A grounded theory study of dream fulfilment in children and young people with life-threatening and long-term conditions and their families.

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Abstract

Background: This thesis examines the impact of dream or wish fulfilment on seriously ill children and their families. Dream or wish fulfilment is operationalised as the actualisation of a seriously ill child's wish by a charity that provides desired experiences. Anecdotal reports suggest that the experience of having a dream or a wish fulfilled can provide seriously ill children and their families with a sense of hope and time away from illness. However, little empirical research has been conducted in this area.

This thesis reports the impact of dream fulfilment on the psychosocial well-being of ill children and their families. The research questions are: what is the experience of having a dream fulfilled for the child? What is the impact of dream fulfilment on the family?

Methods: A constructivist grounded theory methodology was adopted, using theoretical sampling to recruit families from across the UK. Twenty-one families were interviewed, including 15 dream recipients, 8 siblings, and 24 parents. Analysis followed the grounded theory methodology of simultaneous data collection and development of theory, resulting in analytic interpretations of participants' worlds.

Results and Conclusions: This thesis reports for the first time a theory and accompanying theoretical model, that explain the impact of dream fulfilment on families' lives. The generated theory suggests that dream fulfilment was conceptualised as an alternative milestone in seriously ill children and their families' lives. Additionally, the dream experience shifted perceptions of illness by providing instances and experiences where illness did not underscore family life. Findings additionally suggest that the dream fulfilment process provided families with ill children, who often felt excluded and stigmatised from services, with a period of much needed support. Findings also highlight the unintended negative consequences of dream fulfilment. Implications for Dreams Come True, and other dream and wish fulfilment organisations are discussed.

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Chapter 1: Introduction

The aim of this grounded theory study was to generate a theory that would explain the impact of dream fulfilment on the lives of children with life-threatening and long-term conditions and their families. Dream fulfilment in the context of this thesis is defined as the actualisation of an ill child's wish by a charity that provides desired experiences to seriously ill children and young people. The thesis examines the impact of one dream fulfilment charity's service in particular, Dreams Come True (DCT).

Throughout this thesis, the word dream, unless stated otherwise, will be intended to mean dream in the context described above, the actualisation of an ill child's desired wish. Dream may be used interchangeably with wish. This is because resulting theory may be of use to both dream and wish fulfilment organisations within the third sector. Both dream and wish fulfilment interventions imply experiences (for example a trip to Disneyland) for which children with life-threatening and long-term conditions are eligible, as a result of their condition.

Although I look exclusively at the impact of DCT's dream fulfilment in this study, organisations providing dreams and wishes to seriously ill children and young people exist worldwide. Examples of established charities around the world are, Make a Wish (International), The Rainbow Connection (USA) and Dreams Take Flight (Canada). The experiences of dream and wish fulfilment provided by these third sector organisations are, anecdotally, considered positive.

DCT, the charity whose work I focus on in this thesis, report that their intervention provides a positive focus for families with seriously ill children (www.dreamscometrue.uk.com). Similarly, Make a Wish describe their wish intervention as having a transformational, distracting and normalizing impact on the children and families they work with (www.makeawish.org). However, the impact of such charities has rarely been examined.

Prior to beginning this present study Ewing (2007) was the only researcher to have conducted an academic study on the impact of wish fulfilment on ill children. Ewing (2007) conducted a hermeneutic study analysing children's drawings of the wishes they had previously experienced. Ewing's (2007) findings suggest that wish fulfilment provided ill children and young people with an experience that balanced feelings of sadness and

worry with hope and inclusion. Although Ewing's (2007) study was insightful, further research into the phenomenon of dream and wish fulfilment, and its impact on the wider family, was lacking.

During the course of this study, two further pieces of research were published, exploring the role and impact of dream and wish fulfilment (Darlington, Heule and Passchier, 2013; Schilling and Sarigiani, 2014). Both studies examined wish fulfilment from a parental, or adult perspective. Darlington et al (2013) looked at parents' perception of the impact of wish fulfilment and Schilling and Sarigiani (2014) explored caregiver perceptions of wish fulfilment. Both studies found that wish fulfilment was helpful in providing something to hope for and providing memories in bereavement. These studies are discussed in more detail later in the thesis.

Despite Darlington et al (2013) and Schilling and Sarigiani (2014) contributing to knowledge on the impact of wish fulfilment, in-depth understandings of the impact on children and their families were still lacking. Darlington et al (2013) and Schilling and Sarigiani (2014) conceptualised wish fulfilment from an adult perspective using surveys. Each study also examined the impact of wish fulfilment on families with children and young people with life-threatening conditions. My thesis encompasses the views of children and young people as dream recipients, siblings, and parents, thus uncovering the impact of the dream intervention on family systems. My thesis also examines the impact of dream fulfilment on children and young people with both long-term and life-threatening conditions. Grounded theory methods had additionally not yet been utilised to examine dream or wish fulfilment.

As such, there was an absence of theory that conceptualised dream or wish fulfilment's impact on both children with life-threatening and long-term conditions and their family members. This thesis works to address some of the weaknesses in current knowledge of the impact of dream or wish fulfilment. It strengthens understanding by including children and young people's voices from in- depth, qualitative interviews and examines dream and wish fulfilment's impact on the wider family.

The additional understanding my grounded theory of dream fulfilment brings to the wider field of dream and wish fulfilment is important. A greater understanding of dream and wish fulfilment's impact is important in part, because of the spending power of the dream and wish fulfilment sector. Dream and wish fulfilment organisations both raise and spend

hundreds of millions of pounds every year. Make a Wish America has revenue of 265 million dollars. Within the UK, Make a Wish's revenue is upwards of seven million pounds. DCT additionally make upwards of one millions pounds per year.

