Umm so, and her white blood cell count on diagnosis was ridiculously high umm and I think we could have been prepared better for, her failing induction, which umm, and to be fair to them, they see it so rarely, for a child with refractory, that literally one unit in maybe two or three years have a child that fails induction with ALL so, but even so the signs were there, maybe

> we could have been better prepared, because when they said she failed induction, you know, we'd been expected to go onto, you know, to go home and umm, she'd be like an outpatient for chemo from then on umm, and suddenly it was like, well you've got to come into hospital next week for a month of chemo, and we're just like 'what? This is not what you told us was going to happen'.

As Bev continues to describe her experiences, it is clear from the language and the detail that she uses, that she has a lot of knowledge about her daughter's illness. It is also evident that she is in tune with the hospital habitus, and in a way talks to me like I am also fluent in the hospital language. My experiences of the BMT unit allowed me to let her speak without much interjection and this allowed her narrative to flow smoothly. Thus her narrative expresses a linear trajectory of treatment that shows how it did not go as planned or meet her family's expectations, and this can be seen when she says, "this is not what you (doctors) told us was going to happen". The unexpected treatment outcomes for her daughter led her to turn to other sources of information so that she could better understand the treatment options that were available to cure her daughter's cancer. Parents often turn to the internet and other forms of media, because of a sense of unease with the information that they receive from clinical teams.

Bev continues to tell me about her search for clarity on her daughter's treatment because of the uncertainty that she felt.

> Bev: So umm, yeh, I think that was the only thing, is we weren't prepared for what was going to happen if she'd failed induction. I mean after that it's just, I think I had the worst moment, was knowing that, and then feeling very unsure of what to do, or what was going to happen, that's when I went home and read everything and googled everything, and you know, it was horrible, it was scary and you know, I didn't think she'd survive. You know they didn't think she'd survive to be fair-
>
> Interviewer: oh, what during the first chemo or during like BMT, where did-

> Bev: I think, I think, because her, her leukaemia was so aggressive, I think that they thought, even with the, what they called salvaged chemo, the second set of chemo, even then I think they thought it was unlikely to work, but it did work and it worked beautifully, and we were very fortunate that it did-

Bev's narrative in this study is a classic story where she has managed to tell me the beginning and end of her daughter's illness journey in a summary, above. However, within this narrative there is a richness that will show how she navigated through the consenting process and how communication was managed. For her, managing information came in the form of gaining knowledge through personal research. The limited information from the doctors led Bev to conduct her own research into her child's illness and treatment. This illustrates the process of accumulating a desired amount of knowledge to assist with the decisions that the parents had to make- from whatever sources are available. I return here to Bourdieu and his framework on capital. What Bev is doing here is adding to her embodied cultural capital by learning more about childhood cancer and the treatments available (Skeggs, 2004). Moreover, it appears that in the act of doing this, she is displaying what appears to be a 'concerted' habitus. As I mentioned in chapter 2 Lareau identified particularly dichotomous parenting strategies which are linked to the habitus, and Bev's 'concerted' approach falls into the category of Lareau's concerted cultivation parenting style (Lareau, 2011). This is because Bev is showing that she is involved in a way that seeks growth of knowledge in the form of capital accumulation, in the hope that she can exchange this knowledge which will shape her experiences in the hospital.

Indeed, every parent who participated in this study mentioned conducting their own research to satisfy their understanding of the information that was being given to them by their clinical teams. However, the most reliable source of information should be the medical team, and the internet can be a dangerous place for parents who are trying to inform themselves to make life and death decisions about their children as argued by clinicians. This issue of parents using the internet to inform themselves medically is also touched upon by du Pre and Brierley (2018), who identified it as a factor which affects the decision-making process. As can be seen, Bev felt unprepared by the amount of information that was given to her family in the initial stages of her daughter's treatment and felt that she had to fill the gaps herself. She preferred this approach, rather than the approach of challenging the medical staff for more accurate information. Though as Silverman found, as families become more familiar with their medical teams, the decision-making power can begin to shift in favour of more shared decision making, where parents' preferences become dominant in the clinical interactions (Silverman, 1987).

Other parents in the study who felt they had gaps in their knowledge also looked for other ways to fill them in. Matt's experience of his daughter's treatment offers a different perspective on the idea of the 'drip feed process'. Like Janet and Bev, Matt had also completed the online survey and opted to participate in an interview afterwards. During our interview, he told me that when he was told about complications that the BMT treatment could involve, the lack of detail about these complications did not seem to have had an effect on the realities of being given a little bit of information, over being given a lot of information.

> Interviewer: Yeh, were you told about complications beforehand?
>
> Matt: Yeh, and we signed a disclaimer and all that kind of stuff, and they said this could happen and umm, maybe not specifics, like Emma had something called CMV[Cytomegalovirus], which is just a really normal virus and, umm the doctors did say that she's really susceptible to sort of viruses and things like this, and there is a chance, and it could be fatal and things like that, but we maybe didn't go into the specifics of the complications because, A, there's probably loads and B, they're probably all different to everyone, so there probably isn't sort of a standard complication. We learnt about graft vs host disease umm because that was a big one umm and it was just rea – quite reassuring, they said they did some sort of medicines there that were really good and it was something that they knew about, so they had to look out for it, so it put us at ease definitely. Umm so we were aware but maybe not drilled down into the real specifics.

It appears that Matt is reflecting about the initial consultation where the parents are given information about the transplants. Reflectively speaking and not as a matter of presenting my reflections as data, my position as a mother who has sat in medical consultations for my own children helps me to understand what Matt is saying about being "drilled down into the real specifics". This is something Alderson (1990) also touched upon in her earlier work on consenting to children's surgery, and I mentioned this in the literature review chapter. Parents can be overwhelmed by the information that they are given and yet find that the essential information is lacking. This is another aspect of the dilemma of uncertainty in which they find themselves. They know that they cannot make the decisions for their children because they are not medical professionals, yet they also know that they have to make decisions which allow medical professionals to proceed with treatments for their children. But Matt's narrative here gives an indication of how this may be possible and how this dilemma may not be obvious to parents when it comes to sharing decisions. Matt says, 'it was quite reassuring' and 'it put us at ease'. His experience shows that he had trust in the information that his clinical team were giving his family. Although that is not to suggest that Janet and Bev did not trust their clinical teams, it just means that Matt may have not experienced the same unease and uncertainty as them, but he did worry.

So I continue to probe Matt about any reservations given that he alludes to the vagueness of the 'specific' information given to his family.

> Interviewer: Yeh, and in terms of like worrying, what were you worried about before she had the transplant? Or –
>
> Matt: If she'd survive, we, coz, you only look for the bad kind of things and we were- you'd go online and you google stuff, which is the worst (both laugh) and obviously the doctors, they had to tell us, "you know what, it's not 100% guaranteed, and it might not go well", I think sometimes you cling on to that a little bit, so that was our biggest worry that she wouldn't survive, and she might die from the transplant. We never really worried about major complications, we worried about graft vs host disease, umm and we worried about the transplant not working, umm but that was it.

Matt’s narrative here displays the anxieties that he had about his daughter’s transplant, and like Bev, he too talks about using the internet to find some reassurance, and to know more about the treatment options. This is a way of accumulating capital and from a Bourdieusian perspective, what Matt and Bev are doing is attempting to gain knowledge so that they exchange value in proceeding medical encounters. Silverman (1987) did not come across this in his study on communication given that the internet was not a place that parents used to get their information from at the time of his study. However, as I mentioned in chapter 2, he did acknowledge that there was a capital exchange through communication between the parents and physicians which was centred on capital accumulation (knowledge). Again, this in turn changed the power dynamics within the physician-family relationship.

The idea of ‘drip feeding’ is more than the idea of providing information, it is about managing the anxieties that families face during the transplant process. ‘Drip feeding’ may be problematic as the participants suggest in this study, but it may also have value. It is a ‘method’ that highlights the complexities of the information which clinicians have to give to families (Herrmann *et al.*, 2021). There is so much information to give about the transplant process that clinicians appear to give it in small chunks of information, rather than risking overwhelming the parents, as Janet suggested earlier. And what can be seen in these extracts is that it is only in hindsight that parents realise that the information has been given to them in small chunks which can only be described as drip feeding.

Although I have alluded to the theme of drip feeding in a negative manner, the data also indicates that there is too much information for clinicians to give to families all at once. In one way or another, the parents in this study display an understanding of this problem: there is too much information to be given about transplants. However, Cathy, the mother of a teenage boy who was suffering from the effects of sickle cell disease (SCD) has a different narrative. Like the other interviewees, Cathy also completed the survey before opting for a follow up interview.

Even before she was referred to a BMT unit with her son Troy, there was a build up to the idea of him having to undergo a bone marrow transplant to cure his sickle cell disease. This build-up to decision-making is what Mekelenkamp et al., (2023) refer to under 'preference sensitive' decisions when they explore HSCTs and haemoglobinopathies. "Preference-sensitive decisions refer to decisions with scientific uncertainty with no clear-cut answers, where the offered treatment options' advantages and disadvantages depend on personal values" (Mekelenkamp et al., 2023, p.2).

I also note here that there are similarities between Cathy and Bev's story telling techniques and they both offer contexts to their narratives with additional background information. This is what Frank talks about when it comes to telling stories of illness and allowing the storyteller to fill in the gaps for the listener (Frank, 2010)

> Cathy (discussing what happened after her son's first stroke): …… but once he had that, they started to say, I remember the first thing what happened, I was pulled, into, he was having his trans—his, one of his transfusions, one of the consultants called me into a meeting quickly, which was quite out of the blue coz again when we go for a transfusion we don't normally see any consultant we're just booked in for a transfusion, you have it and you go. And she said to me, basically she's just saying look, that TIA is becoming, it could be a problem if it happens again, it could be worse, it could be, more detrimental or even, you know. Anything could, you know she just doesn't know so she's now saying we need to try something else so, the suggestion was, at that point, going for, having a bone marrow transplant but at that point, it was to have a child by IVF that is, umm screened to be a match for him, so it would be the best possible match because its screened, the egg won't be implanted until its and that route, go down that route, umm----

As Cathy tells me about the start of her son's BMT journey, she is not only unpicking it slowly in a way that highlights each point of her interaction with the consultant. She is also showing how long the decision-making process for BMT consent can be. This indicates how long the decision-making process can be for some families, especially those whose children have long term non-malignant illnesses. Cathy's son Troy had been suffering from Transient Ischaemic Attacks (TIAs) which are mini strokes, and the doctors had begun to offer her solutions for successfully treating his SCD. Although Cathy recalls these as suggestions, she is in the middle of the decision-making process, and specifically the BMT consent process. I say this because the other stakeholders in the process, here it is the clinicians, have already started looking at other options to treat her son. And in the discussion about her having an IVF baby they are already presenting her with their ideas for a bone marrow transplant (Kakourou et al., 2017; Kahraman et al., 2014).

I probed Cathy further as she was discussing the possibility of having a 'saviour sibling' for her son. A saviour sibling is a child who has been specifically selected through IVF to be an HLA match for their sibling (Cherkassky, 2015). Once they are born, they can become donors of stem cells or bone marrow for their sick sibling, often starting with their cord blood (Lucchini *et al.*, 2017). As mentioned in the opening chapter, this is one of the issues covered in Jodi Picoult's novel 'My Sister's Keeper (2004)'. This is also the reason for discussing children's agency in relation to HLA donors, because this is where the parent's position becomes unclear within the BMT consent process as the HTA oversees this part of consent (stage 3 in the consenting process see fig.1). I ask Cathy whether the hospital team that were suggesting IVF were going to pay for it.

> Interviewer: would they have paid for that (IVF)?

> Cathy: umm, we seemed to fit, we did fit a criteria, in case, in our case, in that Troy was in that sort of need, we fit the criteria. I think we would have been funded for three cycles umm, yeh so. I was…very, that was, I know it was… a way forward with Troy, but for me it was quite a…big thing …after we started to go through that process…we didn't actually then have the meeting with…a consultant at 'London 3', the bone marrow specialist now, consultant which was the first time we had gone into another hospital and started…. seeing the other side to how things go. And umm…he was really good, he explained to us how transplants work and coz I, I didn't really have much knowledge for them---

Looking back at figure 1 of the BMT consent process, Cathy's account highlights a detail that is not part of the consent process, the phase before a family is referred to a BMT unit. As Cathy's son had sickle cell anaemia, the option for them to go down the BMT route was a slow one, and one that they had some time to think about. Cathy's narrative indicates a missing piece (the pre, pre-BMT consultation) of the consent process and it is the gap which this study will also address, in conjunction with the current process. But at the same time Cathy's narrative also points back to the habitus. She has already developed the hospital habitus and in the above extract she mentions the shift of moving towards a BMT habitus when her son was moved to another hospital for the BMT treatment. I distinguished between these two habitus from Janet's earlier narrative on the culturally embedded habitus which led to her experiences of being drip fed as being 'British'. Thus I took note that there is a hospital habitus and a BMT habitus at play in the narratives, where the parents moved between the two. As Cathy says, they started "seeing the other side of how things go".

Cathy and the other parents' experiences of their children's illness journeys can be understood more clearly through their narratives and what these narratives have to offer. Only they can effectively report how they experienced life before and after the BMT unit. In this thesis, their testimony encourages thought about what can be done with their accounts to enhance the experiences of others in the BMT consent process.

The way a family processes the small chunks of information that they are given may depend on their prior knowledge and experience of the hospital treatment processes (hospital habitus). For some, the “drip feed” method might give them key insights into the treatment; for others, the lack of context may be a serious problem and make it difficult to process the information they have. Moreover, the knowledge that families accumulate through their children’s illness journeys may offer an insight into how to tailor the consent process. Cathy’s narrative has shown a little on how this can be done without impinging on the time constraints of illness when it comes to decision making.

This points to a refocusing of the drip feed idea. Rather than focusing simply on what information is given at what stage, it is also useful to focus on how the information on which parental consent is based is processed and understood. Going back to Janet and Bev’s narratives, it is evident that there can be problems if a family gives consent for a procedure, only to be told about further elements of the procedure along the line. Although not everyone finds this troubling, as can be seen from Matt’s observations, it is clear that there are differences in how information is processed and appreciated by those with different illnesses, and different backgrounds.

Matt and Cathy’s journeys are similar in that their children did not have malignant illnesses, as Bev and Janet’s children did. This arguably gives the impression that the information given to families for malignant illnesses may follow the trajectory of the disease and previous medical outcomes (as it did for Bev), by contrast with the curative approach that may come with non-malignant illnesses. With these two distinctions of malignant and non-malignant illness types in mind, a further question arises: In whose interests is it to encourage shared decision making in the BMT consent process?

Having established that information about the transplant is not given at once, I now focus the next part of this chapter on how of the information was remembered by the participants. BMTs/HSCTs have a high risk of mortality, as the data will show, but for consent to be truly valid it has to be informed as well as voluntary. In their account of informed consent, Beauchamp and Childress (1994) include understanding as one of the factors that must be present for consent to be informed (See Chapter 2). The first part of this analysis has focused on this kind of understanding. It has considered how well parents who were drip fed information understood what they were consenting to. Now I want to add the complications and side effects of transplants and see how the participants recalled the information from the initial consultations and their time on the BMT unit. These side effects are important because they have a bearing on the validity of consent.

The aim is to see how the BMT consent process unfolds, understand how parents experience it and explore how decision-making authority is constructed within this process. Taking account of the types of habitus that are amongst the BMT field will be one way that can support a broader understanding of what the paediatric BMT consenting process is like and how shared decision making can be supported within it. This is because the habitus is embodied unconsciously and understanding the value within it can only come from an understanding of people's experiences. Additionally, taking account of the participant's understanding of the side effects of treatment will also offer support to exploring how information is understood in BMT spaces.

As the transplant process has a high risk of mortality (Herrmann et al., 2021), I will explore how the parents in this study struggled to understand the complications associated with consenting to proceed with a transplant. The uncertainty, unease and worry already identified in the first narratives presented show that the parents struggled with the information that was given to them at some points in their experiences.

Complications and Side-effects

I have shown how the drip feeding of information occurs throughout the transplant process. I now turn to two further issues: the complications associated with transplants and the issue of recalling the information given to families throughout the treatment consent process. My rationale is that if the parents perceived the information given to them during the treatment process as being drip fed, I can assume that they perceived this as applying to the information they were given about the potential complications and side effects of transplants. I note here that the list of side effects given in table 5 is usually given to parents at the initial consultation, although, as the opening narratives in this chapter have shown, additional side effects and complications are discussed once treatments have started.

Before parents and families consent to transplants, they are given a list of possible side effects, which consultants discuss with them during the initial consultation before admission onto a BMT unit. The survey in this study asked the parents to recall the side effects that they were told about, although it did not specify when they were told about these (i.e. during the initial consultation or after admission onto the ward). This was in list form, and they ticked all that they could recall (see table 5a). The parents were also asked to give a brief description of the side effects that their children suffered (See table 5).

The list in table 5a was taken from an actual BMT/HSCT transplant consent form and is the list that was used in the survey. It includes 13 possible side effects, each with its own vast bodies of literature explaining what it is (Mohty and Mohty, 2011). The actual form itself is restricted and cannot be shared in the appendix of this thesis as I do not have ethical clearance to do so.

Table 5a; Transplant side-effects	
Infection	Blood product support
Graft v Host disease (GvHD)	Toxicity (e.g. Veno-Occlusive Disease)
Rejection/Graft Failure	Hearing
2nd Malignancy	Cataracts
Pneumonitis	Endocrine
Fertility and Growth	Drug Toxicity
Neuropsychometric	I don’t remember

	Table 5: Side effects		
Participant	Can you give a brief description of the side effects that your child had from the treatment?	Which of these side effects were you told about? (Tick all that apply)	Was the treatment what you expected? Please write a little about your answer.
Matt	Hair fell out, vomiting and lost all appetite. She also complained of headaches.	• Infection • Blood product support • Graft v Host disease • Rejection/Graft failure • Hearing • Endocrine • Fertility and Growth	We didn't know what to really expect. In all honesty it wasn't as severe as we thought. The hardest part for us was living with other families and silly things like 1 toilet for the whole ward as we couldn't use the one in her room or not eating or drinking in her room. The hardest thing was not being able to hug or kiss her for 7 weeks
Janet	Slight skin rash, infections including BK virus	• Infection (Trouble selecting options)	On the whole we didn't have too bad a time the ATG a bit of a drama as it caused a reaction which was quite bad. Recovery wasn't dissimilar to that of a typical cycle for use to be honest. Day 28+ things worsened and with the onset of BK Virus things took a dive , added to disease being picked up on a bma on day +28 things didn't improve.
Bev	Primary Ovarian failure, growth issues, cognitive issues, fatigue	• Infection • Blood product support • Graft v Host disease (GvHD) • Toxicity • Rejection/Graft failure • 2nd Malignancy • Cataracts • Pneumonitis • Endocrine	Pretty much. My daughter engrafted quickly and despite some long-term health issues she is living a surprisingly normal life four years on.

		• Fertility and Growth • Drug toxicity • Neuropsychometric	
Cathy	GvHD (skin, muscles), shingles, bk virus, pericarditis, fungal lung infection etc	• Infection • Blood product support • Graft v Host disease (GvHD) • Rejection/Graft failure • 2nd Malignancy • Pneumonitis • Fertility and Growth • Drug Toxicity • Neuropsychometric	No, I didn't really have a particular expectation as I knew each patient may have different difficulties to overcome, just tried to deal with each issue as it arose. It did take longer than I could have imagined before we got to a safe place with my son's health.
Kate	*Donor child: Aches pains tiredness* Sick Child: Gvhd /extreme sickness / mucositis	• Rejection/Graft failure • Infection (Trouble selecting options)	No it was much harder than described
Zoe		• Infection • Blood product support • Graft v Host disease (GvHD) • Rejection/Graft failure • Fertility and Growth	We obviously did not know what to expect, reading about something is nothing compared to going through it. I had not anticipated how poorly my son was going to be and also the pre-treatment(Radiotherapy & Chemotherapy) was very intensive.

Looking at the first column in table 5, it is evident that the participants' children suffered from a range of complications, with a high degree of similarity as 6/6 of the children suffered from GvHD which is a main side-effect of bone marrow/stem cell transplants (see chapter 1). The other 2 children accounted for were sibling donors and hence they did not suffer from

GvHD. The parents also recorded other side-effects for the children who received transplants, and these were, extreme sickness, loss of hair, skin loss, BK virus, primary ovarian failure, HPV virus, shingles, mucositis, pericarditis, fungal lung infection and others that were described to me during the interviews. Apart from Graft vs Host Disease, the other side-effects are not listed in table 5a but fall under those different categories. But if the side-effects in table 5 are compared with the side effects in table 5a, it could be hard for a lay person to understand which category each effect may fall under.

The pre-BMT consultation brings together the clinical specialists and the families, and it usually lasts for at least 90 minutes, sometimes much longer. During these first consultations parents are given a large amount of information to consider, not just on the side effects but also on survival rates. These survival rates are given for individual types of transplant. They do not reflect the overall survival rates of other children on the wards. Table 5 shows the side effects that the participants remembered the consultants telling them about. The table also shows the side effects that their children had, and whether or not the treatment was as they expected it to be. These latter 2 questions on the survey were open ended and thus they produced qualitative data.

After this initial BMT consultation the parents are sent a detailed letter outlining what was covered, with further information regarding the transplant procedure before they return to the ward to sign the consent form. The time between the first pre-BMT consultation and the day patients are admitted onto the ward to start treatment can vary significantly. The survey asked participants how long it took after the first consultation before they came onto the ward. The results of this question can be found in table 6.

Table 6: Length of time between consultation and ward admission

Participant	How long did you wait to come onto the hospital ward after the first consultation about the treatment?
Matt	A few weeks
Janet	6-8 weeks
Bev	We didn't really go home from the time of diagnosis.
Cathy	2 years
Kate	3 months
Zoe	Only about a month

Table 6 indicates that the length of time between pre-BMT meetings where bone marrow transplants are discussed can vary between individuals. The participants' data in this study shows that Bev did not leave the hospital once her daughter was admitted for her initial cancer treatment. Whereas Cathy waited 2 years for her son's transplant treatment to start after being told about BMTs, and this could have an effect on how well parents recall information given at the pre-BMT consultation. Research has found that recalling information for HSCT can be difficult for patients (D'Souza et al., 2015), but parents tend to have higher level recall for side effects (Lesko et al., 1989). The consent form also allows families to recall information at a later date by reflecting on the things they consented to and can be used as aide for this recall.

However, given the length of time between the BMT consultations, the child's admission to the ward, and the complexities of the side effects, families cannot be expected to give formal informed consent by signing the consent form on their return to the unit if following the BMT consenting process (see figure 1). For example, the way the information regarding side effects is presented on the consent form is not adequate for families to have a clear understanding of the medical terms as the side effects are listed in bullet points. For transparency, I am referring to the form that I have and used for table 5a which was used on a BMT unit. But I assume that this is similar across NHS BMT units given that the participants in this study responded to it on the survey. Additionally, without a further consultation before treatment begins, families cannot be expected to give informed consent, because the burden on them to recall such information in distressing times would not be an ethical expectation. The length of time between the first consultation and the participants' children being admitted onto the ward varied, and it shows how individualised each person's journey was. Especially as each family is assigned a nurse that they can contact in between the initial consultation and bringing their children to the ward for admission.

The parents were probed on the survey (was the treatment what you expected?) about the information given to them before the transplant, and it is evident from their responses in column 3 of table 5 that they all had different experiences ranging from feeling prepared to not knowing what to expect during the transplant process. This may have been one of the reasons the parents in this study sought further information from the internet and others around them to prepare their expectations. The drip feed of information that the parents felt they received during their children's treatments may have also been based on the number of side-effects that can happen because of transplants. In a way the question of whether parents are giving informed consent becomes quite important for how parents can be supported in the shared decision-making process.

I used the answers from the survey as prompts during the interviewing process, so I asked Janet again if she felt like she was given enough information to give informed consent, and this was her response.

> Janet: yes, they gave us enough information….but in hindsight again and what what I know now- I think the information was biased and one sided-

Here again, Janet's narrative is centred around the limited information that she felt was given to her family and the uncertainty of treatment success. But she also reflects on the motives of the doctors and understands that they are working for more than just treatment solutions. She recognises their candour and where their concerns with the child lie.

> Interviewer: why?
>
> Janet: it was given to us by a….very optimistic transplant doctor. And he was only ever looking at it from a transplant success point of view- and I don't think that was a fair overall picture…
>
> Interviewer: the first one or the second one?
>
> Janet: the doctors ((first)) or the consultants- oh the whole thing- I think all the way through they were over optimistic- I think they were dishonest with their over optimism I think they did it with the best intention- I think they are optimistic because they think- and they are right to a degree- they think that if they are not optimistic- what are they being- are they being negative or are they being honest? Or are they being realistic? And what do you do with that as a parent- when you're sitting in that room with your kid in the middle of the night and don't know if they are gonna make it until the morning- it helps you having the optimism behind you- because you're gonna give up- you could commit suicide or you cant cope- you cant. They have to get us through it as much as they have to get that kid through it…. Sorry

The optimism from the medical teams that Janet describes also shows that transplant outcomes can be unpredictable, and she recognises that the doctors sometimes have to be mindful of how the parents experience the transplant process too and this is clear in the last line of her extract above.

Cathy's narrative adds scope to Janet's thinking about the doctors' motives and their 'dishonest optimism'. Cathy touches on the fact that the healthcare teams cannot prepare parents for everything until the procedure is underway. She also indirectly says this in table 5 when she comments on her expectations of the treatment. During our interview I asked Cathy the same question I had asked Janet, about whether or not she was worried about the transplant. This was her response.

> Cathy: I feel like in some- I think they told me what they could tell me- but they could never tell you- when you've gone through it- its impossible for them to tell you all of that—it's impossible- I think they tell us enough, you get a book, you can read and stuff- you know, but it's impossible for them to tell you what you actually go through because everyone is different as well and what Troy has gone through, another transplant patient would not, might not go through. So—
>
> Interviewer: and do they tell you that before you have it?
>
> Cathy: what that its different? Well you kind of work it out
>
> Interviewer: or is there like a list of things that they can't tell you and-

Here I am probing Cathy to see if there was anything that she felt was deliberately left out because she says that it is impossible to be told everything.

> Cathy: umm I don't think there was things that they held back from me, I felt they told me- like for example they could say- you know there is a risk of him having graft versus host disease- yeh so I say okay, but who- that covers- that can be so many things and he had them all and he had graft versus host- they told me he could have it and he did he had it of the skin, he had it of the muscle, he had it of the lung, he had it of the ermm heart- he had it- yeh- he had it all different places- you know- he also had it where he had something called umm, he had BK Virus, which was a virus that was-I don't remember how that affected him-that's why I write things down- umm, I mean if there's other things that you want to be more specific on, I can literally find out and maybe over a phone call or something- cause it's all stuff I have written down and umm, have in different places- this was a diary I had with the transplant- the actual diary I had- which I didn't particularly wanna keep a diary- it's just there to keep dates and stuff yeh so- I'm just- I haven't looked at it since [flipping pages of diary] yeh umm, so even like phone numbers of all the ((consultants))

Although Cathy felt that she was told what was possible to be told at the time, notice that in her narrative that she says she kept a diary, in which she stored all the information relating to her son's transplant. She used a filing system, partly because she felt that there was a lot of information to take in, but also to have the information at hand when needed. Cathy also mentions additional resources (a book) that was given to her and Troy to learn more about transplants. Matt also refers to these additional resources that were given to his family by their medical team.

Like Cathy, Matt tells me that parents can never truly be prepared. I asked him if they told him what to expect with the transplant and if his daughter was also informed of what to expect. Here is his response to that question.

> Matt: We were yeh, the hospital, we've got a specialist umm nurse assigned to us from the bone marrow team, and she was our point of contact, and we had sessions with the consultants and things like that, and they gave us a little tour of the ward and everything and they gave us a DVD and a booklet to read. So the DVD was more for me and my wife, and the book was for Emma, and it was a bedtime story book, and it was about – I think it was called 'Ben', and he was having a bone marrow transplant, and it was really really good, umm so that was really like, beneficial for us. And yeh it made it, it made it real, but we also knew what to expect. Visiting the hospital is great, visiting where we was going is great, sort of meeting the nurses, they would tell us "oh you might want to bring a DVD player in" or you might wanna do this, and that was all really useful,

I then probed him to find out whether he was told about the complications of the transplant beforehand. Notice that he is also very aware of the complications his daughter had, just like Cathy described Troy's complications.

> Matt: umm and along with the doctors, the consultants they told us that yeh she'll probably get ill and yeh this is what will happen, your hair will fall out, this is the kind of stuff so we were prepared for it by that. So I don't think that we weren't prepared. I think, I think the things you weren't prepared for is things that the doctors could never have prepared us – is when she had complications, umm she caught a virus and that's when it went

> into her brain and she was really ill, she couldn’t talk and she couldn’t walk, she had to wear nappies again, she couldn’t eat anything, and, she couldn’t speak it was awful, and that went on for about four weeks and that was the lowest point for us definitely. That was the point that we were the most scared I think because we thought that was it. You know the doctors would come in, but it, if there was more than one doctor and there’s a team of them, you’re in trouble, you know…Because they all sort of come in together and things like that, but if it’s just a doctor on her own or a nurse on their own its just normal

The narratives in this section about complications and side effects highlight the difficulties of transplants, and they show the problematic nature of the BMT consent process if the goal is to obtain practical informed and voluntary consent from families. Note that I am considering “practical” rather than “absolute” informed consent. The participants note that the information provided about transplants is drip-fed and given in small chunks and is also selective for good reasons. So the data shows that families are only informed to a level necessary to have reasonable expectations about what is to come. This is evident in their reflections of the complications that their children had and of the complications that they were particularly given a lot of information about. Each participant also shows an understanding of the possibilities which make it difficult for the clinical teams to relay all the necessary information involved with transplants, and it is over time that the parents become content with this reality. Their narratives indicate that understanding what the consenting process is like for families becomes important when considering how decisions for treatments are made for such major medical procedures.

Summary

This chapter has focused on the information that the participants were given at the start of their children’s treatments on the BMT unit through the initial consultation. The theme of ‘drip feeding’ information during the transplant process was dominant throughout the analysis and it carried with it the feelings of uncertainty, worry and unease as the participants’ narratives showed. From this I moved on to examining the data on how the participants recalled the information they had received, in particular the side effects that they were told about, as these are important for the element of ‘understanding’ for consent. I have aimed to expand the way we think about the consent process, as more than just an event where parents officially sign the consent forms. As the parents’ understanding of the treatment process broadens, they continue to be given information that is needed for valid informed consent. Thus the first significant event of signing the consent form for transplant appears to be a performative one. From this, consenting is no longer an event, but a process.

The latter half of the chapter evidenced how much information the parents were given and how much they had to comprehend before making the decision to proceed with a transplant for their children. This raises the question of whether families can be truly informed about the transplant before proceeding or even signing consent documents. Their narratives suggested that they cannot be informed about all the possibilities that can happen as a result of the transplants. Each family had a different outcome from the one that they had imagined when they gave their original consent for their children to undergo treatments on BMT units. I will now present the data which shows the consent process as a continuous process on BMT units, where families have to make multiple consent decisions whilst their children are in-patients. This part of my study is informed by data which has so far pointed to consent in BMTs as not being restricted to the start of treatment (initial consultation) and ending there. The consenting process continues after the first (original) consent form for treatment has been signed.

Chapter 5: The consent process as a process

> You know, you're only having a bone marrow transplant if the alternative is death, frankly. They are not gonna do it for anything else, so it's not like there's even a question of consent or choice or anything (Bev)

Introduction

In the previous chapter I looked at how far the information given to parents in the early consultation stages gave them the knowledge that they needed to consent to their children's treatment. This chapter will examine how far their resulting decisions can be described as voluntary at the time they consented to start the transplants for their children. This analysis will support research question 2 (how informed and voluntary were their decisions for HSCT/BMT?) and the overarching theme here is 'limited choice'. This will be seen throughout the data presented and it reflects the unease experienced by the parents as explored in the previous chapter.

Choice as an ideal for informed consent

Chapter 4 showed that freedom to consent to medical procedures is not always freedom to choose medical procedures. The narratives in that chapter have thus far shown that there were no medical alternatives available for the participants other than to consent to transplants for their children. In reality, the choices available to the participants were limited and constrained and sometimes boiled down to no choice at all, given that the only treatments available on BMT units are transplants. Looking at how choice, and often the lack of choice, works in BMTs, may help us to appreciate the extent of how parents' abilities to exercise choice in the BMT/HSCT context may be limited. I will now examine the limitations of choice for the participants in this study.

When I introduced Informed Consent in chapter 2, I drew upon Beauchamp and Childress (1994)'s analysis of the factors that must be present in order for consent to be valid and truly informed. One of those factors was voluntariness, and the other was understanding, which I focused on in chapter 4. I will now address voluntariness. The first relevant data points concerning the voluntariness of the parents' decisions to proceed with treatments that can be seen in this study, come from their Decision-Making Control Instrument (DMCI) scores (survey data) alongside the interview responses. The scores from the DMCI questions align with their understanding of their freedom to decide on transplants, as will be shown from the interview transcriptions. Here, the participants' responses tell a story of wanting to get back to normal life. Although they are uncertain about what will happen once the treatment has started, they know that there is nothing that they can do but to trust the information that clinicians are giving them to consent.

The results in table 7 show the DMCI score for each participant, their total, and the level of voluntariness these totals suggested. Additionally, the DMCI scores when accompanied with the qualitative data generated from their interviews, indicate that their scores were congruent with their reflections on the voluntariness of the decisions that they made for their children to undergo treatment. Figure 2 shows the items used in the DMCI with the permission of its owner Victoria Miller, and Table 7 shows the participants' results.

	Fig.2 DMCI items					
	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
1. I was powerless in the face of this decision.	1	2	3	4	5	6
2. Someone took this decision away from me.	1	2	3	4	5	6
3. I made this decision.	1	2	3	4	5	6
4. I was passive in the face of this decision.	1	2	3	4	5	6
5. The decision about the protocol was inappropriately influenced by others.	1	2	3	4	5	6
6. I was not in control of this decision.	1	2	3	4	5	6
7. Others made this decision against my wishes.	1	2	3	4	5	6
8. I was not the one to choose. 9 The decision was up to me.	1	2	3	4	5	6
9. The decision was up to me.	1	2	3	4	5	6

Scoring of the Decision-Making Control Instrument (Fig.2)

Reverse score all items except 3 & 9. Total score= sum of all 9 items

Subscales

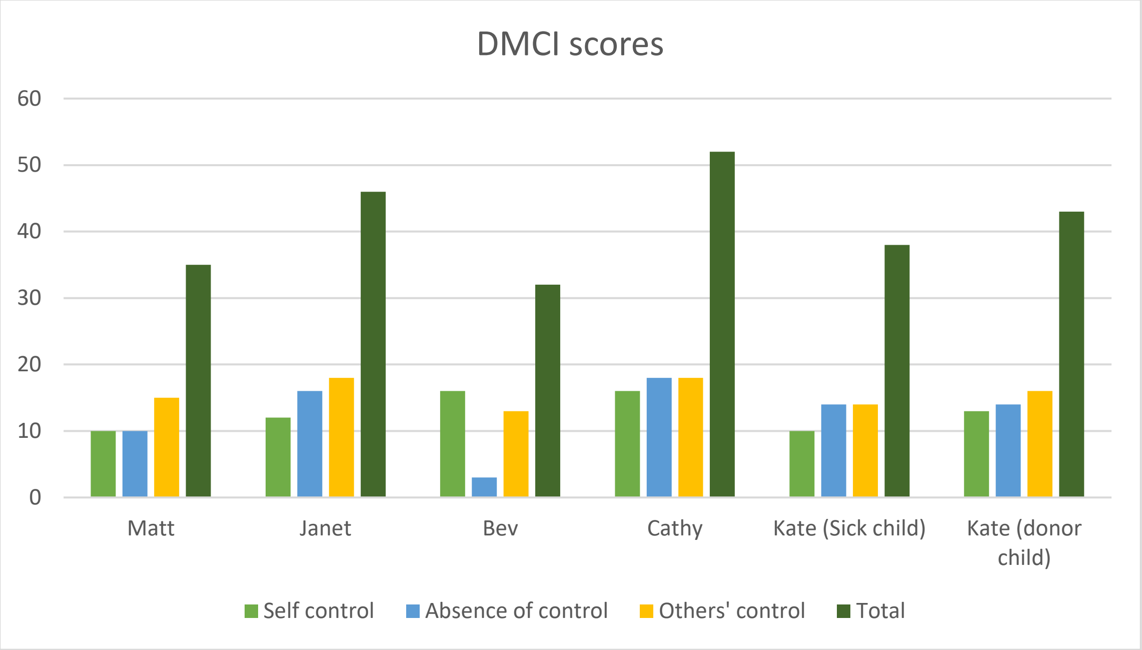
Self-control subscale= sum of 3, 8, 9. Absence of control subscale= sum of 1, 4, 6. Others control subscale= sum of 2, 5, 7

Table 7: DMCI Subscale Scores

Participant	Self-control score	Absence of control score	Others' control score	Total overall score
Matt	10	10	15	35
Janet	12	16	18	46
Bev	16	3	13	32
Cathy	16	18	18	52
Zoe	No scores were available			
Kate (Sick child)	10	14	14	38
Kate (Donor child)	13	14	16	43

The higher the total overall DMCI score, the more voluntary the decision was. Here the highest overall total score in the instrument is 54, and the lowest score is 9. The highest total in each subscale is 18.

The highest overall score from the participants in this study is 52 (Zoe's scores are not included in this total). The mean score is 41 (7.42SD). This can be interpreted to show that overall, the parents felt that there was a degree of voluntariness in decision making. The results lead in the direction of moderate to high levels of voluntariness in decision making. These scores can be seen clearly in the following chart.



However, although the scores show high levels of voluntariness (see overall total in table 7) for some of the participants, the instrument does not say in what context decisions were made, as in this study the DMCI is being used post-transplant and not during the transplant as originally used by Miller et al., 2011. While the scores are not definitive, the measure of voluntariness is a good indication since the transplant was the only decision at issue. There were no other external controls that might have led to a lack of voluntariness over the decision to proceed with transplant.

Now, looking at the participants' reflections in their interviews, the data shows that there was often no choice of treatment when proceeding down the transplant route. Moreover, the high scores of voluntariness should not be viewed as a measure of congruency with the meaning of choice. As the narratives show below, there was no choice; so choice, in the sense of choosing between courses of action, and voluntariness are not synonymous in this study. Choice in a way is arguably an alternative to voluntariness. Parents 'chose' transplants for their children; but because there was no medical alternative, they were arguably constrained by circumstances to the point where they had in effect no choice and in this sense their decisions were not voluntary. I am aware that I am using the notion of 'voluntariness' in a particular way that deviates from some of the literature, but I am doing so to introduce a more flexible way of thinking about the process of BMT consent.

Mekelenkamp et al.,(2023) mention the scope in which shared decisions should be made with families when it comes to HSCTs, by recognising that transplants are preference sensitive decisions in medicine (Mekelenkamp et al., 2023). However, the data in this study presents the idea that HSCT is about preference in a different light. For the parents in this study, there was no way of sharing a preference to the treatments that their children received because they were for curative purposes. Matt reflects on the whole experience; he tells me that there were no other options for his family when it came to the treatments that were available to ensure that his daughter could return to good health. Matt makes it clear that his family's decisions were limited in/to what was suitable for their daughter, and this fits in with his total DMCI score of 35 out of 54.

> Matt: So yeh, I, I think that if we asked Emma questions she just wouldn't know, she would have no idea. And umm I mean she was involved definitely in the transplant, but she wasn't involved in, in decision making if that makes sense. She was involved with the day to day living with the transplant stuff like that, but she wasn't she wasn't involved in you know, this is when we're gonna have it, this is the treatment you're gonna get and things like that. And to be honest I don't know if there really was any options, if that makes sense.

I asked him to elaborate on what he means by a lack of options. For me as a researcher and not a BMT specialist, this probing is important because I know that my knowledge is limited in the treatment options available to those with Fanconi Anaemia.

> Interviewer: What do you mean by that?
>
> Matt: There, there wasn't multiple courses of treatment she could have had – This was sort of the treatment that was available that would work for her, and that's all, that, that was our main drive, we just wanted to get something that would make her live for a bit longer if that makes sense – Umm so yeh, that was it. I and I'd

> nah, I definitely don't think Emma could have made a decision on it

His last sentence indicates that he is aware of how difficult the decision was, and how much competence the decision needed that he knows his daughter could not have made it. This also suggests that he may be talking about competences of multiple kinds, not just knowledge in the sense of information, but emotional competence as well. Matt and his family had been told about what could happen if Emma was not treated with a transplant. Though it appeared like a preference sensitive decision, it turned out not to be.

Like Matt, Cathy remembers that she felt like she had no choice but to proceed with a transplant for her son. Although her total overall score of voluntariness on the DMCI is higher at 52, she had an immediate idea of the possible outcomes for her son if he did not have a transplant as he was suffering from mini strokes. The doctor had told her that " *look, that TIA is becoming, it could be a problem if it happens again, it could be worse, it could be, more detrimental or even, you know" (*Cathy's interview*).* Both parents in this case are reflecting back and considering what was best for their children at the time. Though for Cathy the decision was very limited since she had an idea of the impending consequences if her son did not have the transplant.

> Cathy: in a way for me, our decision to make the transplant, I think was taken away- I don't think I had a choice
>
> Interviewer: how comes?
>
> Cathy: because he was having strokes, I didn't know what was going to happen next, I just felt like the decision was- I, I didn't have a choice. There's a way he could be helped, there's a chance, I have to take it. If Troy was perfectly well, okay- I just do not think I would have gone for that as much as I would have been, huh I wish he didn't have it because of the risk, cause of the risk, and even when we had the transplant…umm…children who was in the hospital with us- one lady she travelled all the way from Nigeria, her husband is a politician, the child was six, and the child didn't make it-she died- and there's quite a few children who have passed away- and we're in the same hospital

> Interviewer: what with sickle cell
>
> Cathy: transplant, it's not the sickle cell it's the transplant

Cathy tells me that her son's strokes were the main reason that she consented to a transplant despite knowing the risks involved, and she balanced these risks against what another stroke would mean for his quality of life. But notice in her narrative that she also mentions a family whose child died from the transplant process, and she adds this in as presumably a way of constructing meaning to her choice or lack of it. She is reasoning that even with the risk of death from the transplant process, families still go ahead with the process, and so did she.

Janet's reasoning regarding choices is the same as Matt and Cathy's. These parents all want healthy children, and they believe that they are making decisions in the best interests of their children. Here Janet talks about the difficulties of making such decisions for a very ill child.

> Janet: The heart thing --- his heart function had become affected by some of the chemos – we knew that – that could've happened – didn't have any choice – you don't have any choice in this , got a child that's basically dying from cancer, if you don't give him the treatment, you go to court – so it's not like the optional things. Although, once we'd got to the transplant meetings, I started to feel that s – maybe – some of the stuff I didn't want anymore, - I was starting to think along those lines, because the chemo hadn't been so successful , my husband certainly wanted to go ahead with the transplant and had more of a positive outlook – me- I was more of a realist, and I felt there was a strong chance this – this – this transplant – I think when we finished those initial meetings we were getting given things – survival rates with like 55% , which isn't great ((no)) – umm we did talk to other parents, and other parents would say to you that maybe 70% chance – or whatever – an – and I just thought … this isn't looking so good for James , umm the consenting process, and even talking about things like GVHD – they become a little bit irrelevant in the overall scheme of things – although I made my feelings quite clear to the doctors and I'd said – I'd want a healthy James at the end of this – I want the James that can go out in the garden and play

> football with his brother like he used to be able to – you can't guarantee that to me can you?

The desire for a healthy child and the imperative to act in the best interests of one's child on a BMT unit sometimes puts the child through a series of difficult procedures as Janet describes. Her narrative shows how much her family had been immersed in the treatment process and the lack of choices that they had when she talks about being taken to court if they did not agree (West et al., 2020). She also talks about how she felt as the process of consent continued and her awareness of the statistics that were involved in determining treatment success for her son, especially after the effects of chemotherapy on his body.

Bev echoes Janet and explains more about the difficult procedures that children have to go through during treatment. She also adds clarity to the treatments that parents must consent to. Neither is easy, from what Bev says.

> Bev: it, they only go to transplant as a, you only get a bone marrow transplant if there is absolutely nothing else they can try because the effects, the long term health effects of transplant…particularly with ALL because they throw in total body irradiation to condition the body is so so damaging and you know the risk of, a transplant in itself carries a 10% risk of death just from the transplant; so the lifelong effects of a transplant are so damaging that it is a last resort…if there are no other options so yeh, things are desperate at that point, so..umm I did think when I answered the questions on your quiz, questionnaire sorry, umm, it was…almost an implication that as parents we had choice.. there was no choice

Bev is clearly expressing how major a transplant can be, especially for children who have had previous treatments for cancer. She also notes that transplants carry long term health effects and the decision to proceed with them is "a last resort". She also reflects back on how she felt when she was completing the survey for this study, so I probe her and ask her if there was no choice at all about proceeding with a transplant for her daughter Misty. My question is in the interjecting speech, and this is a continuation of Bev's extract above. These two extracts are part of the same topic of conversation, and they show how much depth Bev is adding to her narration of her experiences to me.

> Bev: ((was there not at all)) it its just you know, you fail induction with ALL you are going to have a transplant if they can get you there because there's nothing...nothing else, its it's a last resort umm and you know very very quickly there are, you know, you turn up, we're not doctors, we're fairly well educated, well read, we have an oncologist in the family and everything else, you turn up at the hospital and you're presented with this diagnosis and you have no idea what's best for your child or how to treat it umm but they are…literally doing the best with what they've got and you have to listen to them, you have to go with their recommendations because it is just trial and error over many decades, you know, 30 years ago, 10 years ago my daughter would not have survived, so umm, yeh but even if there were elements of choice, it rapidly narrowed down to, this is all we've got left to do.

I mentioned in chapter 1 that bone marrow transplants have not been around in the medical domain for a long time and clinicians are still advancing in the methods that they are using in this field (Roberts and Hann, 2020). Bev refers to this in relation to her daughter's chances of survival at the time of the transplant. As the interview progresses Bev explains to me that to proceed with a bone marrow transplant is not a choice-based treatment decision, even for the doctors. She highlights that sometimes doctors are limited in their capacities to make decisions if they are limited by treatment options for their patients. Here she tells me why.

> Bev: yeh, I mean like I say, they only do bone marrow transplants, because bone marrow transplants…are really expensive to do, they're upwards of £250,000 at least for the NHS, umm and because it carries such long term, you know, side effects, you know, daily growth injections, that's an extraordinarily expensive drug to buy, so they are not going to give a bone marrow transplant for any reason you know, you're only having a bone marrow transplant if the alternative is death, frankly. They are not gonna do it for anything else, so its not like there's even a question of consent or choice or anything, if you're, you're having a bone

> marrow transplant, its because they've run out of any other options so its as simple as that. Its, it's a devastating procedure to have done-
>
> Interviewer: yeh yeh, and I haven't met anyone who has said no just yet-
>
> Bev: yeh well no, coz the alternative would be, they would be dead that's it a bone marrow transplant, you know and, a bone marrow transplant will carry significant risk of death in itself, it's a, it's such a risky procedure because there is a window of two to four weeks were that person will not have an immune system at all and they are open to all sorts of opportunistic infections, which wouldn't even bother a person like me or you but for somebody who is, who has no immune system, it will kill them so you, yeh, so you know, they don't do bone marrow transplants lightly. Its not a treatment choice, umm if there is something else available, because if there is something else available they'll try that thing first—

I noted in chapter 2 that this thesis is about the latter aspects of decision making, and it is focusing on reflections about the voluntariness and informed nature of the consent given by the parents in this study. At present I am not concerned about exploring the shared decision-making models that were at play during the participant's experiences of BMT consent (Bomhof-Roordink et al., 2019). Rather I want to explore the meaning of consent during such major medical treatments and Bev's insight above evidently shows how major BMT transplants can be. Bev is trying to make an interesting point about the lack of choice for all the stakeholders involved in the transplant consent process which may have some bearing on how decisions are shared within these particular contexts.

The participants in this study all indicated that there were no options when it came to their children being offered bone marrow transplants and stem cell transplants, especially if the alternative as Bev describes is death. She also touches on the risk of death from the transplant a few times in her interview and here she mentions it again, echoing what Cathy said back in chapter 4. However, Bev expands on why death is a possibility more than Cathy does.

Her narrative above is full of reasons why transplants are risky, and it is clear that she knows a lot, especially when she talks about the financial aspects of treatment too. In the last chapter she also spoke about conducting further research into her daughter's treatment and that can be seen in the knowledge that she has developed over time. She is constructing her experiences in a way that she can exchange that knowledge with me, adding depth and context to the ways that she has embodied her new cultural capital. Again this is another example of the BMT habitus that she has developed over time on the unit, and in particular she shares this habitus with Janet. They both give similar figures of how much transplants cost, and I surmise these are the figures that were given to them on the same BMT unit that their children were treated on. The data in Table 3 (chapter 3) shows that their children were treated three years apart on this unit so I cannot comment on whether they knew each other or not, but it is clear that they share similar knowledge.

In addition to Bev's analysis of the limited choices that families have on BMT units. Janet's insight into her family's decision adds another element to this analysis on choice. She not only mentions her sick child dying if they did not proceed with his transplants (he had bone marrow and stem cell transplants) but she is also aware of the legal dilemma faced by all parents (Wilkinson and Savulescu, 2019) as I also mentioned in chapter 1 and in Janet's previous admission.

> Janet: got a child that's basically dying from cancer, if you don't give him the treatment, you go to court – so it's not like the optional things.

Parents can be taken to court if they make a choice which is against the healthcare team's recommendations. As I also noted earlier in Chapter 2, this is where the courts become involved in consent decisions, especially with sibling donors. This further limits a parent's choice in making treatment decisions, with the often-unspoken element of court referrals, which could arise out of disagreements within the 'Bermuda triangle' (doctor, patient, and parent). "Human rights law dictates that specific court authorisation should be sought when there is dispute between a child carer and his or her health care professional" (Mason and Laurie, 2013, p.75). Even though this study is driven by a paradigm shift in our view of authority and power within medical decision-making, this concern may not seem so pertinent when there is a lack of choice. And in a way this lack of choice supports my decision to explore the other aspect of medical decisions (informed & voluntary nature) rather than who is at the table when decisions are being made (shared). Understanding the nature of decisions in haemopoietic stem cell transplantation is arguably a logical task so that one can start to explore how the shared decision-making objectives can be effectively supported on BMT units (Stigglebout et al., 2015). This was Mills' idea when it came to sociologically exploring the social world (Mills,1959) and I echo this from the opening chapter, because unless the troubling issue is understood, a solution would be difficult to find.

Doctors without choices

There are strong parallels between Bev and Janet's narratives about choice and their experiences of how choice seemed limited in BMTs. Both parents express how they experienced moments where the doctors treating their children were at a crossroads when it came to treatment choices and decision-making. As I have noted above, at one point, both of their children were treated at the same hospital for their transplants, but it is not clear if that was the same hospital in which their children had their cancer treatments. To show the similarities between their experiences, Janet further highlights what Bev means about the lack of choice, as they thought about it from the doctor's position.

> Janet: it's not the doctors' fault either though – I think it's wrong when people love to blame a doctor don't they- but I just- I feel like they are playing God at times, but they've got no choice too, they have to make a decision, they have to move on with this ((its numbers))- its gonna go this way or its gonna go that way-

Janet's observations highlight the changing relationship between families and healthcare professionals (du Pre and Brierley, 2018) when both are put in similar situations such as having no choice but to go down the bone marrow transplant route. Both Janet and Bev are displaying compassion for the doctors when they try to see the decision-making process through clinical lenses, and this is evident in their reflections of the decisions doctors make. They understand the lack of options available to both parties, clinicians and families. In contrast to Chapter 4, where the participants felt that the lack of information was based on what the clinicians knew and chose to tell them, here the feelings towards doctors' choices are now based on a deeper understanding of transplants on the part of both Bev and Janet. Silverman also identified this in his observations of the clinic (1987). He found that communication changes through the course of the illness trajectory and decisions become somewhat collaborative (Silverman, 1987). I noted in chapter 2 that Silverman also relied on Bourdieu's theoretical framework for his analysis of how clinicians, patients and parents communicated within paediatric clinics.

As Bourdieu leads one to expect with his theory of the habitus, the dynamics on clinical wards change as families become familiar with the workings of the units and as they build relationships with the nurses and doctors. At this stage, voluntary participation in different types of choice begins to develop. There is a shift in the balance of choices on a BMT unit, as Janet points out, such that the consent to transplant issue becomes less important in the grand scheme of informed and voluntary consent.

As I pointed out earlier in this thesis, HSCTs/BMTs are of particular interest because they can be independently funded. So when thinking about the choice element of consent, as opposed to its voluntary aspect, I want to touch on what some would call medical tourists - those parents who either travelled to the UK so that their children could be treated with bone marrow transplants, or who travelled abroad to treat their children after the first transplant was unsuccessful. Data about this group emerges from the parents' narrative of others' experiences, and it highlights a different level of choice for those parents who have the economic capital to travel for treatment and are able to make this choice voluntarily. Travelling abroad can also happen when parents disagree so strongly with their medical teams at home that they choose to travel elsewhere for the treatment of their children (Wilkinson and Savulescu 2019). This is where I argued that Bourdieu's forms of capital also play a role in the BMT consenting process especially for those who have the means to exchange this capital within the transplant process. In this chapter I showed how Bev had developed her cultural capital in terms of knowledge about her daughter's treatment. And I noted how she embodied this capital and exchanged it in the language that she used to narrate her experiences. Here I want to highlight how economic capital works in BMTs, and how money can influence the choices that families make.

Some UK parents choose to travel abroad because the NHS cannot fund second transplants, or because their medical teams do not agree to their children having a second transplant (Ham,1999). Again, taking away a clinician's choice, because the family have the means to pay for a second transplant or get more medical opinions, and other treatments which require independent funding. Crowdfunding sources on the internet have also allowed some parents to raise funds for further bone marrow transplants- for example, celebrities like Ashley Cain (whose daughter passed away in 2021 after they crowdfunded for a second transplant) have tried this route to treatment.

In the interviews there is a real sense of how expensive transplants can be. Janet and Bev make clear how this type of choice relies on economic factors. Here, Janet drums home the expense of bone marrow and stem cell transplants.

> Janet: do you know how much a transplant costs, do you know how much, my kid must have cost the NHS in the region of half a million pounds (£500,000)… from his treatment, from day one to the end, the days he had in intensive care, the processes that he had, some of the medicines he had are very very expensive there's a family we know at 'London 1' who are going in for a second transplant, but the NHS has said No to funding, and the parents want it, they have done a go fund me thing, they have been told by 'London 1' that they have to have £400,000 to get through the door , they've got £300,000 they've started the process-

As well as funding transplants for eligible patients, the NHS also provides transplants for private fee-paying patients who are often cared for on different wards but by the same clinical teams. In chapter 4 Cathy also referred to medical tourists when she spoke about an African politician's child. Therefore the ability to pay can literally be life changing and I noted at the beginning of this thesis that this is what makes BMTs interesting to study from a sociological perspective. There are subtle undertones of almost a 'Cost of illness' politics where the idea of money is presented in 3 out of 4 of the interviews (Janet, Bev & Cathy). Earlier I asked Cathy about who would have covered the cost of the IVF that was offered to her. Janet also mentions how much her son's treatment cost the National Health Service (below) and now Bev is being mindful about the drugs her daughter needed for her cancer treatment and the cost of her overall treatment. Notice how Bev comments "that adds to the expense" if a transplant is added onto previous treatments.

> Interviewer: How much was that drug? Sorry I never heard of it, the one that they gave her-
>
> Bev: Oh I have no idea, expensive enough to be.. one that you have to apply special funding for ((oh wow)) so because it com- it isn't necessarily the cost of the drug as alone- it's just because the drug is so umm, so powerful, the only way to describe it is that, it, it came, you take this drug and you end up in hospital for a month, so it isn't just the cost of the drug, it's the cost of hospitalisation, tests, nurses, so you know you're taking a bed up for literally a month. So umm..yeh so that adds to the expense of it, so I have no idea, a lot of money I suspect ((mumble)) but umm, yeh a bone marrow transplant I think in this country is valued at around £250,000 ((oh wow)) so…

It is clear that Bev and Janet are aware of the transplant costs, and the role that money may play in the decisions for transplants. I also see how the opportunity to choose another hospital for children to receive treatment can factor into the choices of the healthcare professionals involved in a child's care as Bev and Janet highlight this. This further sheds light on the complexity of this high-risk treatment and the sensitivity required from all those involved in decision making.

> Janet: if our consultant who had looked after us through this journey had said look the chemo is not doing what we need it to do- we've done three cycles of chemo we are seeing every time we are seeing this residual disease it's too high We are not getting it down we haven't got anything else, we would have gone to America it would have cost us 400,000 pounds my husband would have lost everything not working would have uprooted everything my other kid I don't know where he would go for six months. We would go there, he would get transplant there….There is no simple answer

There is a feeling from Janet's narrative that parents have many things to think about during the transplant process, particularly when treatments are not working. Janet takes a moment and continues to talk about the difficult choices that parents are faced with, and how doctors sometimes manage these choices for the best interests of the child.

> Janet: I've had many many hours thinking about this and the doctors know that's what people will do imagine if you are on a transplant team and you've got a family sitting in front of you and the consultant before you says no, we don't think your child is suitable for transplant the very first thing that they will do is say give me a copy of our medical records. And they'll go to America and the doctor has no choice….I think even in that situation the doctor is looking at the child's best interests If you're going to uproot a family and take them to another country for treatment {London 1} are like, we'll keep them here we'll manage things here will slow things down and do what we can. Keep everyone happy will [inaudible] and will do the bare minimum We'll see how it plays out and generally the kid will get an infection, and they don't get transplants and they die. I've seen that so many times

Janet understands that the doctors are not the only ones who hold the choice cards, and at times the power dynamics can shift as parents try to act in the best interests of their children. Especially when the question of choice is presented as a financial decision. She reflects on what I analyse to be 'unconscious palliative care', where the doctors manage a child's illness without entering into conflict about treatment with the family. In the above extract she talks about the doctor's strategies for managing conflict with parents, when the financial aspects and economic choices about transplants are introduced into the consent conversations. Analytically, these narratives of other's experiences are what Frank talks about in his method of analysing stories of illness. He talks about how "a storyteller tells a story that is his or her own, but no story is ever entirely anyone's own" (Frank, 2012, p.35). And in this data the parents tell stories of others within their own experience narratives. But also, their experiences are co-constructed by others' stories, and in a way, this is how the habitus is formulated and reformulated within spaces (Bourdieu, 1984). There is a shared reality here and Janet and Bev show this in the ways they both see choice as being limited on the BMT unit. But their echoing message of economic sensibilities surrounding BMTs brings back the unease I mentioned in chapter 4. It appears that it may be an underlying theme that is evident when the information is limited (chapter 4) and when the knowledge of the process is developed/built upon by the parents (chapter 5).

Donors, HLA donors and Parental Consent

There is an additional party in this whole process who needs to be considered in the transplant decision process: the donor (Pentz *et al.*, 2014; Cherkassky, 2015). As noted in table 3 in chapter 3, Cathy and Matt were both haploidentical donors (usually parents) for their children, which means that they were able to donate their bone marrow without needing to search for donor on the national databases or use a sibling (HLA) donor (Schaefer et al., 2022; Veys, Amrolia and Rao, 2003).

Janet's son James had a donor from Germany, and he was asked to donate to James on multiple occasions. Each time James needed blood products from the donor, the donor had to go through a consent process. This is another reason why I want to reimagine consent as an ongoing process in BMTs. Janet explains in great detail about the ongoing consent process here.

> Janet: So they got him into remission after all of that, the doctors had arranged to do a donor lymphocyte infusion- so they'd written back to our original donor and asked for some top ups of

> some lymphocyte cells. The donor had responded and said that yes he was willing to give them- so they'd started to do those, I think we had our first one as well before we got discharged, umm and then we started being reviewed at the transplant clinic. It was supposed to be a weekly review, but he was needing blood products, and we were in there three or four times a week after we got discharged. But he started to strengthen up at home, he was eating a bit better, he was more mobile at home than he was in hospital cause he wasn't in that bed. And then in the middle of April…they wanted to do another bone marrow aspirate, so they did and he was clear of disease. And they said you know, he is in remission and it looks like we've got a good chance of curing him. Umm….but he was having problems with is blood, so he wasn't producing any blood, sufficient blood and he was reliant on blood products. They decided to do a second transplant of certain cells from the same donor, so instead of lymphocyte cells they wanted all the other cells. So they were doing a second stem cell transplant….which we had to give consent for, all this stuff has a form everything- and they did that umm, we stayed well, they did that in August, so August of 2018, and then he relapsed in October and passed away [inaudible]

For James there was an ongoing process of signing consent forms for further treatments on the BMT unit, not only for him but for his donor. But, unlike sibling and haploidentical donors, other donors do not know who they are donating to. They have restricted access to the recipient's story and vice versa, so they tend to not know the outcomes of their donations until years afterwards, if at all. Therefore, the circumstances surrounding their choices are not known to the parents interviewed in this thesis. However, Janet's experience highlights that as stakeholders, donors are also an important aspect of the BMT consent process, because without their donations, transplants can take a long time to get started.

Parents and sibling donors seem to have limited choices because of the close relationship that they have with the patients. This has been reported in a recent study conducted by Schaefer et al., 2022, where they interviewed haploidentical donors (parents) about their experiences of the donation process. Utilising a questionnaire that was constructed after interviews with seven parents, they found that 56% of their respondents felt that they had a choice and 44% felt that they did not have a choice. However, in their analysis of the interviews which were conducted after the questionnaire, much similar to my study here, they found that people contradicted themselves on their perceptions of choice, as the only choice was to save their children's lives (Schaefer et al., 2022). These results support my desire to use the word choice in my discussion, rather than voluntariness. They also support the assertion echoed by the participants in this study about the lack of choices when it comes to BMTs.

In other medical contexts there would be no argument for mentioning children when the main focus is on parents. However, as I am focusing on parents' experiences of paediatric BMT consent, it is important to mention HLA sibling donors. As a mother I can relate to how the process for these children may cause cognitive dissonance for parents when it comes to consent. Although not quite a dissonance as Bev discusses. The closeness of the donor-patient relationship also has to factor in age and donor choice, given that donors can also be siblings. For example, Bev addresses the question about the age of participation in decisions with regard to her son being a donor for her daughter.

> Interviewer: so he was the donor, what do you think about sibling donors. Do you have an age for them, in terms of donation, what do you think? How old do you think they should be in terms of making decisions?
>
> Bev: do you know, if you have a sibling donor you have to jump at it. You should just, it would give the best outcome and its so rare, literally 1 in 4 siblings may be a donor, and…you know Jacob, what, oddly of all the things, Jacob had a choice. I'm not sure if he should have had the choice [giggles] but he had a choice and he said yes. Umm….but you know if you have a sibling donor, irrespective of age, you have to use them because you will get….you get a better outcome, the recovery is, I think smoother
>
> Interviewer: did you give him the choice or was it the hospital or was it—who gave him that choice?

> Bev: oh legally he has to, he has to be asked- it’s weird of all things he legally has to be asked for his consent

I probe her on her decision to allow her son to be a donor, especially as he was younger than her daughter who needed the transplant. Bone marrow transplants are the only surgery where a living child under the age of 18 years old can donate biological material (Pentz *et al.*, 2004). In Chapter 2 I explained how the Human Tissue Authority becomes involved in these decision for the donor child.

Although she found it “weird”, in Bev’s case, she felt that her son had a choice.

> Interviewer: you wouldn’t say no would you, you wouldn’t say find somebody else
>
> Bev: and that’s [inaudible] coz you don’t want to put the pressure on an eight year old boy, but at the end of the day you just think, if you say no and you grow up knowing, she would have died if you he’d said no , you know, how do you live with that as a grown up if you said no? you just, it’s kind of…I doubt there are very few children who would say no you know if you explain the situation, and you know you explain that you will be fine, you know, umm, you will be recovered within a month, you know you will be back at school next week and…its. So for him I think he’d spent so much time in the hospital, so for him it was also a safe place, and he was happy there…umm, like I say we were lucky with the unit, it was a nice clean modern building, I think if we’d been stuck in the children’s cancer unit at ‘LONDON 2’ that would have been awful. Because ((different))- its small, tired shabby, umm, yeh just just unpleasant umm, but you know ‘LONDON 1’ was a big, clean, modern friendly unit, and I think that really helped us so umm yeh, so it’s a win, we were fortunate with the unit-

For Bev it is an obvious decision to allow HLA donors to participate in decision-making, given that for them it is not a last resort, life or death decision. However there is still the curiosity of whether or not donors really do have a choice. But Bev also believes that her son felt safe in the hospital where he spent time with his sister. Of course Bev is also speaking from the perspective of what she imagines her son would be like as an adult. But allowing him to make the decision without causing conflict is the focus here. As a parent, her ability to consent for her 8-year-old son has been taken away by the nature of BMT transplants And, again here is where other stakeholders (the HTA) become relevant to the consenting process.

As I have mentioned already, this study has a strong focus on a deep narrative analysis of the data, and how these stories can help to understand the BMT consent process. Moreover, the depth of the data thus far highlights points where communication works for habitus formation and development for the families on BMT units.

I discussed the issue of choice with Janet, and we spoke about the HTA and their role in the sibling donor aspects of the treatment. We considered the situation where parents' consent for sibling donors who are themselves against donating. She responded with a story about the coercion involved in the decision-making process. Janet is comfortable on the BMT unit and here she is talking about a conversation that she had with a consultant. This conversation appears to be informal and not based on Janet's son's treatment. And it highlights how comfortable people can become with each other on the unit.

> Janet: yeh that's like what this consultant was saying to me the other day about this girl that had been coerced- I knew the family- I knew the mum and she had explained it to me- and if I was in her situation I would have done the same…what do you do if your eight-year-old needs your fourteen-year old's cells? And you know that it's not gonna harm her to give it to him and… and you know she's being a difficult teenager —what do you do with that? Have you got a choice? I don't think you've got a choice. If people like Anthony Nolan and the ethics committee had decided that you had to take those cells from her as opposed to going to the register and taking cells from someone else- which I don't understand when they would rather the sibling- but if that has been decided, then they are gonna coerce aren't they? They would do way more than coerce so how is it not alright for a parent to be involved- of course they would coerce that kid- yeh who wouldn't unless you're [inaudible] how could you turn your back on it-

What Janet is clearly saying here is that parents' abilities to take part in HLA donor consent can be effected, especially when coercion may be the driving factor in these cases. But families often do not have a choice in the process of finding a donor, and as Janet explains, it can become difficult with siblings. There is often a medical preference for sibling donors and the Human Tissue Authority guidance helps in these situations (HTA, 2021), working for the best interests of the children (donor and patient). The guidelines do not permit donors to be coerced by their families, which makes it difficult for some to comprehend, as can be seen from Janet's story. The lines of course can become blurred when asking children to partake in non-therapeutic treatment such as donating stem cells or bone marrow (Cherkassky, 2015).

However, the focus of my thesis is not on minor sibling donors, but I wanted to highlight the experiences of the participants when it came to choice and show how choice impacts all those involved in the treatments on BMT units. Everyone seems to be involved in making decisions in one capacity or another, as I shall illustrate in more detail in the next chapter. However, ultimately it is the patients and their parents who experience the illness journey most immediately. To fill out our understanding of BMT consent, I want to introduce another important element: multiple transplant consent decisions. Again these situations have their limitations.

Multiple Transplants: Death and Trust

It is not always the case that treatment is in the "best interests" of the child, and this is particularly so when it comes to considering further treatments if transplants fail the first-time round. Parents sometimes have to go through the treatment consent process again. When a transplant fails and a second attempt is considered, this can sometimes cause conflicts depending on how soon after the failure a second transplant is needed (McIver and Ham, 2000).

When discussing further treatment consent decisions Janet refers to the clinical relationship as the 'Bermuda Triangle' (doctor, patient, parent). She astutely points out the perspectives of all the parties involved in making the initial decisions, and drawing on her testimony, I want to think about whose best interests treatments serve. Does one person benefit more than another in this triangle?

> b: …I think if there's a query somewhere in the Bermuda triangle as I call it, because you've got doctor, you've got patient, you've got parent…if somewhere in that triangle there's some element of question let's say the doctor is not sure, so there'll be times where a doctor is looking at doing a transplant, and they're on the fence, they know it's a last ditch attempt, there will be someone in the background saying let's just go down the palliative route one option, and then you've got a case the doctor is sitting there and is looking at this patient, the patient is okay but they've got I don't know, bad liver function, a couple of other things that they know are gonna cause problems, so we are not starting from zero point perfect health they're talking about, and they might have disease burden as well, so you've got a child who is not a perfect candidate for a transplant and then they've got, I don't know, a poor match, say they didn't get a good match, they got a 9/10, and they are looking at that, and they've got a pushy parent, parent saying 'YEH YOU'VE GOTTA DO SOMETHING, YOU GOTTA SAVE THAT KID', and then you've got, the kid is sitting there ravaged, they've been through hell who is standing up for that kid? Is that doctor actually gonna say no, the doctor is gonna say 'let's give this a shot', yeh you give it a shot, you cure him, and he's got a lifetime of long-term chronic conditions that he can't get out of…is it the right thing to do?

Janet paints a vivid picture of what a transplant consultation for further treatments may look like. When it comes to the best interest principle, the 'Bermuda Triangle' gives a glimpse into the complexities of decision making, where I argue that age has to be set aside. Primarily, it is not about whether a child is old enough in terms of being Gillick competent, if the adults are considering how and who makes the decision; rather it is about whether the decisions made benefit the paediatric patient and in some cases the sibling donor. The healthcare professionals here work under specific guidelines published by the UK Royal College of Paediatrics and Child Health (RCPCH) which are designed to assist them in determining treatment protocols. The parents are guided by their own instincts, experiences, and parenting principles, but what are their experiences of the BMT/HSCT consent process, as I ask in my first research question.

In what follows, I want to open up their part in the consultation dialogue around haemopoietic stem cell transplants, by first highlighting what the BMT consenting process is like. Janet raises two issues: one about what it takes to be qualified to make decisions on second transplants (discussed in the first three extracts below), the other about who should make these decisions. Again, this speaks to the question of whose best interests transplant decisions are based on, especially when, after a transplant has failed, a decision has to be made about whether to go ahead with further treatments.

Janet also highlights the harm that can come from further treatment and considers whether or not there should be a separate process, involving a variety of specialists beyond the ‘Bermuda Triangle’ when transplants have to be attempted a second time. These extracts all form part of Janet’s experiences of the BMT consenting process. Here she introduces a further theme relating to consent which will be discussed further on: the quality of life after transplant, and the risk of death. I have chosen to discuss Janet’s narrative as she has a lot to offer; because her son James had multiple transplants, and she spent a lot of time on a BMT unit. In addition, Janet is a storyteller. She uses others to inform me in greater detail about life on a BMT unit. In saying this, I would also like to remind the reader that our interview lasted over 3 hours and many cups of tea in a very accommodating café situated just on the side of a country lane. At times the interview could have been mistaken for a conversation between two familiar mothers.

> Janet: I think the other thing that you need to consider with this is, what happens if a child consented to their own transplant…I know, I’m not gonna mention the actual name, but I know one patient who is a teen, she’s now thirteen, she was diagnosed with leukaemia when she was ten, she had her first transplant when she was nine after she relapsed, umm, that transplant didn’t work, and she had to have a second one a year later, she made a special application, had a second transplant, now that transplant has been successful, so her disease hasn’t returned, but she has got chronic

> GvHD with her eyes, her skin, her lungs, she can't eat, her stomach, so her digestive tract has been affected as well.

GvHD is one of the main side effects of transplants, and it can cause a variety of complications for transplant recipients. I touched on this in Chapter 1, and the data in Chapter 4 also showed that 6/8 of the participant's children had GvHD as a side effect from the transplant. Janet continues to tell me that the decision for another transplant was made by the mother of the young girl she is telling me about:

> Janet: It was not her idea to have a second transplant…it was her mother's, her mother is lovely by the way, I really like her, she's a really good friend, and I completely get where she was coming from but it was her mother's idea , so at the age of eleven she was re-admitted into hospital for a second transplant, her body is already shredded to pieces from the first lot of stuff…she survives it, she comes out the other end, a year post-transplant now and she doesn't have a day in the week where she doesn't have a hospital appointment for one of her problems. Very poor quality of life, if she had consented to that second transplant herself, if she was allowed…how would she live with that, maybe if she regretted it, what if she turns around and says to her mother 'why did you let me sign that form, why did you make me sign that form, why, how did it even come about that I could sign that form?'. How, how does a twelve-year-old make herself available for a second transplant if her parents don't get her there or her doctors don't get her there? she can't do it to herself.

Janet supports her argument about further transplants by suggesting that there should be a team of external decision makers based within the hospital. Her long experience of living in the hospital shows that she is aware of what happens on the unit, and her narrative shows that she has considered how decisions for transplants are being made. She displays a heightened sense of awareness in her storytelling, and this reflects her interactions with other members of the BMT unit community. Again in relation to external decision makers, she continues to question who should make transplant decisions.

> Janet: It's a bit like the euthanasia thing, cos there's so many angles to it I think unless they have a higher, something like 60 % curative rate they can expect, where the proportions are strongly in the favour of the patient, I think it should go, it should go to a board of people that can help with the decision making and it needs to get taken away from that doctor, and from that parent, and from that patient. Because actually, none of them are qualified to make that decision. The child is too young to understand the enormity of what they are going through or what it means to have GvHD or any of those other side effects they can end up with; the parents too emotionally attached to the process, they are not allowed to make any other decisions, why are they allowed to make that decision? and then the doctor… what's the doctor got to prove in all of this, the doctor wants to cure the child the transplant doctors by nature are very used to putting patients in very difficult situations, should they be allowed to do that to a child? I just, there's not enough…. unaffected uninfluenced people

Janet's account gives an insight into the experience of her family, and she shows how much she knows about the lasting health effects on the everyday lives of the patients. These lasting effects help to explain why Janet feels like the 'Bermuda Triangle' decision-making model, which is essentially based on shared decision making needs to be reviewed, so that more weight can be given to the pros and cons of further BMT/HSCT transplants. For Janet , the triangle diminishes in power once the disease returns, and the consent process begins anew. Her time on a BMT unit also shows how relationships between clinicians and families change over time. Here Janet has been recalling a conversation between her and a consultant, and it shows how her habitus is shared with that of the clinical team. Janet continues to talk to me about how her experiences have shaped how she feels about transplants, especially after the initial transplant has failed, and death becomes visibly part of the picture (Herrmann et al., 2021). Here Janet talks about death and the survival rates of transplants.

> Janet: I don't know whether bone marrow transplants are what they are sold to be whoever knows about the success rates of transplants- like how many do survive and how many survive

> well- how many, especially out of the paediatric—fifteen kids went in, I know two that are alive…
>
> Interviewer; when recently?
>
> Janet: in our twelve months that we were in there…….and when I spoke to the consultants about it- I'm a very honest person and I said 'this is bad'- I said is this normal- they said yeh- I said- they said the only bit that was not normal was the number of kids that were in at the time- there happened to be a lot of children on treatment having transplants- and they've actually stopped doing that now cause its too much for the team to look after- they've pulled back the numbers so they only have a certain amount on the ward– and they said- a key difference in the way that they manage transplants here and in America…so in this country- they haven't lost a child to transplant- so the transplant process- the conditioning for something like four years on that ward- they lose them to disease after transplant.

Janet makes a distinction between the deaths of the children on the ward her son was on; some are due to disease and some to transplant. She notes that the deaths were mainly due to disease and not to transplants alone. Her testimony makes it clear that the relationship between her and her medical team has evolved. As I mentioned in the literature chapter, Silverman also found this in his study (Silverman, 1987). This can also be seen in Janet's extract, "I said is this this normal-they said yeh". The frankness that she relays to me about the medical team shows a level of trust in the honesty of the answers that the clinicians give her. In a way, this goes back to her earlier admission in chapter 4 when she said, "only if they see that you've either got enough ability to cope with the truth". Thus the reason she knows a lot about the deaths of the children concerned is that she spoke openly with the consultants on the ward. An analysis of the language Janet uses when talking about her son's illness journey shows that she is comfortable using medical terminology, and this further illustrates her immersion within the hospital way of life and the BMT habitus. Moreover, she displays an understanding of the medical differences in the causes of BMT unit deaths. She continues on the subject of death.

> Janet: Like James, he died from disease not transplant…in America, they lose them to transplant…they hit them harder with their conditioning they give the worse conditioning- there's different conditioning regimes they can use…in this country they said they try to balance that off with GvHD- they would rather have a child living with GvHD any by-products-problems- rather than dead. So you get a lot more of that- but in America if you had a child with that level of toxicities and difficulties they couldn't function in their system-

I must emphasise that it is not the transplant that kills the patient. It is the procedures a patient has to go through to make the transplant possible; it is the critical period after transplant when the body is readjusting to the new cells; it is the medication given to them, and as Cathy pointed out in her interview, sometimes it could be the care that the patient receives.

> Cathy: [shows more pics of GvHD and another child] that's another boy who had it, but it didn't work for him- that's what I'm saying, he had the transplant and everything – actually, I don't know if they will speak to you cause they very much- I don't know if they are someone who would have responded and said yes we want to speak to you – I doubt it.

Here Cathy deeply tells a story of not only how she had learnt more about her son's treatment but also how she adjusted to hospital life like Janet. She also talks about how this helped her to oversee and support her son's care. This is where she also exchanged her newly accumulated capital that was gained through her experiences, and she used it in her interactions with her son's clinical team. She tells me a story about how she attempted to share her new knowledge to help another family through their child's transplant.

> Cathy: (talking about the other family) But he had the transplant. There's a point in the transplant where, you have the actual infusion of the marrow, and then you…as I said, you have- if the immune system is down, the new marrow, you want to establish itself _ the old marrow, you want to go away- yeh so you put- you're on an immunosuppressant called umm, M, MSF, M-something, can't remember, it's a long name but- I've probably got it in here [her diary]- yeh so what you do-…you suppress the old

> marrow- well you have the suppress- the whole point is to suppress the old marrow allow the new marrow, then once that neutrophil is on I think number 1 you remove the immunosuppressant- and so the new marrow should take

This first part of hr story clearly shows that Cathy knows how the transplant works, and she goes on to confirm that she had been reading about transplants.

> Cathy: over…our consultant was on holiday, and umm their [close contact] died- not on holiday, sorry for the funeral I said to that dad (of the child she is telling me about) cause again, I'm new, he was two weeks ahead of us but I said to him, when Troy's neutrophils were up, they stopped the immunosuppressant….trying to think….yeh so the consultant was away- so I had started to read up on everything and I said to him- shouldn't have they stopped the immunosuppressant?- and the dad was saying 'I don't know'- and I said talk to the doctors, talk to the doctors.

Cathy is expressing how much she really wanted to share her knowledge with the other parent, but she also recognises that she was 'new' to the unit and the other family had been there longer than her. I explained in Chapter 4 how much information is required by parents throughout the BMT/HSCT transplant process, and it is evident that each stage of treatment requires new and/or further information.

Cathy's narrative shows how much a parent's knowledge bank changes through the illness journey and, like Janet, this is evident in the medical language that she uses when talking to me about her experiences. Cathy goes on to explain how the transplant failed for the other child and talks more about how she tried to offer some guidance to the family.

> Cathy: When the doctor came- I think, was it before he went away? It's like he wasn't supposed to be working that day or he was off, so he just popped in cause it was weird—he was wearing trainers and Troy said 'mummy he's got vans'- cause he had his trainers on- and he just looked ta- didn't look at any notes- the mum has it going- but I knew quite a lot, so I could say to him 'his

> neutrophils are' so he'll say stop the MMF- I think that's what it was called and that was it and he didn't make a note of it- I just wrote it down, cause you have to wean off it- so they say give this dose this day, this dose this day, 5 and you reduce until you're off it and I remember- so I just- we were on our way home I think this was the first time, six weeks- so he said stop it so I just done it myself how he told me- that was that.

The doctor trusts Cathy and her attention to her son's care. She is in the midst of her son's treatment, and she is communicating in a way that the doctor is able to trust her judgement, even without checking her son's notes. My own experiences of the BMT unit had given me an insight into encounters like this too, but Cathy was the first parent from whom I was able to get this first-hand account. She continues.

> Later on when he went away, this other child- the dad said look there's problems blah blah blah- and I said cause he's still on the MMF, I'm sure he's not supposed to be on the MMF cause Troy was off it- you only- you stop it- what you do, you have to stop giving that…particular medication at that time, so that the new marrow will take over, if you don't stop you start to suppress the new marrow- and that's what happened with this boy- they'd kept him with it for too long- suppressed the new marrow and the old marrow came back- so he didn't…it just didn't work for him- for error- this was a human error why his didn't work . So he's gone back to sickle and had that whole process for nothing. I haven't followed up to see where they are now, but the mum was so upset that I don't know if she would have gone through that again.

Cathy is aware that her short time on the unit may have raised questions about how much she really knew about transplants, hence her tentative approach to share her knowledge, although nonetheless she still shared it. Moreover, she also sees another role for the parent during their child's treatment process, and this role requires a shift in their attention towards effective communication. Parents not only have to make critical decisions, but they also have to be alert throughout the treatment to ensure that communication does not break down within the care team, and she explains this.

> Cathy: And that was- this is what I'm saying- this is how- the transplant- when you are in the transplant, that's how much it can be touch and go…..it's not just a smooth thing, it's a lot to do with….awareness…keeping abreast of what's going on, sometimes you have one nurse and another has taken over and- things can happen in between those take overs, somethings can be missed- that's where to me a parent comes in yeh, fills the dots and says well he said this and she said that- that's what I felt that I had to do- I had to be that person in the middle, making sure everyone's got the right story- there could be a lot of miscommunication umm yeh, so much, so much things, so that's why I tell people I never slept for three years- cause while we are there you can't sleep- I need to be awake- I need to know what's going on-

In Cathy's very detailed narrative one can see the changing role of the parent within the transplant process, and how they can transition between different roles on the BMT unit. One can also see that power dynamics can change within the process as parents develop their knowledge of the hospital and its procedures, something already highlighted in the literature (Silverman, 1987). Parents do not require the same educational capital as the healthcare professionals to be able to participate in the medical care of their children. Cathy shows that, as parents develop their BMT-habitus, they gain capital that they can exchange in the day-to-day care of their children. It is in these exchanges of knowledge and interactions with healthcare professionals that power balances also shift, particularly where trust is gained or lost. Cathy's example of the family whose child's transplant failed also shows that sometimes parents' trust in the clinicians may be stronger than the trust parents have in each other, which is understandable. The trust relationship in this case is about families and clinicians and not families and families.

Cathy's detailed storytelling gives a little glimpse into what the dynamics on a BMT unit can begin to look like during the transplant. In her narrative, the child survived but remained with sickle cell disease. Children do however die on the units and Janet explains how hard it is to communicate and talk about death on the unit, and how parents struggle with telling their own children the truth. Janet talks about this struggle here.

> Janet: You know they have the long term follow up, the short term follow up, and the clinic is always that day, and so you've got to know a lot of these families and you would see a lot of these children, and there's a lot that weren't there, you know, they they had deceased. There was a lot of children that had passed away from transplant, and you become very aware of all of this) and the children are quite aware of it you know; they'd say to you, 'oh there's such and such'. And then suddenly they don't see that person and they might say to you 'oh where's Danny today?' And I'd be like oh he's not having an appointment today. He's passed away, and you, you're not gonna-

In the interview I empathized with her and acknowledged difficulties I had in talking about death with my own children. Janet's response indicates how death on the unit is not spoken of, but the other families know. This is an example of the BMT unit habitus at work, where most people know what to talk about and what does not need to be openly spoken about.

> Janet: imagine your child being in hospital, you're another child, similar age to them. They would have went to hospital school together, they'd play in the hospital together, they would play online as well because that was another thing, yeh, but then there were times when you would have to say... they didn't make it. But there was times when you knew you could get away with it why add those people to his list of people that haven't made it through this process. And being a high-risk patient, you do end up being an inpatient with lots of other high risk patients. And so generally a lot of the child are not gonna make it. No one ever tells you that, but you know by process of elimination that they, they weren't making it

The "process of elimination" signifies that there is a deep connectedness of all those who live on BMT units, and because of this, it becomes easier to know who may be missing. What is interesting is the strategies that Janet alludes to about how parents may avoid the subject of death like when she says, " there were times when you knew you could get away with it". This statement was not just for her own child, it was an unspoken about feeling amongst the adults. And when James died, Janet still felt that they had to hide his death from the other parents and not just the children. She tells me about his death and what happened afterwards, and the silent interaction that she had with a new parent as James' body was taken from the ward.

> Janet: when James died on the ward- right we're in the hospital, he died on the ward, it was 7.30 in the evening…the first thing the do- and they tell you this a little bit before- but only if you ask and they realise that you are asking- they turn the temperature down in the room right so a temperature controlled room- they turn the temperature down- and they do that to preserve the body as much as they can- so these children have had chemo- their bodies are in a terrible state- the deterioration is very quick– it's not like a regular person dying, they deteriorate very fast …..luckily I had asked a lot of questions before hand and I had something there that I wanted to put on James, like just nice pyjamas that I had bought him….and err, they changed him, washed him- they took away some of the medical stuff that they could…we had some private time with him…a couple of hours had passed and really it was time to move James- but they don't like to move him while everyone is awake on the ward- they don't want anyone to see him- they don't wanna upset anyone- so we had to wait- and I'm saying that we had to wait like it was enduring- but there was about an hour where we were happy to move James but the process in the ward is that you have to wait for people to be asleep and you go out quietly- there isn't a secret trap door to get you to the mortuary you know and you have to be wheeled out and hope that no one sees…it's this parent- we went out and this parent was coming in from the parents' kitchen and he was in the room next to us- this dad- I met him once or twice- hadn't really spoken to him- we'd been there five and a half months- I knew a lot of people, I didn't really know this guy that much- and his son had been diagnosed with AML, the same as James about a week before James passed away, so he had just started on this journey….I almost felt as bad for him as I did that day…..we were walking along behind James' bed and he's covered with like a sheet- he would have known straight away that's hard isn't it.

In the midst of Janet's sorrow, she felt sympathy for the 'new' parent on the unit.

Summary

This chapter has introduced data which focuses on consent as an ongoing process where there is often no choice for the stakeholders involved, and in particular the parents in this study. The choices presented to them fell into the theme of ‘limited choice’ as they narrated their experiences of consenting to transplants for their children. By showing how parents have in effect no choice but to consent to treatment, I have questioned the meaning of voluntariness in standard definitions of consent. Formally, parents’ consent to treatment is considered voluntary. No one forces them to agree to treatment. However, as I have shown, there is a broader sense in which, since they have no choice, the issue of voluntariness becomes almost irrelevant.

At the same time, and moving beyond the parents themselves, I have started to explain the relationships between other actors on the BMT unit, as these are described in the narratives told by the participants in this study. Those in the ‘remission’ society, namely the participants, have highlighted the politics of BMT consent, and have shown that the BMT habitus is developed throughout the treatment process. The data shows a constant theme of communication between all stakeholders involved in the consent process, and this communication shapes the BMT habitus. Thus communication is maintained as a key factor for parents navigating through the transplant process on BMT units, and it is supported by the increased knowledge that they gain along the way through their children’s illness journeys.

In this chapter I have also identified where all the stakeholders are in the consenting process, but my focus begins with the parents’ experiences. The narratives in this part of the analysis show that there are doctors, child patents, HLA matched donors, adult donors and the Human Tissue Authority who are all involved in transplants as well as the parents. They all have experiences of the BMT consent process that can be shared for building a complete picture of the haematopoietic stem cell transplant consent process.

The final chapter of the analysis will continue to examine communication and how parents share decisions, in relation to the question of how the BMT consent process can be modified to support shared decision making.

Chapter 6: Supporting Decision Making

> I think he should be part of the decision making…you need to be aware about how he feels about things but overall- a responsible parent needs to make the decision - I think. But I think it's good for him to be part of it, for the consultant. (Cathy)

Introduction

This final part of this analysis is centred around data that is focused on research questions 3 and 4, and its main theme is that of supporting decision-making. I begin the chapter with the idea of best interests. I consider this idea from the participants' narratives and their perspectives of the healthcare professionals. My account of these perspectives is drawn from the interview data and is therefore confined to the reflections of the participants in this study.

Within my study, decisions about what is in a patient's best interests are focused on cure and treatment protocols. Is it the case that 'the doctor knows best', or that 'the parents know best'? Either way, decisions are made, and it is through the parents' narratives that we can arrive at an understanding of how informed and voluntary these decisions are. The two, final research questions can be answered by conducting an in-depth analysis of the communication between all the stakeholders on the unit. The data shows this through the parents' reflections, starting with their thoughts and perspectives about the age at which children should be to get involved in decision making. Their thoughts on the age of children's medical participation are centrally focused on their own children and how they navigated parenting. As I did not gather data from the participants' children, the data is presented from the experiences of the parents alone.

When thinking about the best interests of the child within medicine (Gillam, 2016; Ham, 1999; Baines, 2008; Archard, 2013), it may be useful to consider these interests within a triangulated process, as the analysis of best interests is not only about parents and doctors, but also about the child. (Just like the

‘Bermuda Triangle’ that Janet talks about in the previous chapter.) What is best for the child? Who should decide what is best for the child? Should the child be involved in decisions about what is best for them in terms of their health and who has overall decision-making authority (Birchley, 2021). Going back to the research problem, I raised the issue of clinicians being concerned about who holds authority in medical decision-making. This issue mainly arises in relation to parents and doctors, where there is a growing unease about decision making authority (du Pre and Brierley, 2018). However, it is also necessary to make reference to the child, as they are the subjects of the decision-making conversations in the paediatric context.

The idea of the best interests of a child is a modern one and there is a long history of medical practice predicated on the paternalistic view that “the doctor knows best”. Traditionally patients were expected to follow the recommendations of medical professionals without question (Archard, 2013; Ham, 1999; Wilkinson and Savulescu, 2019). However, when considering the theme of ‘best interests’ within this thesis, I argue for the focus to be on the parents as co-fiduciaries in their child’s care (Linney et al., 2019; Wilkinson and Savulescu, 2019). There are a number of issues to consider here, such as who has the right to choose treatment protocols, who should involve the child in decision making and moreover, whether the child should be allowed to declare their desires within the consultations relating to their treatments. I distinguish between three ideas in this chapter: 1) parental discretion on the age of involvement in shared decision making; 2) the best interests of the child; and 3) supporting parents in sharing decisions.

Parental Discretion

Parental discretion in the medical context is all about the decisions that clinicians are comfortable with allowing parents to make for their children’s treatments. Lynn Gillam describes this as the ‘zone of parental discretion’ (Gillam, 2016) and I touched on this in Chapter 2. I believe that the ‘zone of parental discretion’ may be viewed as a subjective aspect of the consent process, where discretion is based on individual perceptions. I believe that putting the ‘discretion’ aspect aside in this chapter opens up a space to concentrate on the research problem, and take account of the fact that views about clinical autonomy in medical decision-making are changing (du Pre and Brierley, 2018).

However, when thinking about parental discretion in this analysis, the data shows that, from the perspectives of parents deciding whether to consent to a transplant for their child or not, there is no clarity on who the key decision maker should be within the family. Indeed, this is what Wilkinson and Savulescu argue. “While there might be agreement internationally that there is a ‘zone of parental discretion’, there is not as much agreement about how wide this zone is, or where the boundaries lie” (Wilkinson & Savulescu, 2019, p.92). In the cases that form the basis of this study, the decision to proceed with a bone marrow transplant is made by the doctors, after consultations with parents and other healthcare professionals. In other words, no single person holds overall responsibility for the decision to proceed with treatment. Rather, it is through a process of discussing the treatment options through what may be a shared decision-making model that a decision is reached.

Moreover, as I have already shown in the preceding chapter, deciding to proceed with a transplant is not voluntary, in the sense that the families concerned can freely choose whether or not to opt for the transplant procedure. This will become clearer as I examine the way that the patient’s ‘best interests’ are interpreted, and particularly the freedoms afforded to the child patient by their parents during their illness journey.

Other scholars have chosen to focus on the Harm principle as an alternative to focusing on Best Interests (Diekema, 2004; Lyons, 2011). I partly agree with this approach. But I believe that, in paediatric BMTs, the issue is ultimately what is best for the child, rather than what might harm them. As the parent’s reflections have shown, most of the treatments on offer cause a considerable amount of pain. I get the impression that, in the literature on the Harm Principle, pain is used synonymously with harm, so that all these treatments would be to some extent harmful.

It is true that the debates about what is in the best interests of a child also involve conceptual difficulties, and they may lead us around in circles (Birchley, 2016). Nevertheless, I think the notion of best interest provides a more appropriate focus for this study, if the aim is to slowly gather a collection of experiences from all the stakeholders involved in the treatment process. This is partly because, whereas the Harm Principle is often applied in a relatively short-term fashion, BMTs are long processes in which harm can be minimised in a range of ways. The question of who has discretion to decide on a child's best interests allows us to take account of time – to focus on the process of consenting. Although this may not be the case in the adult BMT context.

I turn now to my question about the age at which parents thought their children should be able to take part in the consent process, again this is all following the trajectory for exploring shared decision making. This question was asked both in the survey and the interviews ***(What age do you think that children are able to give written consent (signing a form) for treatment on a BMT unit? You can give a reason if you wish)***. The aim was to probe the parents further to aid in understanding their views of the child within the BMT consent process. The two data collection methods that I used in the study elicited different answers from the parents (see table 7). Each of the parents who participated in both the survey and the interview deviated slightly from their survey answers when probed in their interviews. It became clear from their narratives that it was at the discretion of the parents as to how much their children were involved in the consent process. Since the views of the doctors and the children were not collected, I can only analyse the parents' views. The doctors' and children's views can to a limited extent be inferred from the 'others' stories' told by the parents, but it is not a necessary for the reader to do that in this thesis, rather, the parent's views are the most important focus here. Again, the parents were the only ethically accessible group here as I mentioned in chapter 3 in the discussion on the methods and participant recruitment. The parents' responses are relevant to research question 3: How can parents support their children in sharing decisions about bone marrow and stem cell treatments?

Table 8 shows the ages at which the parents who participated in the study thought that children should be to make transplant decisions. The table also shows the answers they gave to this question in the survey and the age they gave to the same question during the interview. I probed these answers further during the interviews to see if the parents’ views had changed in any way between the time that they completed the survey and the interview.

Table 8: Responses to what age children should be able to participate in BMT decision-making

Participant	Child's illness	Suggested age for giving consent (survey)	Suggested age for giving consent (interview)	Own Child's age at transplant
Matt	Fanconi Anaemia	18	Maturity	5
Janet	MDS, Refractory AML with mixed cytogenetic abnormalities	Dependent on individual	Starting from 2 years old to 16 years old	8
Bev	High Risk Refractory T Cell Acute Lymphoblastic Leukaemia	18	Minimum 16 if not 18	11
Cathy	Sickle Cell Anaemia	14-15 years old	???	11
Zoe	Severe Aplastic Anaemia	16 years old	No interview but the child had a social worker and also signed the consent form for their transplant.	16
Kate	Acute Myeloid Leukaemia	18 years old	No interview	Unknown

The following interview extracts relate to table 8, though the table also includes the responses form the survey-only respondents, ‘Kate’ and ‘Zoe’. When the interviewees were probed about the age that they thought children should be able to consent to medical treatment, the parents began to reflect on and reconsider their previous survey responses. This question (number 55 on the survey) made the parents reflect back on the treatment consent process that they had been through, and their qualitative responses began to fall into the parameters of the theme ‘we know best’. The parents, as the witnesses in this study, reflect on the positions in which they see their children and other children, particularly when it comes to agency. Their parenting strategies in a way shaped how they saw the role of the child within the treatment consenting process. Consequently the theme of ‘we know best’ was the most dominant within their reflections and their justifications for the ages they deemed appropriate for their children and others to be involved. These narratives change the idea of the physician-patient model of SDM and almost move towards the coalition idea of having someone else involved on behalf of the patient, like what Charles et al., (1997) mentioned. This is a point in the SDM objectives that may not be so clear for physicians even in the paediatric context. As their focus is on the patient, they see the parent as a problematic addition to what can already be sensitive and critical care plans (du Pre & Brierley 2018).

The reflective results in this chapter show that interviewing is beneficial when researching sensitive issues such as transplants, where people may be less willing to openly share their views within a survey. It also shows the importance of discussing the idea of parent’s experiences of giving consent for their children, especially where they take on the role of advocates for their children’s best interests. The conversations and the reflections from the participants that I present in this chapter offer an insight into the complications of the transplant process and how in some situations “age may just be a number”.

I start here with Matt’s narrative, as the way in which he reaches an explanation for his answer is based on a deep rootedness of his experiences as a child, and his experiences as a parent. Matt talks about maturity being the main factor for welcoming children into the consent conversation. It is clear from his observations below that his current parenting style is driven by his own experiences growing up.

> Interviewer: yeh yeh it's hard. What age, you said 18 didn't you (survey response)?
>
> Matt (**age given on survey:18 years old**): Umm well, maybe not 18, but younger, definitely umm I don't know, it's – it's umm, I'm trying to think it from a mum and dad's point of view as well, I know it's rubbish but, we wanted, we wanted to be involved umm, because they're your kids and you want to protect them and you wanna try and guide them, and you think you know best. And also, I mean, I think, I try and think back when I was maybe like 13 or 14, I made decisions then, I'm sure everybody did that, I would never make now because I thought I knew everything. And I was cocky, and I would think, no I wouldn't need that, but looking in hindsight you think aarh, I was just immature –

After another pause, he gives a reason for his survey response. It is clear from his pauses that he is reflecting deeply about his answer.

> Matt: Yeh you know and umm maybe 18 is a little old but I would certainly… I don't know, if I think back to, if I had this conversation with someone when I was 13 or maybe 12, 13 or maybe 14, I would go no no you know what I don't need it, I can do what I want sort of thing, and actually fast forward a few years I would think what an idiot you were "Matt"

We both laugh and he continues on. What is clear again is that the question is very thought provoking. Matt moves back and forth in his narrative. He is thinking about child development, and he is trying to find a suitable point for what he deems as a good age for welcoming participation from children in the treatment consent process.

> Matt: And I definitely think that there needs to be a bit of, sort of, what's the word umm, not common sense because I don't want to sort of take anything away from the child, maturity, I think there

> needs to be an element of maturity because it's so, it's such a massive thing, it's it's life or death in a lot of people's cases… I don't know, it's hard. I think I ((inaudible)) think that a teenager could make decisions 100% but I would think that there would have to be some form of input from, a parent if they have one, or someone with that sort of maturity umm, but that's just me, you know and loads of kids are different and some kids are really mature and I think I'm just thinking of maybe me. And and to be fair I look around and I see other 12, 13, 14-year-olds and I think, oh I don't know –

For Matt, the question proves challenging, and it is evident that his experiences as a teenager have made him see maturity as an important factor when it comes to the question on the age of medical consent. Age itself is not the defining factor for him, he believes the decisions to allow children to make medical treatment decisions should be on a case-by-case basis with maturity as the key driving factor.

Like Matt, Zoe, a survey-only respondent, gave the following answer in relation to her son, who was 16 years old at the time of his transplant for severe aplastic anaemia. For Zoe, it was about easing her son's worries and giving him the opportunity to take control. He was also at the age where he could be deemed as Gillick competent and mature enough to independently make the decision.

> Zoe: All children mature at different ages, my son wanted me to sign the forms as he was overwhelmed and very frightened, but it also gave him a bit of control over his own treatment. I feel 16 would be an average age to give consent.

Janet also touches on the idea of maturity and on introducing ideas slowly, so that children can be assessed for what they can contribute to the consent process. Like the process of drip-feeding information to the adults during the treatment process, Janet suggests that the same is important when it comes to children. This can allow the adults involved in their care to see how much information to give them, and when to step back from decision and information sharing. This is especially important in relation to information directed at making treatment decisions. Again, I follow this line of questioning with the parents to support research questions 3 & 4, rather than to report anything that makes children take away from the parents as the focus of the study. Janet tells me what she thinks about what age children should be to make treatment decisions. At this point in her interview she is quite teary as she is talking about the family having to cope through the transplant process.

> Interviewer: [Janet is visibly upset] no don't say sorry ((it's the questions)), no no, I think umm…. what age do you think children should be?
>
> Janet (**age given on survey: depends on individual**): here you go, write this one down, write it down…two to sixteen, I'm serious, it could be anything
>
> Interviewer: [laughing] two to sixteen, that is a good one
>
> Janet: or over twenty-four
>
> Interviewer: I mean do you think they should absolutely be involved in making decisions?

I am probing here, as I know that this question opens up a chance for a reflective answer which can generate more insightful data into what Janet really thinks.

> Janet: they have to be involved in making decisions- let's say today you're gonna have a dressing changed on a Hickman line yeh- and the nurse comes in and says we're gonna do your dressing change- they hate dressing change- it hurts, it stings, it's a horrible process- they all know about it right can you help them with the process? Can you help that process work better for the kid?

Here Janet is alluding to another form of shared decision making, the everyday SDM. This is the daily decision making that families experience once their children have been admitted onto the BMT ward. But similarly it is the same day-day decision making that goes on in families outside of the hospital setting. Janet continues talking about the types of decisions children can and should be encouraged to make on the BMT unit, based on her experiences as a mother and as an inhabitant of a BMT unit.

> Janet: You can by involving them in it you can say to them- when would you like your dressing done? Do you want it after breakfast do you want it after lunch, or after playing over there? do you want it while you are watching your favourite cartoon? Do you wanna get a sticker at the end, do you wanna choose something from the treat box at the end? This is helping a child- do you wanna hold some of the stuff? Do you wanna help me to wipe it or to peel it off? that would apply from a two-year-old to a sixteen-year-old- that is involving them in the decision making but its relevant- the degree of that involvement is relevant to their- not their age but their mental capacity….and then if you've got a decision about having a transplant- do you have a transplant- don't you have a transplant? There is no way a child is capable of making that decision

Although Janet understands the importance of allowing children to make decisions about their routine day-to-day care in the hospital, she does not agree with the idea of children being given the decision to make transplant choices. This is what Matt also said about his daughter, and both of these parents are speaking from their experiences of also having to make the decision to consent to transplant. They use the knowledge that they have gained during their children's illness journeys to make sense of the BMT unit and what consenting on the unit entails for the family on a whole. Therefore they do not see children as being part of this type of consent. As I discussed in chapter 4, the parents felt that there was too much information to know about transplants and their answers about age are centred around maturity and mental capacity, which they believe children need to have in BMTs. Janet continues to elaborate on her answer.

> Interviewer: a transplant is different-
>
> Janet: its way bigger….
>
> Interviewer: so we have to start from that- start small before letting them decide-

> Janet: start small and…if you can see they are capable of making decisions about certain things you can improve on that- you can grow on that-but I don't know if you would ever be able to say- a fifteen-year-old could legally make a decision about their medical treatment in this, in this capacity….
>
> Interviewer: it's true, how do you assess their competence?

Janet is clearly pointing to everyday decision-making being a factor into how shared decision making can be supported within BMTs, so I probe her. For some researchers, my last question may appear to overstep the line and be unduly directive. But I have to guide the conversation as a researcher and also as a mother, so I do not refrain from asking leading questions. The narrative analytical approach advises researchers to "see meaning as something which is co-constructed, that is an active process in which both the teller and the audience participate, often in situations of unequal power" (Griffin & May, 2018, p.512). Because of this approach, Janet's response is crucial to understanding how decisions effect people. In response to my question she proposes a longitudinal approach to the research topic.

> Janet: you'd have to revisit them in ten years' time and ask them that question, when they are twenty-five and say- how did you feel about that decision that you made when you were fifteen about that transplant?...and you know what- the ones that are doing well will say- oh I'm so glad I did that. And the ones that are doing poorly- you can't ask them cause they are six-foot under, or they can't speak- or they are not well or whatever. How do you do that? You'd have to conduct this research over twenty years to get a good answer….

For Janet, time is one of the deciding factors for when it comes to involving children in the bigger decisions. Time brings an increase in age, brain development and maturity. Whether or not the maturity is enough for the adults who have to decide on how much to share with the children is another matter. What is evident here is the variation in perspectives which point back towards hospital experience and the habitus. It is clear that the question of what age children should be able to participate in decision making is not easy to answer and has no single right or wrong answer at this stage. But to know whether the adults' decisions are, in simple terms, correct, Janet suggests a need to hear from the children when they too are adults. In a way Janet is accounting for the possibility of children regretting the decisions they may make in regard to HSCT, and she is doing this from a parent's perspective and a grown child/adult perspective which others have also noted in HSCT shared decision making (Mekelenkamp et al., 2023). The parents make decisions for their children by thinking about what the decisions may mean for their children when they turn into adults. They look ahead for them.

Bev, on the other hand, when discussing the idea of maturity and sharing decisions does not agree with children having the options to make major life decisions as others have argued (Alderson et al., 2022). Her views come from her experience as a mother and her own understanding of her children. This subjective and personal experience of knowing her own children that Bev relies on as a starting point for the decisions that she makes plays a significant role in how she views not only her own children, but other children in the medical sphere.

> Interviewer: you just explained chemotherapy to me, I didn't realise how intense it was. So—
>
> Bev: yeh, a child cannot have, just does not have the…the ability to reason, and would they say yes 'give me that bag of medicine that's gonna make me vomit and make my mouth bleed, and put me into so much pain' they'd say NO course they'd, you wouldn't voluntarily, you know you'd have to explain to that child 'well if you take this medicine, it's going to cure your cancer but its gonna make you really ill at the same time, even more ill before you get better, they'll say NO. So you can't give that decision to a child, you just can't—

As a mother of three myself, I know that it is a common experience amongst parents in particular that children sometimes do not want to act when they do not understand something, or when it is not perceptibly affecting them (for example, washing germs off hands). This is especially so when a painful medical procedure is involved as Bev describes in her narrative. In this part of her story, Bev is referring to the effects of chemotherapy, which is part of the transplant treatment procedure that patients go through before receiving their new cells (Dietz *et al.*, 2017). She continues, and I move on to asking her about what age she believes children should be to get involved in shared decision making.

> Bev: yep, you know, you're taking a really sick child and you're going to give them medicine that's going to make them a HELL of a lot sicker, and put them into a lot of pain, if they are already not in pain they'll be in pain, so no they can't consent)) they just—
>
> Interviewer: what age do you think children should be to get involved, in making decisions about their healthcare?
>
> Bev: …oh I think at an absolute minimum 16, if not 18.
>
> Interviewer: reason?
>
> Bev: because you know, I have, you know I have a 13 and a 15, you know they, they can't even make their beds in the morning let alone, I have to nag them to do their homework. They're not going to be able to, they can't be expected to make a decision on whether to take, you know….consent to this kind of treatment—

Cathy, like Bev feels that the parent knows their child and can make the right decision about whether their children should be involved in treatment consultations. Returning here to the theme of 'we know best' this is where the 'zone of parental discretion' comes in (I touched on this in chapter 2), and this is where the parent knows best and is there to determine the child's best interests.

However, unlike Bev, Cathy has a different perspective about the child's involvement. She starts this following part of her story by telling me that she believes that children should be involved in the conversation about treatment, but in a way that they can understand and process. She feels that information should be given to children in an easy and understandable way, and that adults should be sensitive to the language they use in the presence of children.

Through her narrative it is clear to see that she knows that children are not always attentive, yet it is important for adults to know how children feel when it comes to decisions which would affect them. However, she is firm on her view that a responsible adult needs to be the one to make the final transplant decision. Though she is for children being involved, she also recognises that parents should be able to make the final decision. This reflects the 'concerted cultivation' parenting style that I mentioned in chapter 2, and it comes from Lareau (2011)' analysis of families. This parenting style is based on parents being involved in making concerted decisions for their children but also talking to their children a lot about the decisions that they make for them (Lareau, 2011.)

Here is how Cathy expresses her views about children being involved in the decision-making process.

> Interviewer: what age do you think children should be to get involved-
>
> Cathy (lines 843-861): I think children should be
>
> Interviewer: for transplant not just treatment cause treatment is quite easy, isn't it?
>
> Cathy: I think you have to know your child and I think you need to…

Like Bev, she takes a parental approach to the question in relation to being able to know your own child as a parent. And she thinks that it is good for children to be part of the decision-making processes.

> Cathy: I think they should always be included in the conversation but sometimes you do have to transfer it into language that they understand so put for an example- a conversation that I might have with the consultant, a question that I'm asking him, I might not necessarily want Troy to hear that cause I don't want to worry him- cause I ask a lot of questions so what I always say to my mum- cause my mum's funny- she'll be like- I can't believe that they asked me this- and she'll be so worked up about the

> question- and I say it's just that-they've asked you it's you decide- what they've asked you doesn't determine what you are or who you are they've just asked you a question- so I would ask the consultant questions you know- so I wouldn't necessarily think- oh Troy isn't here when I'm asking these question or he needs to be- cause sometimes Troy is there, he's just not…always paying attention to what I'm saying and- but he's there or say he's there and his dad's there, they might be talking and I'd be asking the serious questions and I don't mind that, as long as he is…he's putting-he understands things in a way-probably put to him the way he understands- that's the main thing. And I think he should be part of the decision making…you need to be aware about how he feels about things but overall- a responsible parent needs to make the decision - I think. But I think it's good for him to be part of it, for the consultant.

The amount of discretion that parents have when it comes to decision-making on BMT units and involving their children appears to be left to them, as the narratives show. The parents do not report any clear guidelines as to when a child should be involved, or who should encourage the children to be involved in the process of making treatment decisions. So parents decide for themselves based on their own parental experience, and the data shows that the parents all have different perspectives on the topic of age and sharing treatment decisions in the physician-family relationship. Given that quite a number of consultations take place when families are on the BMT ward, and some even before a family is welcomed onto the BMT unit, it is not clear how each participant distinguishes between the main pre-BMT consultation and other in-treatment consultations that they had for their children. However, once treatment started, the parents talked about how their children participated in making decisions in other ways, such as the everyday decisions. Although the focus is not on the children; as they are the subjects of their parents' narratives, I wanted to know how their parents interacted with them during illness and treatment. I wanted to get a clear idea of what the participants' parenting styles were and how these played a role in the communication that their families had with the healthcare teams on the BMT unit.

Sharing decisions on BMT units

During the treatment process, the parents observed that their children came to accept the decisions made by those who cared for them, although confirmation of this acceptance can only come from further research which has to include children as participants. The current data indicates that the child patients did not formally consent to the treatments that they had, as the parents' narratives reveal. Whitney et al., (2004) describe this type of acceptance as "Simple Consent" as opposed to "Informed Consent". Therefore, the answer to Research Question 3 (How can parents support their children in sharing decisions about bone marrow and stem cell treatments?) comes from the parents' accounts of how their own children participated on the BMT unit throughout their illness journeys, and what their children communicated to them whilst in the hospital and at home.

The parents' narratives show that they attempted to allow their children to make their experiences of treatment meaningful by giving them some control in the course of their suffering and experiences of illness. Thus, the main topic in these accounts is the freedoms that the parents allowed their children to have when it came to being involved in decisions made in the hospital. Involvement in this context includes the day-to-day management of the treatment process, such as taking medications, changing dressings, changing medical devices like nasal gastric tubes, Hickman lines, and catheters. Involvement also includes being part of discussions with healthcare professionals about the procedures required for treatment. The theme is thus 'everyday decisions' based on life on a BMT unit. Therefore, each extract I present is quite unique, and this also highlights how differently each family can experience the same medical procedures. There are similarities between some of the experiences, but each narrative still retains individuality as a reflection of each participant's own life story. As I mentioned earlier on in this analysis, these narratives are not based on truth, but rather on the way one makes sense of their experiences to inform others who seek to know what they have been through (Frank, 2010).

During the interviews I asked the parents how important they thought their children's decisions were when it came to their treatments. I wanted to take account for each (possible) experience that the parents may have had throughout the entire consenting process. Again my own experiences of the BMT unit were the reasons behind my drive to unpick each aspect of the consent process, from finding out about how the parents felt, to exploring how they interacted with their children throughout the treatment and recovery stages.

Here I begin with Bev's narrative and what she observed of her children's experiences of the transplant process. Her daughter had Acute Lymphoblastic Leukaemia (ALL), and her son was an HLA match, so he was the bone marrow donor in their case. Misty (Bev's daughter) had her transplant at 11 years old and at the time of the interview she was 15 years old.

> Interviewer: Does she [Misty] show that decisions are important to her, in terms of making her healthcare decisions at this age now? Has there been a big change from then until now?
>
> Bev: umm so far, she hasn't really expressed any desire to make any decision, she pretty much just goes a long with whatever the plan is umm but umm , they will, I think in about a year's time, she'll be transferring from children to adult services so they will train her to literally you know, to look after her health, so she's supported I think. Umm so I think she's actually going to be transferred to [LONDON hospital] so umm yeh, so she'll just take responsibility for her health as an adult, because you know she can't have mum and dad go her appointments when she's thirty-five

In this extract Bev is content with making decisions for her teenage daughter Misty until she transfers to the adult care team, and she sees this as the right time to leave the 'coalition' (Charles et al., 1997). As discussed before, Bev considers children as being too young to make major medical treatment decisions, and her experiences of her daughter's cancer treatment may also play a role in her perspective. However, it is a little different for Cathy and her son Troy, who is also in his teens at the time of our interview.

Cathy's case deals with a transplant that is the result of a non-malignant genetic condition, and her son had a transplant as a last resort treatment for managing his sickle cell disease (Mekelenkamp, et al. 2023). Most people with sickle cell disease do not go down the transplant route, as I learnt at the start of this research through my scoping exercise of major medical treatments. I met with a specialist haematologist at a hospital in London and discussed treatments for SCD at great length with them. I also met with specialist researchers in London and at a university in the North of England to discuss the issue, and they advised me that not many patients received bone marrow transplants for sickle cell disease. Rather, the condition is usually managed through other forms of treatment such as blood transfusions and daily medications (Leonard, Tisdale and Abraham, 2020; Kassim and Sharma, 2017). I personally have members of my family who have opted for different treatments to manage their SCD, and two cousins who have successfully been through a BMT unit for a gene therapy trial (Sinha et al., 2021), so I understood a little about Cathy's experiences of SCD during her interview.

Cathy's case also opens up the idea of 'quality of life'. A major factor in the consent and treatment process is to understand the forms of treatment that best increase the quality of a person's life (Brice et al., 2016; Rodday et al., 2017; Nickel and Kamani, 2018). Sometimes transplants are used as immediate lifesaving treatments, but they can also be used to improve the quality of a person's life before their condition deteriorates. The cases of Cathy's son Troy and Matt's daughter Emma's are similar, as both their transplants were a preventative measure to avoid more serious health complications. They differ from the others in this study in that Troy and Emma's parents were their bone marrow donors ('Haplo'), which was not the case with Janet's son James and Bev's daughter Misty; but despite this, Troy spent much more time in hospital than Misty, and he appears to have expressed his desires more than Misty who is of a similar age. Like Misty, Troy received his transplant at the age of 11, and he was preparing for his GCSEs at the time of Cathy's interview. Here are Cathy's reflections of what she thought was important to Troy in relation to decision making.

> Interviewer: did your child show that it was important to be part of the decision making?
>
> Cathy: I think he did show that it was important in…he, he didn't feel in any way that something was being made for him-umm the decision, and he wasn't a part of it- and as I said, a lot of it was to do with trust- so he kind of knows if mummy says it- it must be right. He wasn't like 'but why mum' he wasn't like that, he was more like 'my mum must know best' cause he felt that way- and the reason I say that is because now the transplant is over and he's a bit older, and thinks a little bit more independently cause I think when he was younger he was little bit more 'mummy said'- listening, being obedient, you know- don't get me wrong I didn't tell him to- he just tended to- Troy don't-okay- that was more of his nature…whereas as he's gotten older he's much more- questions, its good- independent thinker, its good so now, now he knows a bit more about the transplant, he knows kids what haven't survived- he said mum, once he came and said mum- you never told me I could have died in the transplant and I was quiet and I said…well I never thought of it that way, it was a risk but I never thought of it that way. And I think, that was something- I had this- once in the transplant I kind of had this cold shock go through my body, when he was really that bad

Here Cathy acknowledges Troy's maturity, and she can see that he is becoming an independent patient. They continue to have a trusting relationship. The desire to play a part in healthcare decision making was therefore based upon maturity for Troy, for Misty it was to come with age and the transition within the hospital from the children's unit to the adult unit. This points to maturity being one of the key factors for these two children when it comes to their involvement in healthcare decision making. Cathy and Bev, just like Janet and Matt all believe that the BMT consenting process requires maturity for children to be involved in treatment decisions.

Although the data shows that for Janet and Matt, who both had younger children in comparison to Bev and Cathy, that what was important to their children was not the same as what was important for them. In the previous chapter the data showed that for parents, choice was one of the most important things, but here it shows that for the younger children what was important when it came to decisions on the BMT unit was play. The parents talk about how their children's concerns were centred around their quality of hospital life rather than the decisions made about treatment. This is where the theme of 'everyday decisions' becomes dominant in these narratives. One aspect of play for children was about being able to access their technology devices and being able to play online games with their friends. They needed to have Wi-Fi or good Wi-Fi access. The parents found that access to the internet was important for their children as it allowed them to maintain the life that they were used to outside of the hospital, and it was also a form of communication which allowed them to maintain relationships with family and friends (especially through gaming). From what the parents say, their children thought about and attended to their own quality of life during the transplant process.

Whereas they looked to the future and were concerned with their child's quality of life afterwards, and even the possibility of death. I asked Matt about how his daughter Emma felt about her transplant, which occurred when she was 5 years old.

> Interviewer: Yeh. Was she scared?
>
> Matt: Umm… I ….no, because for all that we spoke about it, umm and we read the stories and we tried to explain to her exactly what's happening, I still don't think she fully understood. Umm and I think Emma thinks that everyone has had a bone marrow transplant.
>
> I: Oh okay
>
> Matt: Well she did at the time, she just thought it was normal life umm, and in hospital she was never sort of scared I don't think. She got poorly but, and she got upset but she never came across as being scared or anything. She got scared of having her medicines that's why she refused to take them, umm but I think that's because she was ill, and it was making her sick and stuff like that , umm I don't know, I can't say, I mean to be honest this gonna sound weird, I think she sort of enjoyed it a little bit. She loved the attention, umm she had this sort of bedroom like in isolation, and we decorated it how she wanted, and the play specialists came in,

> she had a tv and YouTube on repeat all day, and she was getting presents off everyone, so she loved it from that point . Umm yeh, I don't, no, no I definitely don't think she was scared –

This extract shows that as a dad Matt felt that his daughter wanted to feel at home in the hospital and she expressed her preferences very clearly to the adults who cared for her, as his narrative suggests. The same preferences can be seen in Janet's accounts of the way that her son James adjusted to life on the ward. He was 8 years old at the time of his first transplant. Again I am exploring the parents' experiences like this to understand more about how they acted as parents during the transplant process. This gives an insight into their parenting styles and how they communicate within the family when occupying the hospital space.

> Janet:….when they decided that they needed to give them a transplant, they'd bring them up to [hospital] so you're in foreign surroundings- there's a thing that is funny- the things that are important to children are so different to us) so like at [hospital] there's a trolley that comes round, a snack trolley, you know she walks in all those little things- they make you feel at home
>
> Interviewer: they just want Wi-Fi, the kids don't they [as a mother of 3 I know how much children love Wi-Fi]
>
> Janet: see that's the biggest problem with [hospital] is the Wi-Fi so, so the ward's got like a horseshoe shape depending on what room you're in, and the kids know this yeh, they know the rooms which have got good internet and they know the rooms which haven't so we when you turn up, you don't know what room you're gonna put to, so the first thing he wanted to know was which room- he got a room which he thought had good Wi-Fi so he was happy with that and also in the rooms, behind the bed they've got an animal picture like, this great big ---a --- and a---- and all the rooms are different- and the kids can't see the animal because its behind them anyway so it doesn't really matter, but it's like 'oh I've got s ----' [both laugh] its little things like that you're talking about an eight year old what do you think they care about?

> Interviewer: yeh Wi-Fi nowadays
>
> Janet: Wi-Fi, just snacks, decent DVD player, tablet- and as parents we got used to all this stuff, so you bring in a bag of snacks with you, because their snack preferences change

Janet and Matt reflect that their own children wanted to feel a sense of home whilst they were on the wards. This can also be seen in the ways that they described that they wanted their rooms decorated. As they were going to be isolated in these rooms throughout their transplant procedures, the parents noted that they needed to feel that they were in some form of personal space. The parents' narratives indicate that the desire for comfort was a common theme throughout, and their children's concerns were again quite different from those of the adults. This indicates a sense of wanting to be in a home from home space, although that analysis is not relevant here, as that would need to come from further study that can involve children as participants. However, Matt and Janet both observed that what was important to their children was access to internet and having decorated rooms that they were happy in. These nuanced observations from them show that they were vigilant throughout their children's treatments and that they made decisions in line with what they believed was best for them. As well as knowing how their children wanted to spend their time in the hospital, the parents were also aware of what worried their children the most during the transplant process.

Matt noted that his daughter's participation was centred around the day-to-day management of the treatment rather than consent to the transplant. Participation can take multiple forms in the transplant process, and non-medical decisions are sometimes shared across the family and the hospital unit. I observed the sharing of decisions on the BMT unit during the scoping phase of this research, and I wanted to explore this further with the parents in this study to learn more about how they experienced decision making. Note again that Matt's daughter Emma had a transplant as a preventative measure for a more severe illness in later childhood or life, and consequently the family did not have much experience of hospitals before coming to the BMT unit. She suffered from Fanconi anaemia, and the doctors were treating her to prevent her from developing cancer in the future as Matt mentions in his interview. So I probed him about how she participated in making decisions during her treatment. Again I must stress that, though I probed the parents about what their children did throughout their illness journeys, the responses are not intended as a proxy for the children's accounts. The parents here are part of the 'remission society' and thus their accounts are individually valid as being their own witness statements and not those of others (Frank, 1995).

> Interviewer: Did she sort of get involved, because I know bone marrow transplants take quite a bit of time and there's a lot of negotiating things and, talking to doctors and– did she make any decisions sort of, things she – or is it mostly the parents?

My question here to Matt shows reflexivity in my research practice, as I am being explicit with him about my knowledge of bone marrow transplants. When it comes to analysing narratives and stories about illness, Frank notes that "for the narrative analyst, being in the field is less about the content of particular observations and more about experiencing, however partially and even artificially, the same "fire of action" as the storytellers who are being studied" (Frank, 2012, p.40) Given that the participants in this study are what I earlier referred to as being part of the 'remission society', my understanding of the world that they live in was crucial to the rapport that we had. Thus the months that I spent on the BMT unit were beneficial for the in-depth insights that I received from the participants.

> Matt: It was me, me and my wife and umm she didn't really ah nope – I mean when we had the transplant and going through the transplant, she would help the nurses and things like that, and she'd, she got involved in that way, but she didn't get involved in any other, decision making, nah definitely not.
>
> Interviewer: no, not in the medication? Not in the things she wanted?
>
> Matt: umm, food wise she did definitely, umm and what she'd want in her room and things like that, but medication – to be honest I don't think there was really an option for – for

> medication. We were just told, this is what you need to have, this is what you need – to be given and things like that, umm. She, she struggled with her medicines – and we – she, she had a line fitted and we sometimes, or the nurses had to wait until she's asleep to give her these medicines because it was making her sick, and things like that. But I think coz at the time, she, she was having, probably about twenty medicines a day – There was also a time when her stomach was really sensitive from the chemotherapy and things like that, so she wasn't, it wasn't a great time for her – umm but as she got better, she, she accepted it more and
>
> Interviewer: Yes
>
> Matt: Ah it's time for medicine and she didn't sort of kick off as much as normal
>
> Interviewer: Yes
>
> Matt: Umm I mean to be honest there was times during the transplant where we had to pin her down to give her medicines coz she was just, wasn't, wasn't having any of it, it was really difficult, but it got easier, she just got used to it. I think Emma is the kind of person, that she doesn't like change –

As Matt tells me about his daughter's personal preferences during her treatment and how she wanted her space to be on the ward, he goes into the topic of worries. These worries go to form part of the daily 'participation' decisions that parents made with their children. Like Matt's daughter Emma, the other children also had to take multiple medications each day, and this was described as a struggle by all the parents in this study. The parents recalled the side effects and the pain that their children went through because of the treatments.

Cathy's son Troy also worried about having medical instruments inserted into his body. Here Cathy tells me about how Troy's worries determined how she allowed him to participate in his illness journey once she knew more about what to worry about and what not to worry about.

> Cathy:…umm no, this is so the Hickman line. So yeh for example so the Hickman line was something he had to have inserted—
>
> Interviewer: how did he feel about that?
>
> Cathy: well again at first it was like, the biggest worry ever but then later on he loved his Hickman line because it just meant no cannulas and once its inserted and its healed, it doesn't, it's not painful everything's put through there, just clip it, and then he's fine….so what turned to be what we thought 'oh my gosh he's got this Hickman through to the big artery near the heart'….you learn to choose your battles and realise you know, what is really actually important to worry about and which isn't you learn that through the transplant, and that was definitely something which…in hindsight really, is not the biggest worry in the transplant at all so yeh

This statement signals growth and a development of the habitus from Cathy. The more that she understood what was happening during her son's treatment, the more comfortable she became. Staying on the topic of worries, Bev talks about the medications that children on the BMT unit took and talks about some of these reactions that the medicines can have, from her experiences of her daughter's treatment. She add clarity to why Matt's daughter may have been worried about these, as Matt mentioned. She starts off by describing a side effect called mucositis. I remember from sitting in on the 'initial consultation' that this is a side effect that consultants told parents about, so as a researcher I know a little about what Bev is talking about here.

> Bev: so it you know your digestive system, so they get sores in their mouths and along their bottoms, mostly you know, and its everything, it will be stripping the lining of, of your gut umm, and that, that's really painful. Umm you know some children, some chemotherapy drugs will damage your ears, so you might end up with hearing loss, uh the Nelarabine, it's one of the reasons it's not routinely given for the type of leukaemia Misty had is the you know, irrespective of the expense, it can cause uh toxicity in the brain, which is what happened with Misty.

Bev’s daughter Misty had to receive special permission to be given a drug called Nelarabine, and in the above extract Bev has moved from describing mucositis to talking about the effects of Nelarabine. And here Bev continues to describe the effects of this particular drug that is used a cancer treatment and how toxic it can be (Malone and Smith, 2017), and she also talks about the side-effects of the other medicines that her daughter had to take.

> Bev: You know one day she couldn’t even walk in a straight line, she was like a drunk person umm, so you know these drugs are powerful, but they are highly highly toxic, you know, so if you are suddenly finding that, you know, it’s affecting the lining of your digestive system, that is exceptionally painful. They call it mucositis, it strips all your umm, well yeh, lining of your passages, your throat, it’s really really painful which is why they end up on morphine because…you know, it’s bad but also these infections leave you open, these, these side effects leave you open to uh well, chemotherapy it also suppresses your immune system so it leaves you open to opportunistic infections, so umm you know if you get a bacterial infection that’s going to hurt so uh you find that you’ll end up not only on chemo drugs but you’ll end up on anti-sickness drugs, you’ll end up on antibiotics, you’ll end up on IV antifungals and antivirals, so you don’t just take a chemotherapy drug alone, you’ll end up taking I think one stage Misty was taking twenty-three different medications daily for all sorts of things and and that’s quite common

I started this chapter of the analysis by presenting the theme of ‘we know best’ where the parents made the decisions for their children with the focus on optimum health. Though I also presented the idea of how parents may be able to support their children in sharing decisions by exploring the freedoms they allowed them in participating in decisions on the BMT unit. The worries that the parents expressed their children as having during treatment show how much they communicated with them and understood how to make what they believed to be the best decisions for them. The knowledge that the parents also exhibit in their narratives shows how their BMT unit habitus alongside their hospital habitus was at work in the decisions that they made for their children and how they saw their children when it came to the everyday decisions, they allowed them to make.

The narratives show that the effects of the medications worried the children of the participants in this study. As Bev notes, the medications have a variety of side effects, and she became aware of these. The stem cells and bone marrow infusions have side effects on the body, and one of the main ones being GvHD, as the parents noted in the reflections discussed in Chapter 4 and which I have echoed throughout this thesis. Here Janet explains more about her son James' worries about the cells that he was given during his treatment, which enabled her to understand his behaviour more clearly.

> Janet: so once all those doors got closed, I think you got a sense of 'oh what's coming next'- and cause they suffer from things like I don't know- like when James had platelets, sometimes he'd have an allergic reaction to them umm and through the treatment process he learned this and experienced things, so James was worried that he might have an allergic reaction to the, to the cells when they would go in, he started to get a bit anxious about that…umm I'm quite a calm person, I wasn't getting too anxious, I knew it was all rubbish, I really did, but I didn't really let him know that I felt like that so- I think he felt at ease to be honest and the team were so good they- he knew them all, the nurses were fun, you know, he didn't like the play specialist at the hospital, he found them really irritating because they talked to him like he was two and pink! He used to tease them and he used to do impersonations of them it was embarrassing —he was a well behaved kid- a lot of kids on treatment, especially with AML- imagine if you get a two year old, who starts having horrible things done to them in a hospital all the time, their behaviours evolve- they can be quite horrible kids they are not horrible, but they haven't learnt, they haven't learnt how to behave they haven't been able to, they are in hospital, they get away with murder, their parents can't tell them off cause they feel bad, and they haven't learnt to do what's normal like they haven't learnt what other kids learn at like playgroup or nursery or at school, so they [inaudible]
>
> Interviewer: I've seen like a two-year-old say "go away I can't be bothered" when the doctor came

As a reflective researcher, I add some of my experiences into the interviews to show that I understand what the participants are talking about. This aides the flow of conversation and works as a probing mechanism for developing aspects of the narratives which might otherwise have been left unspoken. Moreover, "for the analysis to remain truly narrative, each story must be considered as a whole; methods that fragment stories serve other purposes (Frank, 2012, p.43). This approach of adding my reflective responses may be controversial. However, this is qualitative research and in order to answer my research questions it was necessary to build rapport with research participants. My responses are not part of the analysis, but they were part of the data collection process and are contextually relevant to the analysis. I consider the fact that my reflections within the interview conversations cannot be considered as data as a limitation of the research process. They cannot be entirely separated from the data analysis, since they were part of the research process. The selection of qualitative data in this case does not allow me to decontextualise the data in the presentation of the analysis (Alleyne, 2015). Janet thus adds to my response to continue her line of thought on how she understands her son's hospital behaviour.

> Janet: I know one little girl she swears, and you know to her parents and just generally she doesn't have any children to play with ((yeh)) she's heard from when her mum and dad have been cross and she will repeat that language ((yeh)) and so James, because he was an AML patient, the process is shorter and quicker [waitress interrupts]
>
> [speaking to waiter about an order. Our interview lasted over 3 hours]
>
> Janet: he hadn't had a chance to evolve into all that [inaudible] he was still a nice well-behaved kid- he knew where he had to behave-

Building on Janet's story about her son's worries I probe her further to try to understand more about how families come to terms with life on the unit. To put it in Bourdieu's terms, I try to understand how they enter into the BMT unit habitus. Janet has already alluded to the habitus – to the way that children in hospital develop, and are expected to develop, behaviours in response to their hospital environment. She recognises that her son had not quite developed into a ‘hospital behaved’ child. Janet continues to talk about James’ experience, in particular, and his interactions with the nursing staff. Her extract shows how she also developed as a parent and how she adapted to the requirements set out by the healthcare teams. For example she talks about what the nurses involved in her son’s care expected of her and her family.

> Janet: mean [inaudible] some just are- and he was always a good kid, so he still was kind of thing uh, he had his favourite nurses, like there was one nurse he was scared of, she’s a Scottish lady, she’s a brilliant nurse, but because she is Scottish she had a really harsh accent so he was quite scared of her umm when you go in for transplant, some cases do it and others don’t, it depends on the nurse you get, so when you first get admitted for transplant, the nurse might say to you- you need to bathe every day, you need to change the sheets on his bed every day you need to keep the room dust-free, you mustn’t clutter it up with stuff- if you wanna keep all your things in here you have to keep them in a plastic container and seal it up- other nurses are really laid back and they don’t care, like they are not gonna go through that with you and it kind of depends which one you get as to what you end up with as far as your experience is concerned– and the one we got was really lovely, didn’t say any of that stuff- but then after like day 2 or 3 of conditioning, we happened to get one of those other nurses who was a bit more strict and said to him you’ve got to do this, and you’ve got to moisturise your skin- you can get you know, dry skin from the GvHD it can affect you, and he hates moisturising, he hates it, and he actually had really sensitive skin, he hated things touching his skin- and so when that nurse was on she’d be like you’ve got to moisturise your skin and he’d be like ‘I don’t want –looking after me today she’s gonna make me moisturise’- like little things like that so as long as he got a nurse he liked, he was reasonably happy and he loved the weekends and afternoons cause his brother could visit for a bit, that always perked him up- so he didn’t find the conditioning difficult-----

Janet’s comments do more than describe what was happening on the ward around her; they also give a window into her son’s emotional state throughout the transplant process. Janet gives accounts of how some of the other children on the ward felt and acted during their treatments. These accounts are useful in gaining a perspective on the BMT unit environment in which parents and children spend a long time.

Janet's narrative account offers an insight into how the habitus develops in relation to the hospital setting as she describes what was happening on the ward that her son was on, especially for the younger children where all they know of life is the hospital. Her experiences of the children that she saw around her, such as the young child who swears at her parents give an indication on how families have a different habitus when in the hospital. In some ways, she shows that the norms of behaviour on a BMT unit may be more flexible in terms of childrearing expectations than those one finds in much of the outside world, e.g. the swearing child that Janet is talking about. In other ways it can also be more rigid and demanding than ordinary family life outside of the hospital, e.g. the Scottish nurse who imposes a particular kind of order. These features are some of what gives the BMT habitus its distinctive character and make it a specific habitus as evidenced by the data. The BMT habitus is thus quite unique in that children and the rules around child rearing are not the same when one embodies this habitus. This is similar to what LeGrow et al., 2014, found when exploring the relationship between parents and physicians and how the hospital habitus was at play in these relationships (LeGrow et al., 2014). The parents' accounts in this study help to create a picture of the BMT habitus and its foundation of communication. This habitus in turn helps to explain how their children's illnesses and experiences of the hospital influenced their experiences of the consent process as parents.

Aside from the participants' accounts of their children wanting comfort in their surroundings and worrying about medical procedures and medicines, Janet tells me how her son knew when and how to ask doctors about his treatment. Janet observes how James was able to communicate with doctors on his own terms, showing a level of competence that demonstrates his understanding of the day-to-day life of the BMT ward. I touch on this because in her interview, Janet talks a great deal about how some of her decisions were influenced by how much her son showed an interest in his treatments. His experiences influenced how she experienced the BMT consenting process. Here she talks about the final time he asked about his treatment.

> Janet: ….when he was told that his treatment hadn't worked and he wasn't gonna survive…he actually rang the bell himself and asked the doctor- the nurse came in.- he spoke to the nurse, and I explained to the nurse this is, we'd explained to James cause he had started asking questions, and I'd answered them- he said he wanted to speak to the doctor about it, so the doctor had to come in and sit down and talk to James about why his treatment hadn't worked and give him an explanation- and he asked some questions. And the doctor answered them, and she started crying
>
> Interviewer: the doctor started crying? Aww
>
> Janet: she found it so difficult, umm…

This example shows not only how children may be involved in their own care, but also how relationships can develop on the ward, where the trust between doctors and children moves between professional and personal. The doctor cried. As this shows, professionals in BMTs/HSCT settings, where emotionally overwhelming situations regularly occur, are not afraid to exhibit personal emotions. The duration of BMT treatments on BMT units changes the communication between the parents, patients, and doctors, and in a way that tracks the changing relationships amongst the stakeholders. There is a mutual understanding between James, his mother and his doctor. And this is what makes BMTs interesting. Not only is the relationship described in this narrative real and emotive, but it also shows a fragility that may arguably be hard to observe in other medical treatments.

The data in this section shows that the parents in this study allowed their children to participate in the management of their care in myriad ways, whether through deciding how and when they took their pain relief medications, or from whom they received their nursing care from on the wards. This is not an example of shared decision making in a formal sense, but it highlights that decisions are not one-sided in the family. Although the parents in this study made the formal treatment decisions, once they started to experience life on the BMT unit, they shared decisions with their children. The theme of ‘we know best’ did not dominate how they saw their role as parents on the unit. The data shows that they were attentive throughout and this was evidenced in the language they used to describe side effects and the way they reflected on the decisions they believed that their children should or not be involved in.

Summary

This last chapter of the analysis has examined some of the dynamics of the BMT unit and has shown how multiple stakeholders play a role in the transplant process. As I showed in chapter 5, parents have in effect no choice but to consent to transplants, because it offers the only hope that their children will live. They bear this responsibility. But the transplant process is one they go through with their children, and here they do have some scope for choice. This chapter has shown that there are subsidiary decisions that they can share with their children, depending on what they see as in the child’s best interest.

The themes discussed in Chapters 4,5 and 6 are interconnected. In the complex context of the transplant procedure, the themes of understanding information, choice and voluntariness and sharing decisions during paediatric BMT treatments are all deeply entangled and cannot be discussed in isolation from one another. Context has been critically important in this analysis to support the answers for this study’s research questions. The narratives I chose to address helped to show how the dynamics and relationships on BMT units evolve and change over the course of each family’s treatment. They also help us to understand the modes of communication to be found on BMT units and cast light on how treatment decisions are made.

Crucially, I was able to show that the relationships between the parents who participated in the study and their children are based on trust, and that their trusting relationships make a difference to the balance of authority within the process of consenting to treatment. It is no longer a case of ‘doctor knows best’. Moving away from this traditional outlook, I have aimed to show how decisions are made, and what the current, formal consent process looks like for families. My purpose in providing this account has been to improve our understanding of what it might take to create conditions in which parents were in a position to give informed and voluntary consent to haematopoietic stem cell transplantation.

The next chapter will discuss the findings presented in chapters 4-6 in relation to the study’s research questions. I will also touch on the contributions of this research and how it can be useful for the portfolio of works supporting paediatric consent and shared decision-making in healthcare.

Chapter 7: Discussion

> Enlightenment is man's emergence from his self-incurred immaturity. Immaturity is the inability to use one's own understanding without the guidance of another. This immaturity is self-incurred if its cause is not lack of understanding, but lack of resolution and courage to use it without the guidance of another (Kant, 2009:1)

Introduction

In Chapters 4-6, I have analysed the data and unpacked the findings of this study on parents' consent to BMT treatment for their children. As I have already indicated throughout the thesis, the landscape of paediatric decision-making authority is changing. This fact has already been identified by clinicians (du Pre & Brierley, 2018; Brierley & Larcher, 2016) and discussed in the literature, as I illustrated in Chapter 2. However, as I also indicated in that chapter, that there are gaps in the literature, which have guided my own study and shaped my research questions focused on parents' experiences of consenting to treatments on BMT units, with the aim of understanding what the BMT consenting process is like for families. To recap, the research questions are:

1. What are parents' experiences of the BMT consent process for their children?
2. How informed and voluntary were their decisions for HSCT/BMT treatments?
3. How can parents support their children in sharing decisions about bone marrow and stem cell treatments?
4. How can the BMT consent process be modified to support parents in shared decision-making?

In this thesis so far, I have used Bourdieu's theoretical framework of the habitus, field and capital, to approach and cast light on these questions. I have relied most on narrative analysis to understand the parents' narratives on illness, and the themes these narratives presented in relation to the aims of this thesis. In analysing the narratives I have been able to examine how the habitus and in particular the BMT habitus is formulated through the parents' experiences of the BMT transplant process. The data revealed that a BMT unit is a particularly immersive habitus, where life is governed by norms and expectations that do not apply elsewhere. For example, many of the children on a BMT unit are expected to die. In this case, the notion of habitus helps to draw attention to the specificity of these norms and expectations, and thus to the enormous adjustments that parents have to undergo when they enter the space of BMT units

One might think that such a habitus would be a rigid place; but as Bourdieu helps us to recognise, it contains various shifting powers in the form of capital exchanges. His model helps us to appreciate what these powers are able to do in these intense spaces, and the data has been able to trace the changes they undergo. Although I have used Bourdieu's model as a strong reference to understand the BMT space, the crux of my thesis is very much about having an appreciation for the ecosystem of closed off spaces. Recognising the actions of those in the space of BMT units can also be done without the theoretical concepts that Bourdieu's framework provides. But he provides a hook for this research, which directs our attention to the problems of consent and illuminates the BMT unit in the ways that I have described.

In addition, drawing on Frank's ideas on illness narratives, I argued in Chapter 2 that it was only by understanding what the BMT consent process is like for parents and their families that I could explain the shift in decision-making authority that clinicians are reporting. Rather than focusing entirely on the decisions themselves, I wanted to take account of the narratives within which the meaning of a decision is determined. In Chapters 4 to 6, I considered the process of consent from the perspective of the parents, and what the themes in the data meant for how consent in BMTs could be understood by others. This allowed me to give a contextualised analysis of how these parents experienced the BMT consent process throughout their children's time as patients (in/out) on BMT units within the United Kingdom.

Thus, in this study I have explored what the BMT consent process is like, by using the stories of parents whose children have received treatments on BMT wards. The stories told by the participating parents in this study have created a picture of what the BMT consent process looks like, and they show how they participated in the consent conversations on BMT units. In chapter 4 I introduced the consent process as something that begins at the initial consultation and sometimes even before families are referred to BMT specialists. However, once parents start to live on the BMT unit, consenting becomes more complicated; parents have to consent to a variety of further treatment decisions along the way. Chapter 5 showed that, as the parents started to understand the treatments more fully, they found that the choices available to them were limited. There were very few treatment options, and often only one. This chapter continued with the idea of the BMT unit as having its own individual habitus, situated within the broader habitus of the hospital, and I showed how it was at work in the accounts of the participants, as they experienced their children's illness journeys. This gave rise to the issue of how parents began to involve their children in some of the decisions made on BMT units, which was the topic of Chapter 6. In Chapter 6 I showed how parents adapted to the BMT habitus based on how they experienced the effects of the treatments that their children received. The data touched on the non-medical decisions , and how these impacted on parents' decisions to facilitate shared decision making as much as possible. This chapter also continued to show how decisions were shaped by the habitus of the BMT unit which played a role in the parents' parenting styles. I will now use the findings I have presented in chapters 4-6 to answer each of the study's research questions.

The Lived Experiences of Parents on a BMT Unit

1. *What are parents' experiences of the BMT consent process for their children?*

The parents in this study all had different experiences of consenting to the transplant treatments for their children, but at the same time they all had similar experiences of being on the BMT unit. They shared the same BMT unit habitus as they lived with the norms and expectations that shape life on the BMT unit, and this became their habitus as their children went through the transplant treatment process. This shows how Bourdieu's framework is relevant for understanding how communication works within the BMT consenting process, as I described the BMT habitus as being linked to how parents and clinicians communicate with each other on BMT units.

For the parents in this study, the consenting experience differed mainly because of their children's illness; for example, some had to make multiple major treatment decisions throughout their children's illness journeys. The data shows that there was a stark difference in how the parents of children with malignant illnesses experienced the consent process by comparison with the parents of children with non-malignant illnesses. These findings (which do not bear on the efficacy of the treatments offered on BMT units) will refine our knowledge of the BMT consenting process.

I noted in Chapter 2 that BMT units treat a wide range of illnesses with the support of different types of donors. Although all patients receive the same type of treatment in the form of bone marrow or stem cell transplants, the context of these interventions differs from case to case. The parents in this study had children with Acute Lymphoblastic Leukaemia, Myelodysplastic syndrome, Acute Myeloid Leukaemia, Sickle Cell disease, Fanconi Anaemia, Severe Aplastic Anaemia, and the process of consent from one disease to another was different. As the data in chapters 4-6 showed, consenting to transplants became a process rather than a single event. This process begins away from the BMT unit, but it is the unit which initiates a new sense of being part of the process for the participants in this study. Thus I discuss the process only from the start of when a family comes to the 'initial consultation', and as I mentioned in chapter 4, I use language that is familiar to what it means to be part of the BMT unit habitus and not what the language means away from the unit. Those familiar with the BMT unit know the meaning of the 'initial consultation'

The opening narratives in my study show that consenting to bone marrow and stem cell transplants goes beyond the standard practice of consenting unlike many other medical procedures. In BMTs, consent is an iterative process and continues from the point of the first interactions between the consultant and the family, right through to the end of treatment. This has also been reported in other research conducted into family medical consent by LeGrow et al., (2014). These researchers also used Bourdieu's framework to guide their analysis for promoting a family centred approach within medical settings. In particular, they reference Bourdieu's concepts of the habitus, capital and fields as a starting point for appreciating bedside medicine (LeGrow et al., 2014). The iterative nature of BMT consent is also supported by Silverman's study on communication in clinics, where he reported that the dynamics between physicians and families changed as they continued to communicate with each other about a child's treatment (Silverman, 1987), as I noted in chapter 2.

In relation to the research problem of decision-making authority within medical spaces, the data shows that gaining consent for BMT/HSCT transplants may start from different points in a child's illness. For example conversations about consenting for a transplant could start at the time of failure of cancer protocols as narrated by Bev in Chapter 4, or when it comes to preventing serious medical emergencies as told by Cathy in Chapter 5. This is because BMT treatments require thoughtful consideration and sometimes adaptation to the course of treatment throughout, so the consent conversations continue until treatment is finished. In a way, the trajectory of the disease becomes a factor for how the conversation of consent starts and continues until a patient returns to the desired health outcome. This was shown in the data in Chapter 4, when I explored how much the parents understood about transplants and the entire treatment process. I noted in this chapter how there was an air of uncertainty amongst the parents which was based on the amount of information that they were given and how much it informed them about the transplant process. The sub theme in this chapter was 'drip feeding' and this carried with it multiple feelings of unease and overall discomfort amongst the parents. Regardless however, the parents began to make meaning around the information that they were told as they became familiar with the BMT units that their children were on.

The narratives showed that the parents recalled a great deal of information about the BMT consent process and the transplant process. This was clear in the language they used to tell the stories of their experiences. However, throughout their children's treatments they felt that they could have been told more about what to expect from the transplant, especially after the initial consultation. This caused mixed feelings of uncertainty and a sense of discomfort which came through in their narratives, and this remained throughout their experiences. As transplants became a reality for their families the BMT information given to them began to change, although their feelings of unease remained a dominant part of their experiences.

The data also showed that parents are first told about the transplant treatment process during the initial consultation on the BMT unit, although interactions with consultants can often occur weeks or even months before the child is admitted to the BMT ward (see Table 6). D'Souza, Pasquini and Spellecy (2015) corroborate this in their survey of literature about informed consent in BMTs. They report that the time between consultation and ward admission is difficult for families, who need to absorb a lot of information about transplants. There was also a strong feeling amongst the parents in my study that the information about transplants was given to them slowly, at different points of the treatment process, and they spoke about this in their interviews. It is not clear whether these reflections on the information given are because of the length of time between the initial consultation and the time they came onto the BMT ward with their children, or whether it was because of the amount of information that they had to retain (Herrmann et al., 2021).

Although the parents did not refer directly to the term 'drip feed', which I have used to describe their accounts, they all felt as though the information given about the transplants was either not enough, or that information was being held back. These feelings grew throughout the treatment process as they began to learn more about the process and the effects of transplants. It was clear from the data that, since the process can be unpredictable, there needs to be some flexibility about the way information is conveyed to families. This flexibility was evidenced in the dynamics portrayed in the narratives. This is particularly clear in the narratives given by Bev and Janet, whose children had cancer. For them, the transplants felt like a last resort after other treatments had failed (Lucchini *et al.*, 2017).

When the parents felt that the doctors were not giving them enough information, they conducted their own research into what they did not understand. The parents in this study were concerned about their lack of understanding and gave this as a reason for searching for answers of their own. As other research shows, clinicians are very aware that parents accumulate knowledge from any available source to assist with the decisions they have to make (du Pre and Brierley, 2018). Indeed, every parent who participated in this study mentioned conducting their own research into transplants.

The Habitus of the BMT unit

One of the key approaches I have used to understand the BMT consent process has been Bourdieu's theoretical framework. Specifically, I apply his theories of habitus and capital in the context of transplants in relation to Research Question 1. Narrative analysis allowed me to pick up on the participants' dispositions and understand how they interacted within the spaces that they were in. In chapter 2 I talked about the habitus and how it could support an understanding of communication on the BMT unit. Bourdieu links the habitus to capital and the exchange or accumulation of capital (Bourdieu,1987). His idea is to use metaphors of capital (social, cultural, economic) to understand how actors exchange value within a field/social space (Bourdieu, 1984/2010), in this study the BMT unit is the field in which I refer to the habitus specifically. The parents in the study accumulated cultural capital through their extra research. Insofar as seeking additional sources of medical information was a common goal of the families discussed in this study, it became an aspect of their shared habitus. During the lengthy periods they spend on a BMT unit, parents learned how to equip themselves with knowledge to better understand what their children were going through. This issue will recur in my discussion of Research Question 2.

Their knowledge increased, as did their ability to exchange it. This capital would be classed as ‘cultural capital’ with ‘educational value’ and was exchanged within clinical interactions. This phenomenon was also noted by Silverman in his study of communication between physicians and families in paediatric clinics (1987). It is also what Dixon-Woods et al., (2006) found in their findings on women’s consent to surgery (see chapter 2). Both Silverman and Dixon-Woods and her team found that there was an increase in the knowledge of their participants who were then able to exchange this within the interactions that they had with clinicians. In doing so, they shifted, or as I would prefer to say, rebalanced, the power to contribute to decision-making. Of course this exchange happened on the basis of the cultural capital that the participants had accumulated, where the knowledge (educational) was able to be exchanged between the stakeholders in the clinical relationship. Bourdieu’s idea was to use the metaphor of capital to show how there can be a variety of exchanges in social spaces (Skeggs, 2004).

The parent’s use of the knowledge or cultural capital they accumulated was also evident in Cathy’s narrative. Her experience of the BMT unit, and the knowledge she gained along her son’s illness journey, allowed her to know when her child should proceed through the early days of having his transplant (Chapter 5). She also describes her attempt to share or exchange her knowledge with another family. Parental knowledge thus became important for Cathy’s experience; but she was not alone. The other parents in this study also showed how much they had become part of the BMT unit by the language that they used throughout the interviews.

This is a point touched on by medical ethicists Wilkinson and Savulescu in their discussion of conflicts over medical treatment for children (Wilkinson & Savulescu, 2019). Their work highlights the importance of parents’ personal knowledge of their children, and the importance of this knowledge in medical decision-making.

I explained in Chapter 2, that the habitus works partly at an unconscious level, and it was because of my own experiences of the BMT unit that I was able to understand the parents in this study. Bourdieu touches on the significance of this point in his study of social suffering. He notes that if researchers are to deeply understand the structures and the experiences of their research subjects, they need to be part of/know the field that they are studying (Bourdieu, 1999).

As my study shows, this is partly a matter of language. The language used by parents has an effect on the way clinicians view them as participants in the decision-making process. The parents in the study learned to express themselves in the language of the BMT unit, or as Bourdieu would put it, accumulated cultural capital. Their ability to use this capital in conversations about consent may be unsettling for clinicians (du Pre and Brierley, 2018).

To summarise: In relation to the first research question of this study, I have shown how family experiences as well as family dynamics play a role in the medical consent process. These are both important factors in considering informed and voluntary consent from families within healthcare, and not only with regard to bone marrow and stem cell transplants. As social scientists, legal scholars, bioethicists, health researchers (Lyons, 2011; Cherkassky, 2015a; Brierley and Larcher, 2016; Birchley, 2021, Alderson et al., 2022) and others continue to debate the validity of consent, practical outcomes need to take account of the underlying realities of family experiences and other factors that I will highlight in the rest of this discussion. In this thesis I have started to contribute to the literature on family experiences of medical consent for life-saving treatments.

In terms of exploring the paradigm shift in medical decision-making authority, I argue that it is not enough to focus on one aspect, whether legal or medical, especially within major medical treatments (Alderson et al., 2022). I argue that there is a need for further multi-disciplinary research with a focus on exploring family consent. This research would ideally look at the relationships between all participants in the consent process. I have only looked at the family institution from the perspectives of the parents and again there is scope to expand this further.

This study has shown that the consent process in BMTs can be seen as a series of interactions between clinicians and families, who make major treatment decisions as they arise. But the ways in which they negotiate these decisions are not clear. From the perspective of the parents, who only have experience of their own specific cases, it is difficult to get a sense of who has authority to make treatment decisions. The data has shown that choice can be limited when it comes to making BMT/HSCT treatment decisions, and this is echoed by others (Benedict et al., 2007). There is a grey area where this research is attempting to fill the gap. This grey area I argue is the consent process as a ‘process’ and not as an event for signing consent forms. Thus, patience on the part of everyone in the process becomes a key factor, if trust is to be established and maintained in the family-physician relationship. Once the cells are infused into a patient through a Hickman line, there is nothing that can be done but to wait for the outcome of the transplant. The participants in this study demonstrated through their narratives that all they could do was wait to see whether the new cells established themselves in their children’s bodies. Not even the specialists can predict the transplant outcome with any certainty. A poor outcome, where a transplant fails may lead to further and more difficult consent decisions, that often require further transplants (D’Souza, Pasquini and Spellecy, 2015). All these factors are integral to the process of consent.

Uneasy Options: Informed and Voluntary Consent

2. *How informed and voluntary were their decisions for HSCT/BMT treatments?*

In Chapter 1 of this thesis I noted a definition of informed consent from a paper titled, “‘Is ‘informed consent’ an ‘understood consent’ in hematopoietic cell transplantation?”. The authors outlined a number of factors in relation to adults’ transplant decisions and argued that each factor influenced how ‘informed’ their decisions were (D’Souza, Pasquini and Spellecy, 2015). The factors were: patient factors, in particular the recall of information from consent conversations; physician factors, based on the physician’s experiences and biases for treatments; and lastly social factors that the authors identified within the literature they surveyed. The social factors were centred around the patient’s family and support network (D’Souza, Pasquini and Spellecy, 2015).

The critical analysis of informed consent by D’Souza, Pasquini and Spellecy (2015), and the data from this study, led me to think about ‘choice’ in relation to consent. These authors recognised that BMTs are complex and that “patients also need a higher level of competence, capacity and health literacy to make a decision for undergoing H[s]CT” (D’Souza, Pasquini and Spellecy, 2015, p.7). This comment is in line with the literature, which places great emphasis on understanding and capacity (Mason & Laurie, 2023; Beauchamp and Childress, 1994).

By contrast with this approach, I have mainly concentrated on the notion of choice central to my analysis. My reason for choosing this approach has to do with the aim of my study. My second research question is also similar to Benedict et al., (2007)’s second research question (Do parents feel they provided adequate consent?) for their qualitative study which explored parental experiences of BMT consent and whether they felt that their consent was valid, from a psychosocial perspective. Their focus was on the long-term impact of the decisions parents made from a parental perspective (Benedict et al., 2007). My research on other hand is about trying to understand the entire BMT consent structure, how communication within it works, and how treatment decisions are made. My study does not try to assess how legally valid (how informed and voluntary) consent on BMT units is. Instead, by showing what the current BMT consent process is like, the study aims to start a more in-depth dialogue about how parents can share major medical decisions with their children. Now of the process, and the narratives that shape their choices. The question is not ‘Was this case of consent informed and voluntary?’, but ‘How was this choice to consent to treatment made?’

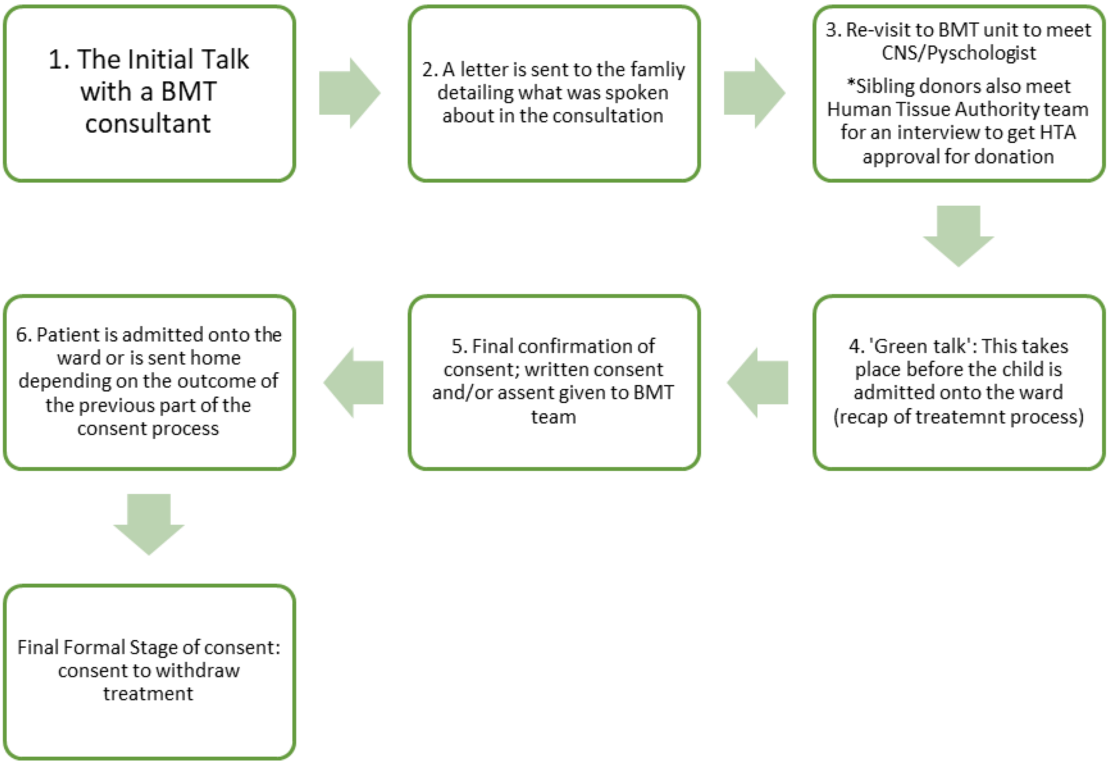
To highlight the difference between these questions, concentrating first on the notion of informed consent, it is helpful to focus on the facts and remember that the list of possible side effects from transplants can be very long (See Table 5a.). If one asks whether consent to treatment was informed and voluntary, then one needs to ask how much the patient knew about these possible side effects. But this takes it back to the process I have studied. The data in Chapter 4 indicates that the extent of parent’s medical knowledge varied over time. At the beginning of their children’s treatment, parents saw themselves as knowing relatively little. However, as treatment continues the families came to understand more about the side-effects of treatments and acquired the language to convey this understanding. They came to know what they were talking about (see Chapter 5). Each parent in the study acquired a familiarity with the medical language that is part of the habitus of the BMT unit, as evidenced by the acronyms they used throughout their narratives. So rather than merely asking whether or not consent was informed, one needs to take account of this process of consent.

The issue of voluntariness is more complex, as my terminology indicates. In ordinary cases, we take choice to be voluntary. A person has a choice when they are in a position to decide whether or not to do something, for example to decide whether to give or withhold consent to treatment. So in examining the choices of the parents in my study, it may seem that I am simultaneously examining the voluntariness of their decisions. Why, then, don’t I focus on the voluntariness of parent’s decisions, rather than on their choices? Partly, I wanted to detach myself from the complex philosophical debates surrounding the notions of voluntariness and involuntariness, and from the question ‘What exactly makes a decision voluntary?’ Instead, I wanted to work with my data, in which parents talk about their choices. In addition, the parents’ narratives do not always fit neatly into the theoretical account sketched above, in which legitimate choices are voluntary. They sometimes describe themselves as having no choice. By focusing on choice, I make space for the way these parents understand their situations.

In the survey that formed part of my research, I used the Decision-Making Control Instrument (DMCI) developed by Miller et al.,(2011). The participants' scores were probed during the interviews for those who participated in both parts of the data gathering methods. For method purposes the DMCI was added to the survey in the case that participants only took part in this option of the study, but more so for comparative purposes as it was created for the same topic. Miller and her team used the DMCI to find out how voluntary parents perceived their decisions to be for their children's bone marrow transplants 10 days post-transplant (Miller et al,.2011). The difference in this study was that there was no set date about when the tool was to be used. This did not concern me, given that families remain part of a BMT unit for a very long time. The results from the DMCI showed that most parents felt that their decisions for treatment were voluntary. However, those who took part in the interviews said they felt there was no choice but to proceed down the transplant route and when probed further in the interviews, they felt that their decisions were not voluntary. Thus it appears that the lack of treatment choices available on BMT units explains why responses in the interviews seemed to contradict the responses on the DMCI, which is similar to what Schaefer et al., (2022) found in their study.

As seen in the first figure in chapter 1 (and again below for easy reference) the flow diagram of the stages of the BMT consent process illustrates the consent process as observed and advised on by a director of a BMT unit. The consent form is signed at the ward admission stage, after the pre-BMT consultation.

Figure 1: Flow diagram of the consent process as observed on a BMT unit



This sequence of steps in the consent process set out in Figure 1 may be different for other units, but I surmise it may not differ substantially, given the similarities of the narratives given by participants whose children were treated at different hospitals. Consent to begin treatment is a clearly defined event, the signing of the form is a specific event, and the DMCI data is based on this (see Chapter 5). As other researchers have argued, the time between the initial consultation and signing the consent forms is very problematic for patients, given the amount of information that they are expected to remember in the interim (D’Souza, Pasquini and Spellecy, 2015). The parents’ narratives in chapter 5 indicated that decisions to proceed with treatments were not adequately informed or even voluntary from the perspectives of the families.

Later decisions - the ‘process’ of giving consent throughout the transplant phase - continue on an ad-hoc basis. This is where the distinction can be made between the event and the process, the two sides of the consenting pathway.

I want to introduce this dichotomy within the BMT field as a means to approach the issues of parents giving informed consent and consider how parents and healthcare professionals can modify the consent process to aide shared decision-making on the units.

As well as showing that parents' decisions to proceed with transplant were not voluntary, the data also shows that decisions made by doctors may also not be voluntary when it comes to transplants. Consequently, clinicians who seek consent start from a contentious point in the consent process. This has been offered as a reason for conflict within medical decision making for children (Wilkinson & Savulescu, 2019). Therefore, it may be advantageous to look at the extent to which doctors and parents are making voluntary decisions when it comes to BMTs. These starting positions of doctors and parents within the consent process should be made clear before children can be welcomed into the consent conversation, both for the 'event' and the 'process' in BMTs.

The 'process' aspect of BMT consent leads into the final dimension of the process: consent to withdraw. I touch on this as a way of looking at doctors' decisions when it comes to having a lack of 'choices' on their part. This is also to give an overall picture of all the stakeholders in the 'Bermuda triangle' relationship mentioned in the previous chapter. One key aspect of consent that the data did not cover was the last part of the consent process (see figure 1) 'Consent to withdraw treatment'.

In the case of BMTs the final stage of the consent process may not actually involve consent, as the right to withdraw often carries with it no choice on the part of the family. The data in Chapter 5 showed that choices for treatment can often start off as limited. Arguably, this right to withdraw can be seen as 'consent to palliative care'. Once the process of infusion begins, it often becomes a question of how well the treatment works, and the process is difficult to reverse once conditioning has started. The conditioning process involves preparations for the patient to receive the new bone marrow or stem cells. Often this preparation involves a course of chemotherapy and sometimes total body irradiation (TBI) to remove the old bone marrow and/or disease. During this critical stage of treatment, patients are left with no bodily defences, are extremely vulnerable to infection and need strict isolation. In the data, Bev's story touched upon this conditioning process in Chapter 6 as she recalled how painful it was for her daughter. With the conditioning process in mind, the right to withdraw is not available in practice until a treatment has been completed, so a parent or child cannot assert that right without dispute (Wilkinson and Savulescu, 2019). Mason and Laurie also point out in relation to withdrawing treatment, which is sometimes synonymous with refusal, that "in principle, consent and refusal are but reverse expressions of the same autonomous choice; the difference is that the level of understanding at which a choice can be said to be an 'understanding choice' is higher than the latter" (Mason & Laurie, 2013, p.97), From this, I can infer that each decision in the BMT consent process is limited by its context, and in the weight it carries for meeting the criteria that Beauchamp and Childress' identified as consent (Beauchamp & Childress 1994). My use of the term 'choice' aims to reflect these considerations.

When transplants can be independently funded it appeared that the voluntariness of decisions to proceed with them is given more weight. Chapter 5 showed how, when families can pay for a transplant after a first NHS-funded transplant fails, doctors were limited in their choices. This is because there is a window of time where patients cannot have a second transplant if the first one has failed (Ham, 1999). In the data reported in chapter 5, Janet and Bev spoke about how expensive transplants were, and Janet alluded to what she would have done to save her son if he needed to have a transplant abroad.

As I mentioned in Chapter 1, BMTs are fascinating in this respect, because here one can see how conflict can arise from the two polar ends of the consent process, where there is consenting to transplant and consenting to end treatment. The data in chapter 5 showed that management of these decisions could play out as what I called 'unconscious palliative care', where the doctors are left with no choice but to manage the expectations of a child, for the child's best interests, as was seen in the case of Charlie Gard (Wilkinson & Savulescu, 2019). By contrast, in the Jaymee Bowen (Child B) case (Ham, 1999; Bendorf and Kerridge, 2011), the media presented the narrative as centred around resource allocation, although clinicians and bioethicists have argued that this was a distorted view of the case (Wilkinson & Savulescu, 2019; du Pre and Brierley, 2018).

The data in this study touches on the costs of BMTs, but not on the principle that clinicians felt was neglected in the reporting of the JB case: that decision should be in the best interests of the patient. I argue that the economic factors affecting BMTs are one aspect of this research that might benefit from further exploration, because in those cases voluntariness in BMT consent may play a larger role. The parents in this study did not face economic dilemmas in their children's BMT consent process, but nonetheless they opened the idea up for an ethical discussion.

Bedside Medicine in BMTs

3. *How can parents support their children in sharing decisions about bone marrow and stem cell treatments?*

In Chapter 2 I raised the issue of the child donor's position within medicine, using David Oswell's idea of agency as opposed to competence. Agency, as Oswell presents it, is based on actions and not on measures that seek to prove competence (Oswell, 2013). I raised the question of whether it would be helpful to consider the child donor's position within medicine as a starting point for discussing how young people can make decisions about their healthcare (see chapter 2). I mentioned in chapter 2 that child donors could not be ignored as their role in the BMT decision-making process had an effect on their parent's ability to consent for their participation in stem cell and bone marrow donations. The child donor's consent process is overseen by the Human Tissue Authority and thus the parents will inevitably play a minimal role in the event and the process of consent for these children no matter how old they are. In this study only 2 parents had children as sibling donors, although I only discussed the data from Bev as she took part in the interview and provided a lot of details about her son's consent to donate to his sister. The other participant, Kate only provided this information briefly on the survey. However, in relation to research question 3, I want to focus on the child patient in relation to the parents' experiences and not the child donor as that would require further research to provide adequate data on the matter. Moreover, as the HTA oversees the consent process for child donors, research question 3 does not apply to them in this instance.

Let me now illustrate how the data showed how parents can support their children in sharing decisions about BMT treatments. The role of the parent in decision making has a significant influence on how the child in each individual family is positioned within medicine (Dekking et al., 2016). This is one of the social factors which was also identified in the literature about consent (D'Souza, Pasquini and Spellecy, 2015). From the parents' narratives in this study, it is clear that some parents chose to involve their children in conversations during their treatment and others chose not to, as was shown in Chapters 5 and 6. However it is not clear whether these decisions to involve children were made voluntarily by the parents or were due to other factors on the BMT units concerned.

It is clear from Cathy's interview that one-way parents can influence how clinicians interact with their children is through their own example of being 'open' in conversation. In her story of Troy's illness and treatment, Cathy highlighted that when parents engage with their children at their bedside in the presence of healthcare professionals, this interaction can facilitate healthcare professionals' connections with the child. This can be seen in chapter 6 when I am probing parents about the age at which they think children should be able to get involved in consent conversations. But Cathy's narrative in particular supports the idea of joint decision-making in a way that may often be ignored. Her practice of openly listening to the clinicians and translating the information to her child in a language he understands shows that parents who are able to use this tactic have the means of supporting their children. I say tactic, because what Cathy speaks of is an embodied mode of communication within the field, which may also be linked to her particular parenting style (Lareau, 2011).

To cast further light on Cathy’s interaction with her son, I draw attention back to sociologist Annette Lareau’s work (2011) here. Lareau’s analysis of how parents treat their children, and how that in turn gives children the ability to inhabit different spaces can be seen in Cathy’s narrative. Lareau found that when parents are more involved in their child’s upbringing, the child tends to have a different outlook in life and in turn participates differently in medical spaces. One example of this interaction in medical spaces from a child in Lareau’s study is Alexander William, as he is on his way to see the doctor:

> [Christina the mother] says quietly to Alex, “Alexander, you should be thinking of questions you might want to ask the doctor. You can ask him anything you want. Don’t be shy. You can ask anything.” Alex thinks for a minute, then says “I have some bumps under my arms from my deodorant.” Christina: “Really? You mean from your new deodorant?” Alex: “Yes.” Christina: “Well you should ask the doctor.” (Lareau, 2011, p.124)

This example shows that Alexander’s mother is encouraging him to be open with the doctor and this is the same openness that Cathy attempts to show her son. Moreover this shows the influence that parents have on their children in medical spaces, and the importance of understanding the family unit in relation to medical consent. This study has started to show how the family plays a role in the BMT consent process, thus showing that the process is not just about the patient and the clinician.

The driving issue of this study was the idea that parents were perceived, from a clinical perspective, as holding the most weight when it came to medical decision-making (du Pre and Brierley, 2018). But what Cathy’s narrative suggests is that decisions may not always be so one-sided. By practicing bedside medicine through her communication with healthcare professionals in the presence of her child (LeGrow et al., 2014), she plays a crucial role in the consent process. Cathy’s example shows that if a parent paraphrases what the doctor has said to them in front of their child, using language the child can understand, it becomes easier for the doctor to draw the child into the conversation. If a child then asks their carers what a doctor means, they can defer to the professional who can answer directly and build a closer rapport with the child. This can be an effective strategy for engaging children in conversations about their healthcare. Such conversations go beyond the interactions that children typically have with nurses or the play specialists who play with them on the ward (as seen in chapter 5). This data, alongside the other data shown in chapter 6 about sharing decisions with children, shows that the adults can enable the child to realize their participation within healthcare, offering more scope for them to be agentic. Of course, further research with children is needed to explore this assertion.

Sharing Decisions in BMTs

The data in this study shows that the parents are the key to shared decision-making in clinical interactions. The data in chapter 6 helps with developing an idea of where the parents think children should be positioned in the BMT consenting process, and it also offers a glimpse into the interactions that families have with healthcare professionals. I argue that it may be beneficial to look more closely at children's bedside medicine (LeGrow et al., 2014) to see how parents can support their children in sharing decisions on BMT units.

The participants in this study made it clear in their narratives that their children were not involved in the initial consultations regarding bone marrow and stem cell transplants. The results also showed that, at the time of the transplants, the children of the interview participants ranged from the ages of five to eleven years old, except for Zoe, whose child was 16 years old (survey only participant). It is not clear from the parents' narratives who if anyone was responsible for the decision to involve the child in later consent conversations about treatments. The parents did say that during the treatment process their children came to accept the decisions made by those who cared for them, as has been reported in other studies (Day 2017). The parents also noted that their children displayed a degree of autonomy when opportunities to make non-medical choices arose. These choices related to the participants' children appeared to focus on details that they felt mattered to them throughout treatment and recovery, as told by their parents.

This last point is discussed in Chapter 6. The data reported there shows that the parents were concerned with managing their children's quality of life in the hospital. The parents' experiences of the transplant process were thus shaped by how their children communicated with them about how they wanted to decorate their rooms and what they wanted in those rooms. They also knew what their children wanted, things such as gaming devices, tablets to watch programmes on and a good internet connection. The decisions that the parents made with their children were everyday decisions and thus non-medical.

The narratives also showed how family dynamics, and the relationships that the families build with the healthcare professionals, played an important role in determining how ill children participated in decision making during their transplants. These dynamics are based on several, but not exhaustive factors (culture, child rearing strategy, illness journey) which are different for each family in this study, but which nonetheless illustrate how some parents may allow their children more freedom to participate in the consent conversations. As I have shown, these dynamics are also an indicator of the habitus at work once it has been formed through a family's time on the BMT unit and in the hospital. The narratives in chapters 5 and 6 showed this.

In particular, the data showed that one participants' child came to know when and how to ask doctors about his treatment. (This again reflects the 'BMT habitus'). As was seen in Chapter 6, Janet talks about how James was able to communicate with doctors on his own terms, showing a level of competence that demonstrated his understanding of the day-to-day life of the BMT ward. She describes how he grew to understand how the hospital worked and was therefore able to have a conversation about his treatment. Once again, this finding indicates that the consent process is not just an event (as in figure 1) but a process. This shows that medical professionals may benefit from an awareness of bedside family dynamics and different parenting strategies to anticipate the interactions that are possible within each family. This observation provides one possibility for considering how to modify the BMT consent process for shared decision making (Question 4). Clinicians could sensitively invite a child into the conversation about consent by appreciating the bedside family interactions, in cases where they believe this would be in the best interests of the child.

I propose that the adults involved in a child's care should consider the psychological harm that might come from allowing a child into the consent process without this sensitivity to family dynamics (Grootens-Wiegers et al., 2017). Even if a child has the capacity to voice their reservations about treatment options, the burden of the details of treatment outcomes might seriously impact their state of mind and their recovery. At the same time, it may impose a burden on medical professionals. By way of an example, I use data from Janet's experience of the interaction between her son James and his doctor,

> Janet: ….when he was told that his treatment hadn't worked and he wasn't gonna survive…he actually rang the bell himself and asked the doctor- the nurse came in.- he spoke to the nurse, and I explained to the nurse this is, we'd explained to James cause he had started asking questions, and I'd answered them- he said he wanted to speak to the doctor about it, so the doctor had to come in and sit down and talk to James about why his treatment hadn't worked and give him an explanation- and he asked some questions. And the doctor answered them, and she started crying
>
> Interviewer: the doctor started crying? Aww
>
> Janet: she found it so difficult, umm

This interaction not only shows a strong personal relationship between the doctor and James. It also indicates that involving child patients in treatment decisions may be emotionally taxing for their healthcare providers. This factor also needs to be considered when thinking about how the consent process can be modified to facilitate informed shared decision making across the physician-family relationship.

As we have seen in previous chapters, the transplant process for BMTs and HSCTs can be unpredictable in nature. The parent's narratives have shown that their children were active observers in the consenting process, but they have not indicated how one might assess the risks that this participation involves. At present, the law is not prescriptive about when children should be invited into the consent process, and my data shows that it would be difficult to set an age limit. This assertion is supported by the responses given to my question about what age the participants thought children should be to participate in BMT decision-making (Chapter 6). In the case of BMTs, ‘Gillick’ is therefore a little problematic (Cave, 2014), because the realisation of children’s rights in healthcare is more complex than it allows (Brierley and Larcher, 2016).

My data indicates that the parents in my study did not have a settled view about the age at which children should participate in the consent process. When I compared the answers given in the eight fully completed survey responses (6 parents= 8 children in total) with the views expressed in the interviews (4 parents = 5 children), I found a divergence (Chapter 6). This suggests that, after careful reflection, and using insights gained during the treatment process, parents came to realise that children were likely capable of participating in decision making conversations before the age of 16 – the age prescribed by the Gillick ruling (Gillick v West Norfolk and Wisbech HA 1985). However, my data also shows that the extent to which children were involved in the consent process was at the discretion of their parents. In a way the parents individually analysed how much agency to allow their own children.

In Chapter 2 I discussed Oswell’s view that children make decisions because of their structures, and that agency should not be perceived as a blanket reality for all children (Oswell, 2013). Oswell encourages us to think of agency as context-specific, and my data supports this view. The parents in this study took a holistic approach to determining how much agency to give their children in the context of the BMT habitus. They were in control of the freedoms and controls (Oswell, 2013) they allowed their children during the BMT consent process.

The narratives in this study show how the knowledge they gained on the BMT unit enabled the parents in this study to understand how their children could and should be involved in BMT treatment decisions. The data in Chapter 6 showed that the question of whether a child should be welcomed into conversations about consent is not primarily a matter of whether a child is old enough. The issue is rather whether this would benefit the child. Where possible, treatment decisions made within BMTs are about the best interests of the child, and decisions are made within what Janet refers to as the ‘Bermuda Triangle’ which involves the doctor, patient and parent. It is clear from her experience that children are part of these decisions in one way or another. So in relation to Question 4, it appears that the consent process has the potential to be modified to encourage family shared decision making.

My data suggests that decisions about the extent and type of children’s participation will also depend on a range of further factors. It will be important to take account of a child’s familiarity with the BMT habitus, and the hospital habitus more broadly. Also relevant are the differences in BMT treatment options for those children with malignant and non-malignant illnesses. For example, when James and Misty were transferred onto BMT units, the treatments they had received for cancer in oncology units had already failed. They were already familiar with a hospital habitus, which shaped their interactions with those around them. By contrast, Troy and Emma were transferred to BMT units for curative treatment, with a preventative purpose in mind. The hospital habitus was slightly new to them, and they had yet to adapt to it fully. The significance of these differences is evident in their parents’ narratives. To corroborate these findings there needs to be a further analysis of the hospital habitus, from the perspective of children. My point here is that an appreciation of the ‘hospital habitus’ is crucial for understanding the types of children who may benefit from participating in medical treatment decisions.

As I pointed out at the beginning of this thesis, the view that parents are ‘third parties’ in medical decisions presents them in a negative light (du Pre and Brierley, 2018). If clinical policy is to enable children to realise their medical rights when it comes to making treatment decisions, children would ultimately need to be able to give written consent (Cave & Purshouse, 2020). Here the demands of legal institutions resurface. However, as this study shows, this is not the only context in which the issue of children's consent to BMT treatment needs to be addressed.

The findings in this study have shown that, in practice, consenting to medical treatment goes further than the legal definition of informed consent suggests (Mason & Laurie, 2023), and thus further than the principles embodied in the Gillick ruling (Gillick v West Norfolk and Wisbech HA 1985). The findings highlight that it is not simple to recommend an appropriate age for children to participate in the consent process because policymakers would have to factor in many different dimensions of childhood (Wyness, 2018; Prout, 2000); indeed, parents and healthcare professionals alike face the challenge of deciding whether to involve the children, and if so, when to do it. When adults allow for children to be present within the consent process, they need to prepare themselves for the possibility of the child playing a major role in how treatment proceeds, and that this participation could further impact the outcome of treatment for the child and for the healthcare teams (Wilkinson & Savulescu, 2019). In the next section I therefore focus on the final research question, by considering how the BMT consenting process can be modified to support parents in sharing healthcare decisions.

Modifying the BMT Consenting Process

4. *How can the HSCT/BMT consent process be modified to support parents in shared decision-making?*

The data in Chapter 6 showed that the participants' children told them about their preferences as patients on BMT units. Again, this assessment of preferences comes from the parents' narratives of their own children's illness experiences. By classing the parents as 'witnesses', this study draws on the way they have previously been conceptualised as belonging to the 'remission society' (Frank, 1995), and as useful narrators of illness (Bourdieu, 1977). The data contained in the study shows that parents may be able to encourage their children to participate and contribute to sharing treatment decisions, and not just to day-to-day decisions about their hospital care. However, children may only be able to participate if the hospital allows them, given that the parents in this study were not sure what age they should be to participate in sharing treatment decisions. To support parents in sharing treatment decisions on paediatric wards, families would require policies that openly welcome parents to encourage their children to participate in shared decision-making. Moreover, parents may need to be advised about the possibility for their child to contribute to treatment decisions during the initial stages of the BMT consenting process. Or during the stages where consultants start to consider the possibility of HSCT/BMT transplants, as was seen in Cathy's narrative about the IVF treatment that she was offered to conceive an HLA matched sibling donor for her son Troy.

The policy idea that I propose may be viewed as positive (Durose, Mazé, & Richardson, 2023), providing guidelines to identify children who may benefit from contributing to the consent process. At the same time, the guidelines may reduce the participatory authority of parents by diminishing their power to determine whether or not their own child would benefit from participation. Both of these aspects need to be taken into account if the BMT consenting process was to be modified with my suggestion as a catalyst for further research.

The findings in this study have shown some key indicators that would assist in developing my proposed assessment tool – which might be called a Consent Ranking Scale (CRS) - for dealing with the issue of sharing treatment decisions and not just day-to-day decisions across the physician-family relationship. A current review of informed consent ranking scales has not identified a scale like the one I am proposing (Sherman et al., 2021), and of course this proposal is in relation to the data in this study. The scale I am advocating is not focused on the validity of informed consent. Rather, it focuses on supporting parents with welcoming their children into treatment decision conversations, as some parents indicated that children may be able to participate in these types of conversations. This proposed scale would take account of the many factors mentioned in this study and would be a starting point for supporting clinicians and families during the consent process. The factors identified in the data from this study, which could be used to develop the CRS are- family experiences (illness narratives), variations in illnesses (malignant/non-malignant), reason for BMT (curative/preventative), medical & non-medical decisions made by children on BMT units, family dynamics (parenting strategy), risks of participation in shared-decision making (burdens of truth), culture (western/non-western).

If developed properly, the CRS could be used at the initial stages of admission to enable care givers to understand where to start when it comes to welcoming children into the BMT consent conversation. The CRS may also be useful for supporting the clinicians during the 'formal consenting process' for transplants. Hypothetically, the higher the score on the scale, the more consideration the healthcare teams could give to the children. The lower the score, the less expectation the healthcare teams would put on the parents for children to be involved in the consenting process. Although this is hypothetical, and a complete scale would be determined by the choices of the research team after working on a full design and checking its validity.

This study thus suggests that for children to be able to consent to treatment, or to participate in the consenting process for bone marrow or stem cell transplants, the consent process has to be holistic. The proposed CRS tool would have to factor in the interactions of all stakeholders on the BMT unit, whilst also addressing the individual differences of those involved, with a main focus on positive outcomes. The factors which I suggest as variables for the CRS assessment tool would of course need to be operationalised (Vaus, 2013), and that is why I have listed them as dichotomies. These dichotomies are a helpful starting point for addressing the ideas that came out of the data in this study (Jenks, 1998). This CRS tool that I am proposing would also need to be developed by a team of specialists. These specialists would need to effectively capture the experiences of all the key stakeholders involved in the BMT consenting process to ensure that the tool is valid.

There are valid arguments for and against the idea that children should be allowed to participate in the consent process (Lyons, 2011; Cherkassky, 2015b; Brierley and Larcher, 2016; Alderson, 2018; Turnham, Binik and

Wilkinson, 2020). And, since a child's capacity to participate depends on many factors, there is likely not a simple answer. My approach is influenced by Oswell's question: "what freedoms or controls are appropriate to be placed on the child" (Oswell, 2013:15). Following Brierley and Larcher (2016), the data in this study has shown that there are no clear guidelines to help adults consider whether or not their ill children should be involved in the consent process for major medical treatment. However, in the case of consent to BMTs, we see at least the beginnings of a shift in decision-making authority, back towards a person-centred approach to medical treatments.

I argue that, within BMT units, a formal participatory role for children in the consent process is particularly challenging because of the characteristic of BMTs as both a process and as a procedure. The findings in this study have shown that transplants and information about side effects is complex and the outcomes are not always certain. This view is also supported by other researchers, who have argued that these factors make valid consent difficult to achieve in BMTs (D'Souza, Pasquini and Spellecy 2015; Benedict et al., 2006). The information on which valid consent is based is hard for patients to understand (Herrmann et al., 2021), and decisions are not always voluntary, as seen in the findings of this study. Many complex medical interventions are also involved (Lucchini et al., 2017), and this complexity will arguably remain present when it comes to making decisions about when or indeed whether to introduce the child into the consent process.

I propose that considering the differences within childhood illness experiences, may offer medical professionals an insight into how they can approach and support parents when it comes to sharing decisions in BMTs. The adults concerned also have to consider whether children actually want to be involved in the decision-making process once they have become familiar with the hospital. And, as the parents in this study show, the adults need to be watchful for how children might express the desire for autonomous control when it comes to their healthcare decisions. Participation in the shared decision-making conversation might come from individual family choice or from policy-guided professional interventions.

The data in this study has shown that children who have been in hospital for long periods of time can and in most cases do acquire a hospital habitus (see Janet's son James as an example). Children like James are in an invisible synchronisation with the adults around them. My own previous sociological research (unpublished) into the differences in the lives of children living with Sickle Cell Disease in the UK and the USA gave me the opportunity to observe children with a 'hospital habitus'. Children with a 'hospital habitus' are open to a wider understanding of their settings, and of the rules, cues, and language of these settings. For example, they may begin to use the language of the healthcare professionals because that is the language which they hear in their day-to-day care. They may begin to see the hierarchies within the hospital and start to understand the roles of the individuals around them. This may give them greater capacity for involvement in the consent process, compared to the child who has only been to the hospital once or never before. However, as I have already noted, this would require further exploration by a larger, possibly multidisciplinary team.

It is possible for the child with the hospital habitus to be seen as having epistemic privilege by comparison with the child without the hospital habitus. Yet the child who has spent more time in hospital and not in school may be at a developmental disadvantage compared to other school age children. Children who come to need major medical treatment after a long period of illness may have very different life experiences from those who are new to the hospital, and the data in this study showed glimpse of that.

The participants in this study have shown that the illness journey causes significant changes to the habitus of the individuals involved. In fact there is a relationship here of habitus, treatment journey and individual. This is another key factor for building on something like the proposed CRS assessment tool for supporting parents and welcoming children into treatment consent conversations.

The complexities of bone marrow and stem cell transplant processes can often only be appreciated with the benefit of hindsight. It is arguably hard to see a benefit for child involvement in major treatment decisions such as transplants which are a question of life or death, as the parents in this study have shown. However, after repeated treatment failures, perhaps a child should be able to make medical treatment decisions, even when that decision is “enough is enough” (Janet).

There is no general consensus about what “informed consent” is and since it is very context specific, it can become a problematic term in healthcare (Millum & Bromwich, 2021). Norms, customs, and community-wide shared perceptions all play a role in the understanding of informed consent as shown in my findings. I have researched paediatric bone marrow and stem cell transplants with regard to the issue of informed consent. The issue of informed consent is the same over a wide range of complex treatments. Ultimately the reasons for such research into the consent process for children (Sutcliffe, Alderson & Mendizabal, 2021) is so that adults can have satisfactory evidence that children play a role in the decision-making conversation.

In order to find a solution to a problem, Mills noted that we must first understand what the problem is (Mills, 1959). This research has shown that, in BMTs, consent as it exists at present is neither informed nor voluntary. This study has focused on the experiences of parents in relation to their children as patients and as donors. I have shown that the BMT consenting process first follows a ritual (figure 1) which leads to the signing of a transplant consent form. However, once the treatment starts, the consenting process can begin again and become an iterative process. In this case, consent for BMTs becomes more than an issue of the event. Consenting remains an ongoing process until the patient returns to a stable “remission society” (Frank, 1995)

Beauchamp and Childress (1994) argue that the best interests should only be appealed for a particular moment in time. In assessing a patient’s interests, the possibility of psychological damage in the future should not be considered. But this study has shown that BMT consent is a particular and serious form of consent to treatment for life threatening illnesses, and therefore essentially involves future possibilities. To do justice to this fact, my discussion has considered “participation in the consent process” rather than autonomy in the here and now. It makes no sense to suppose that children could be considered competent and sufficiently well informed to make legally binding and documented decisions that can fundamentally change the dynamic between a physician and their child patient, and the outcome of a long and uncertain treatment.

There is a significant emotional component in the current BMT consent process. It is not just about being informed; it is also about comprehending the idea of death. The process can be more about appreciating adults’ fears as co-fiduciaries than about shared decision making between adults and children. The adults, both healthcare professionals (Brierley & Larcher 2016) and parents (in this study), want some degree of confidence that they are making the right decisions at each point during treatment. The child’s best interests in the BMT consent process may be the defining factor for understanding the decision-making authority within the current paradigm shift of medical decision making.

Summary

This discussion has highlighted the findings of this study and proposed a set of factors such as family experiences of illness, types of illness, medical and non-medical decisions that are made on BMT units, which can be considered when further researching how parents and children give informed consent in BMTs. The factors that I have addressed in this chapter can also support a broader understanding of how children may want to participate in shared decision-making conversations or in the final stage of the traditional consent process when the forms are signed, which signifies the event of ‘consent’. However, I have shown that the transplant treatment phase is a process and that signing the consent forms is only the first significant ‘event’ in a family’s illness journey, and the consent process continues alongside the treatment phase. The conversation about consent cannot be seen as an isolated event in BMTs, and this raises challenges when the only consent alternative is to withdraw consent. My analysis has provided a framework based on illness narratives that can be used to assess and support children and their forms of participation in the ‘event’ and the ‘process’ of BMT consent.

To summarise, the consent process within BMTs is driven by the course of illness, and whether treatments are successful. The parents experience the BMT consent process for their children and they make decisions with their best interests in mind, as the children are rarely invited to participate in making the major decisions about treatment. But nonetheless, the parents note that their children actively participate in the treatment process. They participate daily as the subjects of the conversations of consent, and they may be able to contribute to the treatment decision conversations as much as those in their medical teams and families allow them to. I have obtained insightful narratives from parents as witnesses of the children’s illness journeys which show that transplants are deeply personal experiences (Frank 1995; Bourdieu 1977). In the absence of ethical and non-intrusive methods of obtaining first-person accounts from children in these life and death situations, the parental narratives have provided a window into their own and their children’s experiences of the BMT consent and treatment process. While my work contributes to the debates about family shared decision-making (Alderson, 1990, 1993 & 2022). I hope that these narratives will support professionals to find ways of supporting parents to share decision making by welcoming their children into discussions about consent.

In the concluding chapter I will discuss some of the strengths and limitations of this study. I will also discuss some useful ways that this study can be continued, and I will add some additional remarks on how clinicians could benefit from further recommendations.

Chapter 8: Conclusions and Recommendations

> Linkage of personal troubles and public issues, which is the foundation of politics, begins in the cultivation of personal stories. People can move from experience to politics only when their experience is narratable to themselves and others, and thus made legible" (Frank, 2002:8)

Introduction

My aim for this study was to follow a line of communication through the narratives of parents who are in the 'remission society' (Frank, 1995), to develop an understanding of what the consenting process in BMTs is like. The data I collected has thus shown a little of what goes on behind the scenes on BMT units, and how parents interact with their children during the transplant treatment process. In the context of BMTs, the findings in this study show that a wider exploration of all stakeholders in the decision-making process may help to support adults in recognising the child's position in medicine so that they can welcome them into medical decision-making conversations. These stakeholders include clinicians, healthcare professionals, children, parents and maybe even social services and the judiciary (du Pre and Brierley, 2018). The law is clear about 'Gillick' (Gillick v West Norfolk and Wisbech HA 1985; Mason and Laurie, 2023), the problem is how the principle can be practically exercised within medical practice without causing confusions for families and clinicians (du Pre and Brierley, 2018; Brierley and Larcher, 2016).

I will now discuss some of this study's strengths and limitations and offer some further research recommendations. I will then follow this on with some suggestions for clinical practice and end the chapter and the thesis with my concluding remarks.

Strengths and Study Limitations

This study was limited in terms of the sample size since the data collection took place outside of the hospital setting, but as Hart (2003) notes, it is the quality that is of importance and not “the size of the contribution” (Hart, 2003, p.22). Originally the study was to be conducted on a BMT unit, and the plan was to use a combination of observations, interviews, and surveys to collect the data, focusing on each aspect of the consent process as highlighted in figure 1 (see chapter 1). However, as Bloomsbury Colleges funded the study, there was a time limit for completion, and the ethical approval requirements (UCL sponsorship & NHS ethical approval) made data collection in a hospital impractical. Therefore, in order for me to meet my deadlines and to get the study running I had to modify the design and focus more deeply on a smaller number of participants which could be recruited outside of the hospital. Thus the recruitment method of my initial design became a limitation as the sample of potential participants became more geographically widespread. Although this could be seen as a strength given that a wider variation of families were able to find out about the study, with the support of the charities that helped me during the participant recruitment phase; this could not guarantee how many people would eventually volunteer to take part.

Therefore, this small sample reflects the difficulty of targeting the BMT population through methods of snowballing as a starting point outside of the hospital (Seale, 2018). Participant selection was also a delicate process because of the sensitive nature of my topic, as very often the transplant ends with poor outcomes, even death for the patients. I touched on this in Chapter 3 when I mentioned the participant who I did not contact because I knew that their child had passed away. Nonetheless, the sample in this study was robust, and the participants offered a wealth of meaningful data, and this also contributes to methods debates. The literature on the number of qualitative research participants often has mixed numbers, ranging from 2-30 participants (Baker et al., 2012). But given that I used mixed methods and my criteria for participation was very specific (see Chapter 3, inclusion and exclusion criteria table), Creswell notes that he has “found narrative research to include one or two individuals” (Creswell, 2018:189). Thus my total of six participants who fully completed the survey and 4 of those who also took part in the interviews is satisfactory for adding to current literature on family medical experiences.

Though, as the study moved from the hospital design to a snowballing design with the support of the charities, it proved difficult to reach a wider sample of potential participants. Again, this could be perceived as a positive for this particular study, as can be inferred from this extract about the outcomes of transplants.

> Janet…They are not classed as failures, but the child has survived the transplant and the disease is returning they are doing alright -I mean are they, the kids aren't they bring them in here, Oh yeah they are dead!
>
> Interviewer: Where are the children?
>
> Janet: That's what you should call your study, they are like shadows in the wind.
>
> Interviewer: Where are the children, I suppose somebody needs to talk to the parents, to find out about that journey I mean it's all good wanting to know the success but in the end
>
> Janet: If you talk to a patient who is 6 months out of transplant, they've gone home kids alright have gone back to school. Getting back to normal, talk to them two years' time when they have relapsed. And are back in the shithole that's what happens excuse my French. Those patients don't want to put you, they don't want to talk to anyone they are busy burying their heads in a pillow crying at night because the process was so horrible..

Another limitation to the research was the lack of knowledge about BMTs that I held at the beginning of the data collection phase. The parents were good teachers, and I had to adapt my interview plans even during a single interview. For example, as I was listening to Janet's' interview (around 16 minutes into it), I as a researcher was able to show my understanding of the consent process with her. But I had not planned on encountering the topic of bereavement. I was unprepared to deal with this topic, and I needed to change the way I was approaching the entire interview. I could not follow the script of the interview schedule that I had discussed in a supervision session days before I conducted the interview. I could no longer treat the interview process in a structured way and the sensitive nature of transplants needed a gentler, conversational approach, which was unanticipated but essential. Thinking back to Janet's interview, I can say that this is one that really caught me unprepared during my research career, and it made me come to terms with my own naivety about this topic of transplants. However, it prepared me for the other interviews and for all possibilities, and I had to be flexible so that I could adapt for any other things that I may have missed during the design stages. In this thesis I have included such background material like this reflection, and while it is not "data" it is shared as a roadmap for future research on the topic.

With hindsight, the survey would have benefitted from adding a check box for "my child has passed away" before making the survey live to potential participants. I did eventually add this screening question, but by that point, at least one parent had left the survey because their child had passed away. This is participant 7 who I mention only as a number in my tally of participants but do not include their data as they did not complete the entire survey. My naivety for not adding the bereaved checkbox earlier may explain why some surveys were started but left uncompleted. I say this because Janet informed me that she had to effectively lie that her son was alive so that she could complete her survey. However, as I mentioned in the methodology chapter (3), the survey had its strengths in being a useful tool for recruiting participants.

I have started to address a complex issue from a narrative inquiry position, and I am aware that I am limited in what I have been able to present of the topic of communication within BMT consent. I believe that a larger multidisciplinary team is needed to take the issue of consent and shared decision making in major medical treatment further. However, this work can be seen as a development study, and it has been able to highlight some of the key points that future research could focus on and the best methods to employ at each stage of the research process.

As the study has had a strong focus on reflecting on the materials that I can use as data or even in parts as reflections from my research diary, there have been limits to what I can and cannot say about the knowledge I accumulated throughout the entire research process. This has made it difficult to use particular supporting examples when needed. Although, I would argue that the stories within the narratives of the participants were useful for adding to the existing literature focused on BMT/HSCT transplants and consent. Thus the narrative approach that I employed throughout this work has been quite effective for supporting some of the limitations that I had in my position as a researcher.

Further Research Recommendations

I now add some brief recommendations for researchers who are interested in exploring this topic further. These recommendations come from the findings and limitations of this current contribution to understanding parents' informed and voluntary consent to major medical treatments. As noted in Chapter 2, these recommendations are also useful additions to Emma Day's recommendations from her study on adolescent consent, also with an element of consenting to treatments on BMT units (Day 2017). Moreover these recommendations are to also focus on children and young people as they are the other actors in the family structure.

Recommendations

- A similar study like this one should be conducted with the children as the main focus, to understand their experiences of the BMT consent process. This will add to what is known about the parents and can be followed up with research on healthcare professionals' experiences.

- A team should consider operationalising the factors I identified in the analysis to design and test a tool like the proposed Consent Ranking Scale that I introduced in chapter 7. This tool could be useful in the BMT context.
- A multidisciplinary team may benefit from exploring new ways of managing the child's medical history as a guide for competency standards to support clinicians in shared decision making.

- A longitudinal research project could explore piloting a multi-factor framework for independent advocates to see if they make a difference to patient and family experiences.
- Researchers could support clinicians with revising medical consent documents to reflect the outcomes of the recommended research.
- In addition to the above revision of consent documents, the team should have an awareness of mental health concerns during healthcare, and these should be put at the forefront of further research into children's medical consent.

These recommendations are for a well-equipped multidisciplinary team and for now, what sociology can do is highlight what the BMT consent process looks like, which is what I have done in this study.

Conclusion

This thesis has sociologically contributed to what is already known about bone marrow and stem cell transplants by showing what the current consent process is like for families, and how parents make transplant decisions on BMT units. The mixed methods approach that I employed for the study was informed by my early observations of a BMT unit, which in turn allowed me to engage with parents who have been through the entire transplant process as parents of ill children. Their narratives of life on BMT units have allowed me to demonstrate and interpret what the BMT consenting process looks like and how an understanding of the communication between families and clinicians can support shared decisions on treatment consent. I will now offer some reflections on how this study can benefit clinicians as it was initiated with the aim of informing clinical practice through its results, and I shall end with my concluding remarks.

Suggestions for Clinical Practice

Currently social scientists argue that children from very young ages should be permitted to participate in consenting to their medical treatment (Alderson et al., 2022). However, clinicians are torn between the decision-making authority that parents have (du Pre and Brierley, 2018) and the uncertainties of authority that they face when they allow minors to make treatment decisions (Brierley and Larcher, 2016). The results from this study allow me to argue that it may not be useful to advocate for children to participate in complex medical decision making, without having a deeper sociological understanding of the processes that families go through during a child's illness journey.

The results of this study point to considering whether policies in the hospital have to change for the inclusion of funding for more research that can support clinicians, and families to facilitate shared decision making for children's major medical treatments. This is where this research becomes relevant within policy. If an assessment tool like the Consent Ranking Scale (CRS) was developed, starting with the factors that I suggested in the last chapter, then outcomes of patient and family experiences may be different to the ones shared in this study. This would of course be in support of the fourth research question of this study, and the CRS for clinicians, could start from the perspective of practicing a form of child-centred bedside medicine, by independently supporting parents to welcome children into the consent process. Given that the findings in this study showed how much information the parents themselves had to comprehend, the CRS could be useful for the clinicians in supporting families with consent discussions in the hospital.

If I revert back to the key issue carrying this study, I propose that the focus should be on whether there would be improvements to the transplant process, in terms of experiences and outcomes if children were involved more in treatment decision making. If the argument is that more can be done in situations where families have to decide on major surgery or life changing treatments and that children should be involved in these decisions (Alderson et al., 2022); then I also argue for further research to be conducted into this topic, to deepen an understanding of why more needs to be done in enabling families to make joint medical treatment decisions when it comes to life-saving treatments. I have briefly touched on what this research can look like in the research recommendations and this proposed research can also be supported by my suggestions for the development of a consent assessment tool (like a

CRS) which I also detailed in the previous chapter. I argue that if there is not an understanding of the importance of the ‘why’ children should be involved in treatment decisions, then clinicians and families will struggle when it comes to the ‘how’ in changing what the current BMT consent process looks like for children (Mills, 1959), or indeed in changing how children participate in making treatment decisions for major life-saving treatments (Brierley and Larcher, 2016). The parents’ narratives in this study show that the child gets involved in the day-to-day decisions that help to bring comfort to their lives whilst they are in the hospital. The parents on the other hand focus on the bigger picture. There needs to be further research into whether there are benefits of involving children more fully in the consent process, before diving into how to implement such a process. This study has shown that consenting to life-saving treatments is difficult and that many variables are at play in the consenting process. Thus I have been able to advocate for the use of something like a consent ranking scale (CRS) once it has been developed, so that clinicians can assess improvements in shared decision-making whilst supporting families through the iterative BMT consent process.

Concluding remarks

In this study the parents’ experiences of their children’s illnesses have shown that bedside medicine is still an important aspect of illness and treatments. Their understanding of their children was at the forefront of the decisions that they made and the decisions that they allowed their children to make. I have argued that the position parents take as decision makers for their children’s interests may be the reason why clinicians are seeing a shift in the authority of who makes medical decisions.

My thesis has highlighted the complexities of the idea of informed and voluntary consent, and I have shown that there are grey areas where the consenting aspects of BMT/HSCT transplants may not be the same for all families. In these situations, their participation will differ during the shared decision-making process. I did not want to argue that children's participation rights do not matter in complicated treatments. Instead, I wanted to highlight the consenting process for major medical procedures like bone marrow and stem cell transplants and show how these processes may not openly allow children to make treatment decisions.

However, the findings from this study have shown that BMTs can be viewed in the same gaze as that of bedside medicine, and in the midst of the treatment process, one has to remember that the agency of children is ever present and interacting in the process as much as their illness allows them to. The parents in this study have shown that children are not ignored in decisions about their care, their illnesses are the deciding factor to their involvement in their care. The complexity of human relationships is what takes place on the BMT unit, and it is these relationships that formulate and reformulate a habitus that only those on the BMT unit understand. The goal now is to move towards practicing the ethics of bedside medicine so that those in decision-making positions of authority can recognise the agency and contributions of everyone involved in the process.

Lastly, I further argue that it may be useful to have a revised understanding of the concept of informed and voluntary consent and what it means in ethics, in law and in medical practice, so that adults can further promote children's health rights.

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Appendices

List of appendices

A: Brief Childhood Histories- extended narratives

1; Participant information sheet

2; Participant consent form

3; Invitation letter

4; Study recruitment poster

5; Interview schedule

5a: PPI feedback on the survey

6; Online survey in Word version

7; Bloomsbury research protocol

Appendix A: Brief Childhood histories

These are the responses from all of the participants about their children.

Matt talking about Emma

Matt (lines 78-117)

Interviewer: ((giggle)) and how was, how was she like before being diagnosed, like as a child, like her character?

Matt: She was I mean, she was great, she was stubborn, she sort of loved life ((yeh)) she wo – you wouldn't know anything was wrong with her. Umm and then she got the pneumonia and she lost loads of weight, and she's only little anyway coz – they – they don't get too big and umm – she lost a lot of weight from then and umm – but she hasn't really changed – you know, she's still the same, she doesn't really understand anything.

I: Yeh

Matt: She's still probably just a little bit little – she knows that she was getting new blood and that her blood wasn't working and things like that ((yeh)) but she obviously just doesn't know the gravity of everything linked with Fanconi Anaemia but – she – nothing ever phased her she just got on with it ((yeh)) she never moaned or anything so – I mean she's good like that and we've been luck definitely.

I: What, was she in like reception at school or nursery at the time.

Matt: Yeh so she was in reception umm and she was sort of at the local school on the estate – she was going in everyday – umm and she went in everyday until the day we went into hospital she was in –

I: Oh okay

Matt: So, she, she was able to do everything, she got a little bit tired and things like that, but the teachers knew about that – so she would – they used to do this thing called the weekly mile where they walk around the playground

I: Yeh

Matt: Emma had a chair so half way round the mile there'd be a chair that Emma would sit on.

I: Aww

Matt: And then, so, it was good – and she, she loved it you know – and umm – she wasn't really any different – she, before the transplant she'd – we look at photos now and we look at her then and think gosh she looked ill – she looked really really pale ((yeh)) really sort of slim and like drawn in her face – and now she's got colour in – a little bit more chubbiness, I mean she's still not, I mean you can tell when you look at other children that Emma's obviously had something ((mm)) but it's not noticeable as it was.

I: Yeh and she sort of knew what she had – you know when you went to the hospital, did nobody talk to her – because you said (survey response) that no doctor spoke to her – was she there at the consultation?

Matt: She was but she was sort of just playing in the background –

I: Oh okay

Matt: Umm she didn't really – she never had a session sort of – sat down with the doctors and it wasn't because – I think they would have done if we'd asked them or anything like that but – we had a lot of questions – so we were sort of asking and Emma just got on, and just played you know – they'd be something called play specialists in the hospital ((yeh)) and they played, with her, things like that so – nah there wasn't really – we sat down with a social worker and spoke through things and it ((inaudible)) and stuff like that in the clinic ((mmh)) – I mean everyone was absolutely amazing – but I don't know if she was just too young – she just wouldn't have understood anything.

Janet talking about James

Janet lines (line 761-828)

Interviewer: that was the question ((was it?)) [laughs] tell me about James' character-

Janet: So James was a typical typical lively eight year old boy, he didn't walk anywhere, he used to hop, skip, jump, trip, he was always a bit clumsy, but he was so smiley, he had shiny skin, he was like a healthy puppy ((yeh)) and he was always happy to do stuff, he loved school, he loved his friends ((ahh)) he loved playing with his brother. He wasn't really naughty, he was very well behaved actually as children go, and I remember when I went to one of his, you know when they go to nursery school and they had like a parents evening thing, and the woman in there said to me, ' if I had a classroom full of James's I would be so happy'. ((aarh)) he's like a, he was in the room without being in the room, he wasn't in your face, he wasn't annoying, he would do what he was told but he'd still have his own mind but he knew how to behave ((yeh)) and to keep it a bit, you know ((yeh just there)). He loved football, and he just loved playing, he was just a happy boy.

I: what happened during his treatment?

Janet: to that or?

I: yeh [inaudible…café is very noisy at this point]

Janet: ….It was very gradual….very gradual. It started off, the first few ((if that's upset you, if it's upsetting then its fine)) nah nah, the first weeks of treatment was difficult for him, he was put on steroids, he had a lot of pain, so his disease was quite a bony king of leukaemia, and it caused a lot of pain in his arms, his joints, his elbows, his knees, his hips…umm he had an allergic reaction to morphine, umm he couldn't have morphine but we didn't know that, he'd never had morphine before ((mmh)) so when they first started giving him morphine, he started hallucinating so it wasn't an allergic reaction, it was like a.. so he'd start halluci-, and he was also on deps [inaudible] to help with some of his pain and to see if it would help with some of his disease, and a combination of the deps? and the morphine had a terrible terrible effect, he woke up all scared, screaming, but he was also hallucinating a lot, like we were in a hospital room with white walls and he said that there was a man at a bus stop, he could see butterflies lying around…umm so they had to withdraw that very quickly and switch to alternatives but umm, the first week or so of treatment was very bad. He had…he deteriorated very quickly from when he was first admitted into hospital, he took a really quick downward turn, he needed a lot of blood product ((for the transplant bit?)) for the transplant bit, when he came in for transplant he had already had four doses of, four cycles of high dose chemo, so by the time we went in for transplant, he'd recovered from that last cycle, but he had started to loose a lot of weight so he started off at 25 kilos when he was diagnosed ((yeh)) and he went in at like 24 kilos six months later. So he started to loose a little bit of weight ((yeh)) he had no hair, he had no little bits of tuffed hair it was growing back, but he was basically happy, he was okay going in. I remember walking in for transplant, he did walk in, he got weighed, his height sort of stuff and he went in, and he was quite optimistic ((yeh)) we'd sold it up, I'd have to say we sold it as- this is going to cure you James, this is what we've got to do, lets just do it ((yeh)) cause we knew we had to get through and there was no point in being negative about it ((yeh)) umm, he knew the hospital that he was being treated at, he knew all the doctors, all the nurses there. leading up to transplant, about a week before transplant, he had to go in and have a new hickman line fitted, so he already had a hickman line but it was a double lumen? And we needed a triple lumen so he had to go in for that surgery. He'd had hickman lines before, they kept getting infected, they kept putting new ones in so that wasn't new- so he had a new hickman line put in but he had to, whilst he was asleep for that they also put, inserted an NG tube just to help with the process that he might need that later- he didn't want

I: what's-

Janet: umm, the nasal gastric

I: oh okay

Janet: and he hated those, he never had one during his treatment, he always avoided it, he managed to eat, and he never liked the look of them and he didn't want one ((mmh)) and so when they were gonna put one in while he was- they were saying "should we put it in while he's asleep, while he's having the hickman line procedure?" we said yeh lets do it that way round- and we did explain it to him before he went to sleep but we didn't explain it to him for weeks and weeks before, we didn't want to go on about it, we didn't want it to be this thing that was hanging over him so that really freaked him out and actually distressed him a lot- he wouldn't have given consent for an NG tube, put it that way ((yeh)) umm…but actually knowing that you are going into isolation ((mmh)) one of the reasons he didn't want it was he didn't like the way he looked to his friends with it ((uh)) and he wasn't going to see anybody with it cause he was in isolation, and that's how we sold it to him and said you're gonna be in there, we're the only ones who are going to see you, your brother wont even be allowed in until after a few days so- he, once he was in hospital and he started to get used to it, it sort of, that went down. Going into transplant I think when they are going into the hospital, he was worried about the isolation process, he was worried about how that was gonna to be, and we explained it wasn't for the first- I think they were allowed 10 days, the way that his condition ((oh okay)) so he had 10 days of being in isolation, equally we were really worried cause once you start conditioning the neutrophils fall down to the floor, and really we weren't having hundreds of people in, we had his brother come in and that was it ((and you cant stop can you?)) what do you do?

I: there's no chance to withdraw is there?

Janet: No and you know that you need that for the transplant ((yeh)) so you need it to work, umm and he went in, it was the beginning of October, so he his brother was around for that first bit

Bev talking about Misty

Bev (lines 163-246)

Interviewer: oh…so you know before she had the treatment and she was diagnosed, can you tell me a little bit about her and her character, and she just was as a child?

Bev: arh she was, umm…she was bright, umm just sparky. You know how some kids can just walk into a room and everyone notices them, and she could just talk to adults with ease, umm and she was playful and curious and just so much energy and so much zest for life, and yeh she is a totally different, you know the experience has profoundly changed her. Umm so umm… yeh yeh she was just, you know she was doing really well academically ((mmh)) umm so yeh she was just just a really good kid ((yeh)) just a, happy, sparkly and bright—

I: when you say its changed her like what do you mean? Can you just elaborate a little bit more on the differences in character--

Bev: uh she basically missed a year of school ((mmh)) umm and the went back pretty much part time, umm…it affected friendships [interviewee house phone ringing in background] umm, so like, just ignore that for now… umm it affected friendships, it umm…it affected her academically, so umm, the you know, a combination of missing a lot of school, umm the chemo and the radiation carries a risk of cognitive impairment so she works more slowly now ((yeh)) umm she suffers fatigue, umm so you know she's still predicted, she's doing her GCSEs next year, she's still predicted 5s and 6s

I: arrh that's good

Bev: yeh its good, it's not, it's not quite….[connection problem]

I: hi

Bev: sorry. It's not what we suspect we would have done just because she just works more slowly, so she has things like extra time in exams, and prompt her if she starts to lose focus, umm so it just requires a lot more effort on her part to get the work done. So we've tried really hard to keep life, make life as normal again for her. You know she's…you know we're really lucky in the sense that, a lot of children, most children, in fact all the other children that I've met who have been through transplant, have, not largely had the outcome that she's had. She's living a more or less normal life ((mm)) and she does have health issues, because you can't have radiation without having health issues, umm but umm these have been as minimal as I suspect they can be ((yeh)) so far. Umm so yeh, and yeh she's, I think socially she's suffered, she's a bit more awkward, umm you know her two closest friends are no longer around, you know, I think when you, I, I read an article a couple years back where a woman said, who had gone through a cancer diagnosis, said that it does show you who your friends are ((yeh)) because some people just can't cope, they just don't have the strength of character to stand by and support you. And I think that was, that was the same with Misty, some, some friends, bearing in mind they are kids, they just couldn't, you know, they were just not there ((yeh)) and yet other friend were, so she does have a couple of really strong friendships now, but you know the girl who was her best friend, her oldest friend is no longer around. Umm and and that's sad because she went through this awful thing and it's just sometimes it feels like she's almost being punished for it you know in a sense and she still sort of just suffering the consequences of what was an awful thing to go through ((of course)) truly awful, so—

I: what does she want to be when she grows up?

Bev: she well actually, before she got ill she really wanted to be a doctor ((yeh)) umm but I think the experience of spending so much time in hospital, and I think with just her growing an interest change, and also academically she's just not strong enough now, I think to kind of get those grades that you would need to get into medical school, she's just not umm that focused I think..and—

I: do you think it had a really big effect on her cognitively?

Bev: oh without a doubt I think it has, and I think it's a combination of things, I think it's a bit of cognitive impairment and I think its uh fatigue, its its missing so much school as well ((mm)) umm… you know, and I think emotionally and uh psychologically she's been impacted by it, and, so anyway she had a chat last week with the careers advisor because we've got to make a choice on sixth form colleges, umm later this year and so we don't know where she's going to go for sixth form college or what A-Levels she might want to do, but she's umm decided on which university course she's going to do (giggles) which is a really ((yeh)) [giggling] so we know where she's going in three years time. So she wants to study **** she likes them ((oh)) so she likes, unlike my son who is very just creative ((yeh)) but rubbish at maths and science, she's kind of an all-rounder, so she likes her sciences but she's doing art GCSE, she does music, she kind of straddles umm a lot of areas, where as my son is very much just arty, umm so she wanted to do something that would draw all these things together, and she just likes [those] things ((laughs)) so she's decided that this course 'up north' in all places, umm it's a bit of science, it's a bit of art and and [identifiable info] so its actually studying [identifiable info] so ((that's really good)) so when, but it's been really nice to give her a focus ((yeh)) you know, so umm she's just trying to decide now, what uh once we get past next week with the exams and things ((mmh)) and she's gotta you know just have a think at where she wants to go, what A-Levels or BTEC she wants to do ((yeh)) so you know its its progress and it feels normal, and normal is quite good ((yeh)) actually, so—

I: did it take long to get back to normal?

Bev: I think we're still trying ((after the transplant)), you know I think the thing is, nothing prepares you for children being that ill ((yeh)) nothing does, umm certainly not your own children, but I think being in an environment where you are not only with your own child, but other children, that, who are profoundly ill and who die…I've known children that have died and they are suffering in a way you just, just isn't fair ((yeh)) and it is profoundly traumatising. You know it's, it's even as adults, its its traumatising to spend, you know months of your life living in a children's cancer unit, because it's awful, you know, this is the worst…it can possibly be in some respects. You know these are children that were, you know, a month or two back just normal healthy kids, living normal lives then suddenly they are profoundly, terminally ill and it's just, it's just awful ((yeh)) but you know, they have such characters, such courage so that you know, and they are inspiring but you know, I think, I don't know, I think with 'Misty', because she changed, and… I don't know, I mean we've been quite fortunate in some respects because we've got quite strong family, and hubby and I are quite close, and you know, this kind of thing does make or break families, umm so…I don't know but, you, I think it just takes time, it's a new normal as they describe it and I can't say that four years after the event we're better or , it, because my daughter is, she has health conditions you know have to be managed and she's on medication, she will be for the rest of her life, you know, she won't be able to have children, she's you know on daily growth injections to help her grow, she's on HRT, to get her into puberty and will be for for another fifty odd years, so we have these things to contend with. You know she has, probably a little bit, cognitive impairment, you know she possibly has a little bit of brain damage from the radiation, she's got glandular damage you know, so it is different, it's not back to normal but its back to a different normal. So, that's sounds all really grim but sorry (giggles)

Cathy talking about Troy

Cathy (lines 575-635)

Interviewer: what was he like before the transplant? Compared to after?

Cathy: what do you mean?

I: what was he like as a child because he had sickle cell so grew up with-

Cathy: again he grew up with it, but as I said, he was alright, he didn't feel like he was different as such, ((yeh)) I think the time when he started to think mmh maybe, was when we started to go towards the bone marrow transplant ((yeh)) but overall he was, I mean he done piano lessons from about five, so he's always played the piano and he- it was something because I tried to think of a…a kind of extra-curricular activity he could do ((yeh)) which he could progress in, accomplish something in but it's not, sickle cell wont effect it ((yeh)) so he did try football, at three he went to try football but he didn't like it ((yeh)) so he plays football with his cousins but he never wanted to do football at training and ((yeh)) so he got piano and drama he started at six ((what grade is he?)) he's doing five now ((what piano?)) yeh cause he had that period where he was away from it, umm in the transplant so he's not as far as he would have been ((yeh)) but he done quite well in terms of getting back into it, but he's, before the transplant he was happy, he was umm…active, he didn't feel restricted, as far as I could ascertain cause I wanted to make sure he didn't feel restricted, so, but we were restricted though that's the thing ((yeh)) he didn't realise it, we were restricted but I don't think he felt he was restricted, because things like bedtime had to be a certain time for him to get enough rest to get through the next day ((ooh yeh)) so his bedtime 7:30-8 o'clock he had to be in bed ((yeh)) but he didn't question it he just knew that was bedtime. I'd always read to him before bed so he looked forward to bedtime ((yeh)) so we went through so many books because he really enjoyed that time ((yeh)) and it was nice for me cause I could go books I used to like when I was a child that I hadn't obviously picked up for years ((yeh)) I could- like Enid Blyton, all sorts of books-umm yeh so we had that was it and yeh he's, he's the only child but he's got a lot of cousins, we live quite close to them so, you know he'd see them at my mum's house, in fact that's another thing, a lot of the time they would come and stay with us ((yeh)) so that was good cause I could monitor how he was but then he's got everyone around him ((yeh)) so I'm quite close with my nephews- I have a lot more nephews than nieces, umm and my nieces, so from young they'd always be around me, so he's never had to miss out on family in that respect, and they you know, they all get a long really well ((yeh)) and they kind of really more, even now they're more brothers than cousins, they're quite close ((yeh)) but they've got their WhatsApp group for advice, the older one, the older one is twenty, twenty-one now, they think he's the big one ((yeh)) advises them and you know- but umm yeh so he's quite happy…umm he's quite happy. I think as a parent I'd probably might have went a bit over, like any birthday he had, I always made sure all the family were involved ((yeh)) he always had like quite big birthdays, umm so- even if it was just at home cooking and everyone comes- or once he went bowling, his class came ((yeh)) he went to- there was a local place near the school called [place] just a little fun place, it's so funny cause when you look at it it's not nothing great, but everyone, it was like everyone needed to have a birthday there ((yeh)) so, his fifth or sixth one was there—umm, so I feel he felt quite happy cause I- maybe I over compensated with things like- but it funny cause once, I remember I used to pick up things- I'd be in Tesco, see a little toy, pick up, pick it up for him- once he said to me, mum why did you buy me this-and he said 'it's not my birthday'- ((yeh)) and it made me think to myself, actually I'm not helping him with just buying him things ((yeh)) so then I realised that's not really helping ((I used to be like hat)) yeh so I realised, I learnt cause maybe I probably had some guilt as well, just having a child with sickle cell- you know ((yeh)) probably I had a bit of that as well…but then I realised, actually, you don't want to have a child that's spoilt, who doesn't know the value of things or doesn't know how to work or earn things- you know, so I had to learn- it was learning for me as well you know, so….umm yeh, so…he was quite happy I'd say, happy, quite content, umm

I; he managed his sickle cell well

Cathy: he managed his sickle cell well enough, because I think, if he had days where he was off for hospital it was always fun. So even now he remembers those days as quite fun, he really does, like even now with his GCSEs he say, I wish I could go back- he, he wants to go back ((yeh)) actually its weird- he doesn't actually remember the pain of ((before transplant)) yeh. Said 'Troy do you remember?' and he said 'to be honest mum because I think it was always, sickle crises, and once we sorted ourselves out we realised okay- I'd always make sure it wasn't just a day at home lounging- we're doing something, board game, something he can do ((yeh)) like if he's tired I'd read to him- he always- so he looks at it like in his lats mother's day card he said to me 'mum, happy mother's day, you know, if you want, go back to how you were in 2013' cause he's thinking before the transplant he had more of my attention ((yeh)) he was sick you know ((yeh)) but now he's a bit older- I'm still here obviously but 'yes Troy you can make your own drink', you can you know ((giggles)) your food don't have to come down on a tray ((yeh)) come upstairs, you know, little things like that ((yeh)) he was king treatment- and you know obviously it doesn't help me to be- help him or myself to be doing that cause he needs to learn to become more- trust me he does nothing, but he thinks small things are something ((yeh)) so a plate is a problem, just his plate, he doesn't even wash the dishes ((laughs)) and he should actually be like washing the dishes, just his plate and his stuff- yeh

Appendix 1: Participant information sheet

Please take time to read the following study information and complete the consent form on the following page. Thank you.

Study Information sheet

How do children and families decide to have a Stem Cell or Bone Marrow Transplant?

Invitation to take part in a research study

My name is Mary Bartlett. I am a researcher looking for families to take part in a study on children's and parent's experiences of blood and bone marrow transplants (BMT). The study will look at how families are informed and decide about having stem cell transplants and bone marrow transplants. I am looking for families who have been through the BMT process, and those who are currently going through it.

I have set out some information about the study below to help you decide if you would be interested in taking part or not.

Why is the study being done?

The study is being done to help doctors, nurses and other healthcare professionals understand what support children and families feel they need to help them make choices about their health and treatments.

Why have I been invited to take part?

You have been invited because you/your child are a patient or have been a patient on a BMT unit. You may also have been invited because you have a child who donated blood or marrow to a sibling who was or still is a patient on a BMT unit. I hope that around 50 families will take part in the study.

Do I have to take part?

You do not have to take part in the study if you do not want to. Participation is voluntary, and if you decide to take part now, you can change your mind at any time during the study and stop taking part.

What will happen to me if I take part?

If you choose to take part in the study you can either complete an online survey or I can meet/skype/telephone to talk to you and your family about your experiences of deciding to have a BMT, but you can pick what you want to help with. I am also interested in exploring children's experiences, so it would be great, if you and your child/children agree that they also take part in the study.

Will I be recorded and how will the recording be used?

With your consent, your interview/s will be recorded and the recordings will be deleted in 2020 after they have been written. Any information which identifies you will be changed at this point.

What are the possible disadvantages and risks of taking part?

I will be following the strict ethical guidelines of the British sociological association. Your participation in the study will be strictly confidential, no one will know if you have taken part. When I write up the findings you will be given a pseudonym (a different name) and all personal details of people, places and any identifiable markers will be changed for anonymity. I will be the only researcher who will have access to the interview recordings, individual answers to the survey and the notes/recordings. If you do decide that you would like to take part, you have the right to withdraw from the study at any point.

What are the possible benefits of taking part?

I hope that you enjoy taking part in the study. This research is aiming to improve the ways children and families make decisions together when it comes to deciding about their healthcare. So the benefits of taking part are that the information collected will be used to help healthcare professionals and researchers think about how to do this in the future.

What if something goes wrong?

If something goes wrong and you do not want to speak me about it, you can contact the principal researcher-. If you are not happy about how any concerns or complaints have been dealt with, you can contact the Chair of the UCL Research Ethics Committee –

Will my taking part in this study be kept confidential?

Yes, your participation will be kept confidential as far as professional guidelines allow. The only instance in which confidentiality will not be kept is if I am worried that someone is in danger of harm. If this is the case I will inform you before I speak to anyone else about it.

What will happen to the results of the research study?

I will write a report at the end of the study as part of my work to get a PhD qualification. I will also publish short reports about the findings to inform healthcare staff and other researchers.

How will information about me be kept secure?

University College London (UCL), where I work, will oversee how I collect and store your personal information, such as your name and age. This is done to ensure that your details are as safe as possible. If you have any concerns or questions about how your personal information is being used or stored you can contact UCL’s Data Protection Officer.

Your personal information will only be used for the research project and will only be seen by me. When I have finished the research I will remove your details from my records. If you join the research project you will be asked if you agree that I can use your personal data in this project by completing a consent form. To make sure your details stay private when I write up the research I will change your name and other details so that no one will know the research is about you.

If you want to know more about data protection and your rights you can contact the Information Commissioner’s Office (ICO). https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is organising and funding the research?

The research is being funded as part of collaboration between two universities - the UCL Institute of Education and Birkbeck. Ethical approval has been granted by UCL Institute of Education.

Appendix 2: Participant consent form

Interview Consent Form

Please complete this consent form after you have read the study information sheet.

Please read the following information carefully, if you have any questions, please do not hesitate to ask the researcher. By ticking the boxes on the right, you confirm that you are taking part in the study. If you DO NOT tick some boxes, you confirm that you will not be taking part in those parts of the study.

You will be given a copy of this consent form which can be read together with the study information sheet.

		Please tick or put a 'X'
	I confirm that I have read and understood the information about the study on the information sheet.	
1.	I agree to take part, and I know that I can withdraw my consent at any time during and after the study.	
2.	I understand that I can withdraw at any time, and this will not affect my medical treatment (if applicable) or my legal rights.	
3.	I understand that my participation in the study will be strictly confidential, and nobody will know that I have taken part.	

4.	I understand that I will be given a different name (pseudonym) throughout the research and all personal details of people, places and any identifiable markers will be changed so that the information cannot be linked back to me.	
5.	I understand that the researcher will be the only person who has access to the interview material in its raw (unchanged) form, and the notes and/or recordings.	
6.	I understand that the researcher may use the information collected from me at a later date for other research purposes.	
7.	I understand that once my personal information has been anonymised by the researcher, it will be used in work submitted for the researcher's academic qualification (PhD).	
8.	I understand that the data will be stored securely, and it will not be possible to identify me in the publications which will be as a result of this study.	
9.	I understand that I reserve the right to withdraw from the study at any point before the end of data collection in March 2020. The data collected from me will then be deleted if I request.	
10	I consent to the researcher using a tape recorder during the interviews. I understand that the recording will be stored securely and deleted after the submission of the thesis in 2021.	
11	I consent to the researcher revealing sensitive data (religious, medical and racial information) about me once	

	they have changed my name and any other data which could reveal my identity for the purpose of this study.	
12	Due to the sensitive nature of the research, I understand that at some points there may be some emotional effects; and that I reserve the right not to share any information that I do not want to talk about.	
13	I understand that there will be no financial benefits from this study, now or in the future.	
14	I understand that if I have any concerns I can speak to the researcher.	
15	I would like to receive a summary of the research once it is completed.	

____

Name of participant Date Signature

_______________________ _______________________

Researcher Date Signature

Study details:

Researcher: Mary Bartlett
Doctoral Researcher, Department of Social Science, University College London Institute of Education
10 Woburn Square, WC1H ONR
Ethical approval granted by UCL Institute of Education

Appendix 3: Invitation letter

Date as postmark

Re; How do children and families decide to have a Bone Marrow Transplant (BMT)?

Dear parent/guardian,

My name is Mary Bartlett, and I am looking for families to take part in my study about children's and parents' experiences of blood or bone marrow transplants, and how they made the choice to have the treatment. I am looking for volunteers who have already been through the BMT process or have children who have already started treatment. The goal is to help doctors, nurses and other adults understand what support children and families feel they need to help them make choices about their health and treatments.

If you choose to take part in the study I can either talk to you, your child and your family about your experiences of deciding to undergo/decline a BMT, or you can complete an online survey about your experiences instead, or both. You could also ask your child/children to answer some questions online too. But you can pick what you want to help with. I have attached an information sheet to let you know more about the study.

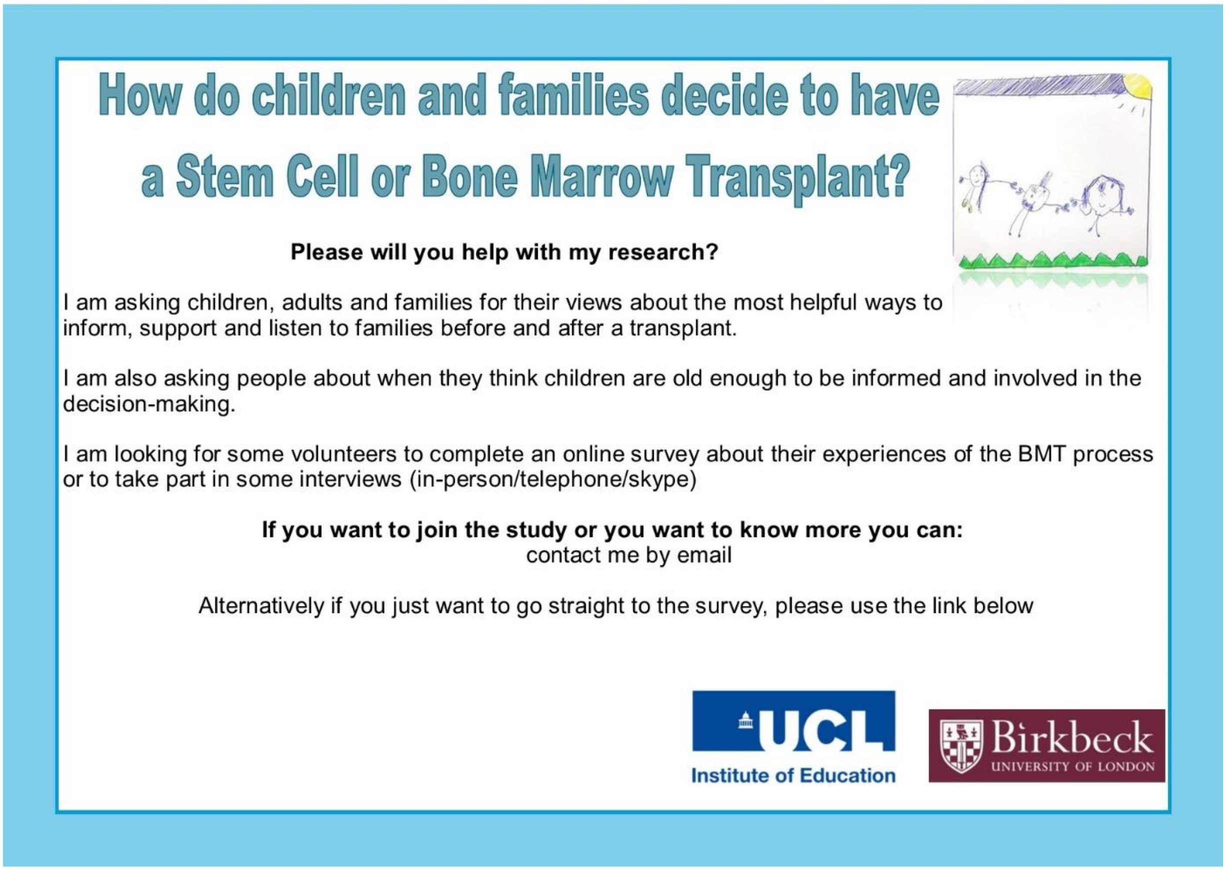
If you would like to take part in some or all of the study, please contact me via email on:
If your child/children would like to take part, please could you also let me know and I will give them a child-friendly copy of the information sheet.

If you have some questions about the study, please contact me on the email address above. I would like to thank you in advance for your time.

Yours faithfully,

Mary Bartlett
Doctoral Researcher,
Department of Social Science, Institute of Education University College London

Appendix 4: Study recruitment poster



How do children and families decide to have a Stem Cell or Bone Marrow Transplant?

Please will you help with my research?

I am asking children, adults and families for their views about the most helpful ways to inform, support and listen to families before and after a transplant.

I am also asking people about when they think children are old enough to be informed and involved in the decision-making.

I am looking for some volunteers to complete an online survey about their experiences of the BMT process or to take part in some interviews (in-person/telephone/skype)

If you want to join the study or you want to know more you can:
contact me by email

Alternatively if you just want to go straight to the survey, please use the link below

UCL Institute of Education

Birkbeck UNIVERSITY OF LONDON

Appendix 5: Interview schedule

Interview schedule for adult family members

(Say to all volunteers) This interview is about finding out how you came to the decision for your child to have/not have a stem cell or bone marrow transplant. I would like to find out what information you were given before you consented to treatment and what you thought about this information. You do not have to tell me everything and you can stop the interview at any time. (Get verbal agreement to questions below in red)

1. Have you been given an information sheet about the research?
2. Would you like continue with this interview?
3. Can I record you? (if yes then switch on the recorder)
4. If you want to stop at any time, please let me know.

Start interview:

Can you tell me a little about your/your child's illness, how it started and how you decided to first visit the doctor?

Can you tell me a little bit about 'CHILD'S NAME' before he/she was diagnosed? How were they as a character?

- What did you worry about before your child had the transplant?
- What did your referring doctor tell you about the transplant before you came to the BMT unit?
- Was your child involved in the decisions concerning the BMT?
- Did your child show that it was important for them to be a part of the decision-making process?
- Is your child old enough to decide whether or not they have the treatment?
- What age do you think children should be, to get involved in making decisions about their healthcare?

Last questions;

At what age do you believe a child has the competence to decide whether or not they have surgery?

Who do you think should be in charge of deciding whether or not a child has surgery, doctors, parents or the child?

Appendix 5a PPI feedback: October 2018

Review brief

Thank you for offering to provide your thoughts on this online survey. Please feel free to navigate through it any way you like. The answers will not be used for any part of the project. Your responses are only a guide for you to see how the survey is set out.

Did you find the survey easy to navigate through?

Were there any questions that were not clear?

Is there anything that you would change about the survey?

Could please you provide some further comments on the survey

Feedback and recommendations from Tom Bishop (Anthony Nolan Trust)

- Intro – due to their distance from the question, it's not clear that the Yes & No relate to the question: 'Do you agree to continue?'
- Start of survey – you may want to be more specific about the type of patient, e.g. 'Patient who has had a bone marrow transplant'
- Recommended change used, another field added to include patient waiting for BMT
- Would you like to continue with the survey? – this question seems unnecessary. And if you answer 'I would like more information' it simply repeats the question: 'Would you like to continue with the survey?'
- How long were you sick for before you came to the BMT unit? – maybe change 'sick' to 'unwell' in case respondents misinterpret 'sick' as 'vomiting'
- Change made to recommendation above
- Before your treatment, who did you live with at home? – maybe have this as a dropdown with options to make it easier for you to process e.g. family, partner, friends
- The above has been left as an open-ended questions as family dynamics can vary and multiple choices may not be able to give a clear picture. Children may also want to write about their pets.
- What did you find useful or not useful (good/bad) from the time you came for your first pre-BMT appointment until you went onto the ward for treatment? - To avoid confusion in the answers, I'd recommend splitting this into two questions: 'What did you find useful' and 'What did you find not useful'

- The above has been split into two questions
- Do you have another child who is a donor? – this question may be irrelevant to many respondents, so maybe re-word it as: ‘Was your donor your brother or sister?’ or even ‘Who was the donor?’ – if they don’t know, they can just answer ‘don’t know’. Question changed to who was your donor
- ‘Would you like to take part in an interview to talk more about some of the questions in this survey?’ – maybe reword this as ‘Would you be willing to take part…’ – this might be more persuasive.
- ‘I have agreed to be interviewed’ – to avoid confusion with the response ‘Yes’, maybe re-word this as ‘I have already agreed to be interviewed’. Changed as to the recommendations

Appendix 6: Online survey in Word version

Children's and Parents' consent to blood and bone marrow transplants

Q1 **How do families decide to have a Stem Cell or Bone Marrow Transplant?** **Study Information** **Invitation to take part in a research study** My name is Mary Bartlett. I am a researcher looking for families to take part in a study on children's and parent's experiences of blood and bone marrow transplants (BMT). The study will look at how +families are informed and decide about having stem cell transplants and bone marrow transplants. I am looking for families who have been through the BMT process, and those who are currently going through it. I have set out some information about the study below to help you decide if you would be interested in taking part or not.

Why is the study being done? The study is being done to help doctors, nurses and other healthcare professionals understand what support children and families feel they need to help them make choices about their health and treatments. **Why have I been invited to take part?** You have been invited because you/your child are a patient or have been a patient on a BMT unit. You may also have been invited because you have a child who donated blood or marrow to a sibling who was or still is a patient on a BMT unit. I hope that around 50 families will take part in the study. **Do I have to take part?** You do not have to take part in the study if you do not want to. Participation is voluntary, and if you decide to take part now, you can change your mind at any time during the study and stop taking part. **What will happen to me if I take part?** If you choose to take part in the study you can either complete an online survey or I can meet/skype/telephone to talk to you and your family about your experiences of deciding to have a BMT, but you can pick what you want to help with. I am also interested in exploring children's experiences, so it would be great, if you and your child/children agree that they also take part in the study. **Will I be recorded and how will the recording be used?** With your consent, your interview/s will be recorded and the recordings will be deleted in 2020 after they have been written. Any information which identifies you will be changed at this point. **What are the possible disadvantages and risks of taking part?** I will be following the strict ethical guidelines of the British sociological association. Your participation in the study will be strictly confidential, no one will know if you have taken part. When I write up the findings you will be given a pseudonym (a different name) and all personal details of people, places and any identifiable markers will be changed for anonymity. I will be the only researcher who will have access to the interview recordings, individual answers to the survey and the notes/recordings. If you do decide that you would like to take part, you have the right to withdraw from the study at any point. **What are the possible benefits of taking part?** I hope that you enjoy taking part in the study. This research is aiming to improve the ways children and families make decisions together when it comes to deciding about their healthcare. So the benefits of taking part are that the information collected will be used to help healthcare professionals and researchers think about how to do this in the future. **What if something goes wrong?** If something goes wrong and you do not want to speak me about it, you can contact the principal researcher. If you are not happy about how any concerns or complaints have been dealt with, you can contact the Chair of the UCL Research Ethics Committee **Will my taking part in this study be kept confidential?** Yes, your participation will be kept confidential as far as professional guidelines allow. The only instance in which confidentiality will not be kept is if I am worried that someone is in danger of harm. If this is the case I will inform you before I speak to anyone else about it. **What will happen to the results of the research study?** I will write a report at the end of the study as part of my work to get a PhD qualification. I will also publish short reports about the findings to inform healthcare staff and other researchers.

How will information about me be kept secure? University College London (UCL), where I work, will oversee how I collect and store your personal information, such as your name and age. This is done to ensure that your details are as safe as possible. If you have any concerns or questions about how your personal information is being used or stored you can contact UCL's Data Protection Officer. Your personal information will only be used for the research project and will only be seen by me. When I have finished the research I will remove your details from my records. If you join the research project you will be asked if you agree that I can use your personal data in this project by completing a consent form. To make sure your details stay private when I write up the research I will change your name and other details so that no one will know the research is about you. If you want to know more about data protection and your rights you can contact the Information Commissioner's Office (ICO). https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is organising and funding the research? The research is being funded as part of collaboration between two universities - the UCL Institute of Education and Birkbeck. Ethical approval has been granted by UCL Institute of Education.

Page Break

Q2 **Consent Form**

Thank you for thinking about this research. If you are willing to take part, please tick each box you are happy to agree with. If you do not agree, then please leave that box empty.

Q4 I confirm that I have read and understand all of the information on the previous page.

○ Yes (1)

○ No (2)

Q6 I know that in all reports about the research my name will be changed, so that no one reading the report will know I was in the research.

○ Yes (1)

○ No (2)

Q3 I agree to the researcher revealing sensitive data (religious, medical and racial information) about me once they have changed my name and any other data which could reveal my identity for the purpose of this study.

○ yes (1)

○ no (2)

Q5 I know that saying 'no' to this research or 'stop' will not affect my legal rights.

○ Yes (1)

○ No (2)

Q7 Do you agree to take part in this study?

○ Yes (1)

○ No (2)

Skip To: End of Survey If Do you agree to take part in this study? = No

Q8 Please type your name

____

Q11 Thank you for your time. This survey should take no longer than 20 minutes to finish.

Q12 Who is completing this survey? (if you have more than one child who had treatment or a child who donated to a sibling please could you complete a survey for each child)

○ Parent (1)

○ Carer (2)

Q13 What stage is your child at in their treatment?

☐ In-patient (on the ward) (1)

☐ Out-patient (living at home) (2)

☐ We have had the first consultation about treatment options (3)

☐ Child is/was a donor (4)

☐ Already had treatment (5)

☐ We declined treatment (6)

☐ Not sure (7)

☐ My child passed away (8)

Skip To: Q17 If What stage is your child at in their treatment? != We declined treatment

Q15 Would you be willing to be interviewed to discuss your decision of declining treatment?

○ Yes (1)

○ No (2)

○ Not applicable (3)

Skip To: Q17 If Would you be willing to be interviewed to discuss your decision of declining treatment? != Yes

Q16 If yes could you please leave a contact email or telephone number with your name, and I will be in touch to arrange a suitable time for the interview.

____

Q17 Are you completing this survey for another one of your children?

○ Yes (1)

○ No (2)

Q18 How old is your child?

____

Q19 What is your child's sex

○ Male (1)

○ Female (2)

○ Prefer not to say (3)

Q20 The following questions are about your child’s treatment What treatment did your child have? (Tick all that apply)

☐ Bone Marrow (1)

☐ Cord Blood (2)

☐ Not sure (3)

☐ Do not remember (4)

☐ They were a donor (5)

Q21 What did your child donate? If applicable

☐ Bone Marrow (1)

☐ Peripheral Blood (2)

☐ Cord Blood (3)

☐ Not sure (4)

☐ Do not remember (5)

☐ Not Applicable (6)

Q22 Do you know what type of stem cells your child was give?

☐ Autologous (own cells) (1)

☐ Matched unrelated (2)

☐ Mismatched unrelated (3)

☐ Matched sibling (4)

☐ Other matched related (5)

☐ Haploidentical (6)

☐ CART (7)

☐ Not sure (8)

☐ Other (9)

Q23 If other please give further information

____

Q24 Who was the donor?

☐ Brother (1)
☐ Sister (2)
☐ Mother (3)
☐ Father (4)
☐ Other family member (5)
☐ I don't know (6)
☐ Other (7)

Q25 If other, please give further information.

____

Q26 Who did your child donate to? (if applicable)

____

Q27 How many bone marrow transplants has your child had?

____

Q28 How many stem cell transplants has your child had?

____

Q29 How many times has your child donated bone marrow? (If applicable)

____

Q30 How many times has your child donated stem cells? (If applicable)

____

Q31 When you went into hospital (on the ward), who signed the consent form/s? (Tick all that apply)

☐ Doctor (1)

☐ Nurse (2)

☐ Parent (3)

☐ Carer (4)

☐ My child (5)

☐ Interpreter (6)

☐ Don't know (7)

☐ Don't remember (8)

Q32 Do you remember what the form/s were for?

Q33 Can you give a description of the side effects that your child had from the treatment?

Q34 How long did your child stay in hospital for?

○ They are still in hospital (1)

○ Less than 2 weeks (2)

○ 0-3 months (3)

○ 3-6 months (4)

○ More than 6 months (5)

○ Not sure (6)

○ Don't remember (7)

Q35 Do you know what illness the treatment was for?

○ Yes (1)

○ No (2)

Q36 What was the illness? (please write as much as possible about it)

____

Q37 What year was your child diagnosed with their illness?

____

Q38 How long was your child unwell for before they went to a BMT unit?

____

Q39 What was the reason for the treatment? Please write as much as possible about it

____

Q40 Has your child's entire medical care taken place at the same hospital? If not, could you say why?

____

Q41 When you first went to the BMT unit, did a doctor talk to your child about the treatment they were going to have?

○ Yes (1)

○ No (2)

○ Don't remember (3)

Q42 Did your child ask the doctors any questions?

○ Yes (1)

○ No (2)

○ Don't remember (3)

Q43 Do you remember the questions they asked? If so, could you please write some of them down?

____

Q44 Had you ever considered a stem cell/bone marrow transplant or the other treatment offered on the unit for your child, before you were told about it?

○ Yes (1)

○ No (2)

○ Not sure (3)

Q45 In what format did you receive further information about the treatment from the hospital before you or your family made a decision? (Tick all that apply)

☐ Consultation letter (1)

☐ Booklet about BMT (2)

☐ Leaflet (3)

☐ Telephone call from hospital team (4)

☐ Video (link) (5)

☐ Do not remember (6)

☐ Other (7)

Q46 If other please state

____

Q47 How long did you wait to come onto the hospital ward after the first consultation about the treatment?

____

Q48 Did you ask any questions about the procedure when your child was admitted onto the ward?

○ Yes (1)

○ No (2)

○ I don't remember (3)

Q49 If yes, what did you ask about?

____

Q50 Which of these side effects were you told about? (Tick all that apply)

☐ Infection (1)
☐ Blood product support (2)
☐ Graft v Host disease (GvHD) (3)
☐ Toxicity (e.g. Veno-Occlusive Disease) (4)
☐ Rejection/Graft Failure (5)
☐ Hearing (6)
☐ 2nd Malignancy (7)
☐ Cataracts (8)
☐ Pneumonitis (9)
☐ Endocrine (10)
☐ Fertility and Growth (11)
☐ Drug Toxicity (12)
☐ Neuropsychometric (13)
☐ I don't remember (14)

Q51 How did you find the process of giving consent for your child to have/ not have treatment?

____

Q52 Who talked to your child the most about what the treatment was going to be like for them?

____

Q53 What did you NOT find useful from the time you went for the first pre-treatment/BMT appointment until you went onto the ward for treatment?

____

Q54 Was the treatment what you expected? Please write a little about your answer.

____

Q56 Looking back at the whole experience of treatment, did you want your child/children to have the treatment and why?

____

Q57 *There is no right or wrong answer to the next question** What age do you think that children are able to give written consent (signing a form) for treatment on a BMT unit? You can give a reason if you wish.

____

Q58 Did you have your child's reproductive cells preserved?

○ Yes (1)

○ No (2)

○ It was not offered (3)

○ I don't remember (4)

Q59 Does your child go to school when they are not in hospital?

○ Yes (1)

○ No (2)

○ Sometimes (3)

○ Home schooled (4)

○ Not applicable (5)

Q60 What year are they in? (leave blank if they are not in school)

____

Q61 How many children live in your home?

____

Q62 What borough do you live in?

____

Q63 What is your current marital status?

- ○ Single (1)
- ○ In a relationship (2)
- ○ Cohabiting (3)
- ○ Married (4)
- ○ Divorced (5)
- ○ Widowed (6)
- ○ Prefer not to say (7)

Q64 What is your current occupation (or most recent occupation in the last 12 months)? Tick all that apply

- ○ Employed (full time) (1)
- ○ Employed (Part time) (2)
- ○ Student (3)
- ○ Unemployed (4)
- ○ Retired (5)
- ○ self-employed (6)
- ○ Homemaker (7)
- ○ Full time parent (8)
- ○ part time parent (9)
- ○ volunteer (10)
- ○ prefer not to say (11)

Q65 What is your job title?

____

Q66 What is your ethnicity?

○ White (1)

○ Mixed/ multiple ethnic group (2)

○ Asian/ Asian British (3)

○ Black/ African/ Caribbean/ Black British (4)

○ Other ethnic group (5)

○ Prefer not to say (6)

Q67 If other please state

____

Q68 What is your sex?

○ Male (1)

○ Female (2)

○ Prefer not to say (3)

Q69 How old are you?

____

Q70 Would you be willing to take part in an interview to talk more about some of the questions in this survey?

○ Yes (1)

○ No (2)

○ I have already had an interview (3)

○ I have already agreed to be interviewed (4)

Q71 If you want to be interviewed, could you leave a contact email or telephone number with your name, and I will be in touch to arrange a suitable time for the interview.

____

Q73 This section asks you, the parent/carer about your decision to consent for your child to undergo a treatment protocol or a research trial protocol.

*** Please pick an answer from each statement which is close to your opinion about the decision**

	Strongly Disagree (1)	Disagree (2)	Somewhat disagree (3)	Somewhat agree (4)	Agree (5)	Strongly Agree (6)
I was powerless in the face of this decision (1)	○	○	○	○	○	○
Someone took this decision away from me (2)	○	○	○	○	○	○
I made this decision (3)	○	○	○	○	○	○
I was passive in the face of this decision (4)	○	○	○	○	○	○
The decision about the protocol was inappropriately influenced by others (5)	○	○	○	○	○	○
I was not in control of this decision (6)	○	○	○	○	○	○
Others made this decision against my wishes (7)	○	○	○	○	○	○
I was not the one to choose (8)	○	○	○	○	○	○
The decision was up to me (9)	○	○	○	○	○	○

Q72 Thank you very much for your time in completing this survey. The results will be used to form part of a PhD thesis.

Appendix 7: Bloomsbury research protocol

Research Protocol in the application for the Bloomsbury PhD studentship October 2016
By Prof Priscilla Alderson and Dr Katy Sutcliffe, Department of Social Science UCL
and Prof Susan James, Department of Philosophy, Birkbeck College.

2.1 Project Title

Children's and parents' informed and voluntary consent to major medical and surgical treatment

2.2 Description of research project and references (up to 4 key references)
Please give a full description of the proposed project, outlining its rationale, aims, objectives, proposed methodology, significance, timescale, outcomes and plans for dissemination. Do not attach additional material in reply to this question. Please note that the maximum length of the project description should not exceed 1,000 words and the font size used should ensure that details are clearly legible (e.g., 12pt. type).

Rationale. Patients' informed voluntary consent to major treatment is vital: legally, to avoid litigation by non-consenting patients for battery or negligence; clinically, to observe agreed high professional standards; ethically, to respect patients as persons; and therapeutically, to promote more effective care by encouraging patients' questions, willing informed cooperation with treatment, and trust in its efficacy.

Questions arise about how far children can and should be informed and involved in major decision-making. In English law, consent to treatment can be given by children <16 years if they are assessed as 'Gillick competent': having 'sufficient understanding and intelligence to understand fully what is proposed' and 'sufficient discretion to enable [them] to make a wise choice'.

UK-led respect for Gillick competent minors' consent is undermined by US-and EC-led concepts of assent, when patients aged up to 18-years may not necessarily be informed or consulted. Medical and ethics journals debate confusions about current law and guidance on children's consent, which further complicate the great challenge for clinicians and parents: to inform and involve child patients respectfully and supportively.

Parents', children's and clinicians' reported views on the age of competence to give consent/refusal range widely, from 21-years downwards (1). Heart-lung transplant teams, for example, tend to wait until the informed child aged from about 6-years is willing, in order to avoid imposing treatment on a resisting child (1). Effective care for young children with diabetes depends on their informed involvement (2). However, respect for children's consent is controversial. Some experts ignore the views of all patients aged under-18-years (3). Others, concerned about clinicians' current confusion, highlight 'the need for a comprehensive review of legal policy and practice in this area' (4).

Aims of the interdisciplinary study
to clarify philosophical, legal and clinical confusions around children's consent;

to provide evidence of the views and experiences of a range of young patients and adults on effective and less effective methods of sharing decision-making;
to study degrees of children's and parents' sharing of information and decision-making;
to reduce children's suffering from fear, ignorance and coercion;
to promote respect for their informed voluntary involvement as far as each child prefers;
to discover the different ages when children and adults believe that children are as competent as their parents to consent to major medical treatment, or refuse it.

Objectives and proposed methodology

Supervisors will:
support the doctoral student's critical interdisciplinary literature review and ethical research;
work with the student on research design, theories, methods, analysis and reports, while respecting his/her ownership of original work;
co-author journal papers.

Partly working with supervisors, the student will conduct:
an interdisciplinary literature review informed by philosophical insights and the latest advances in research synthesis methods;
ethnographic observations in wards and clinics of how staff, parents and young patients negotiate major decisions;
semi-structured Interviews with 40 children aged 6- to 15-years having major treatment, their parents and 20 healthcare professionals;
critical interdisciplinary data analysis informed by social science and philosophy.

The student will:
promote high ethical standards in research methods, topics and aims;
work with two groups of advisers, young patients and parents;
create a project website, and moderate anonymised discussions among young patients and adults on effective, shared, major healthcare decision-making;
produce a thesis, co-write conference and journal papers, and disseminate findings through professional and family networks.

The three co-supervisors each specialise in some of these areas.

Significance

Collaboration between UCL-IOE sociology and Birkbeck philosophy supervisors will deepen inter-related theoretical and practical understandings of minors' consent. The research will examine and clarify views and experiences of what does/does not 'work well' to address young patients' hopes and fears, their autonomy and preferences, to promote shared decision-making, and reduce confusions in present law, ethics and practice.

The disseminated analysis and evidence will inform families, and also professionals working in relevant medical, nursing, legal, ethics and policy specialties.

References

1 Alderson P. (1993) *Children's Consent to Surgery*, Open University Press, plus many widely-cited papers.

2 Alderson P, Sutcliffe K, Curtis K. (2006) Children as partners with adults in their medical care, *Archives of Disease in Childhood*, 91: 300-303.

3 Gillam L. (2016) The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child, *Clinical Ethics*, 11: 1-8.

4 Brierley J and Larcher V. (2016) Adolescent autonomy revisited: clinicians need clearer guidance, *J Med Ethics*, 6, oi:10.1136/nedethics-2014-10256