Although it is not the purpose of this thesis to make recommendations to the practice of dream and wish fulfilment organisations, it does make sense to understand as fully as possible the impact that an industry of this size has on ill children and family members' lives. The thesis presents a theoretical model of the dream fulfilment process, and also uncovers unintentional negative impacts of the dream fulfilment experience. Data such as this is important, as although anecdotal reports suggest that dreams and wishes are helpful, evidence underpinning the work of the sector is lacking.

This grounded theory study thus evaluates the impact of one dream fulfilment organisation, DCT. I present a grounded theory of dream fulfilment that, it is hoped, will be useful to DCT and to the wider dream and wish fulfilment sector. The remainder of this chapter presents an introduction to dreams and wishes, my research questions, and a note on the structure of the thesis.

1.1 On dreams and wishes

In evaluating the impact of a service, this study looks more broadly at the importance of dreams and wishes. Therefore, it is helpful to briefly examine the importance of dreams and wishes historically and look at how dreams and wishes are conceptualised in society today.

The concepts of dreams and wishes, as aspirations, ambitions or hoped for experiences appear across history, and have influenced much art, music and writing over centuries. I subsequently present a range of examples of the role of dreams and wishes throughout history and across societies so as to add context to my study of the impact of dream fulfilment. As the literature on dreams and wishes is wide-ranging, I look to a small subset of examples from the literature so as to highlight the relevance of dreams and wishes over societies and time.

In Roman and Greek mythology heroes and monsters were conceived by the deities (Evslin, 1976), and represented by stars and planets. Wishing in myths such as those originating in ancient Greece was about appealing to these gods, who could affect the

weather and the tides. Wishing on a star is a remaining superstition emerging from these times. The superstition of wishing on a star originated around AD 130 when astronomer Ptolemy, wrote that the Gods occasionally peer down at the earth from between the spheres, where stars could sometimes slip out of this gap, thus becoming visible as shooting or falling stars. Wishes were made when individuals saw these shooting or falling stars as it was believed that the gods tended to be more receptive to wishes made during these times (Mikalson, 2009).

Many Germanic folk stories written by Jacob and Wilhelm Grimm (1812) also focus on the wish, with such stories entitled, 'The Wishing Table' and 'The Three Wishes'. McGlathery (1991), writing specifically on the stories of the brothers' Grimm, suggests that narrative folklore texts have human fantasy and imagination, as dreams do. He suggests that fairy-tales, such as those written by Jacob and Wilhelm Grimm (1812) deal with a repression of fear and a world of wish-fulfilment, and writes that perhaps fairy tales such as Grimm's have no other mission than to make us forget everyday reality, with its cares and problems (McGlathery, 1991, 146).

Dreams and wishes continue to be popular themes in stories contained in children's literature and film. From Enid Blyton's 'The Wishing Chair' (1985), to Disney's popular film 'Frozen,' wishes and dreams are notable and important themes in children's media. Wishes and dreams are additionally concepts occurring in adult culture, with attractions such as the Trevi Fountain in Italy drawing millions to tourists yearly to throw coins in its water and make wishes.

Buonfino and Guglielmi's (2009) research for UK political thinktank DEMOS on wishful thinking additionally suggests that dreams and wishes are important in adults' lives. Buonfino and Guglielmi (2009) interviewed individuals of different ages from around the UK. The researchers' (2009) work focused on practical, or real-life wishful thinking, rather than the magical wishes portrayed by Disney. Findings suggest that participants' wishes were generally for a better world, for good relationships and for participants and their families to be happy and healthy. Buonfino and Guglielmi (2009) thus conceptualise wishful thinking as a feeling of solace when in difficulty, a way of imagining new alternatives, and as a way of coping with the stresses of everyday life.

Although the wishes discussed within Buonfino and Guglielmi's (2009) study are practical in nature, and could perhaps be conceptualised as hopes rather than wishes, hope being

defined as, "the process of thinking about one's goals, along with the motivation to move toward (agency) and the ways to achieve (pathways) those goals" (Snyder, 1995, 355), Buonfino and Guglielmi's (2009) research suggests that individuals still wish or dream about possible aspirational or positive experiences in the future.

There is a larger discussion to be had on the differences between hope, and dreams and wishes and how such concepts are similar or different to the concept of dream fulfilment in this study. However, this empirical study evaluating a charity's impact is not the place for such discussions and I move on to discussing the details of my research question and methodology. The next section of my thesis presents my research question, and shows where this study is positioned within a broader search for understanding of dream fulfilment.

1.2 The research questions

My research questions were, what is the impact of dream fulfilment on children and young people with life-threatening and long-term conditions? What is the impact of the dream on the ill child's family?

The purpose of the study was to understand the experience of having a dream fulfilled by children and young people with life-threatening and long-term conditions, and their family members. This study thus looked to conceptualise dream fulfilment using grounded theory methods, and explore its impact on ill children and young people and their families.

The research questions are broad, due to the lack of literature on the impact or experience of dream or wish fulfilment. Although anecdotal reports emerging from the charity suggest that the experience of having a personal dream fulfilled was helpful, as discussed, there were few published studies in the field at this study's onset. Morse and Field (1995) write that in situations such as this, when little is known about a phenomenon, qualitative methods should be used. Qualitative methods are open and generative in nature, allowing for the exploration of issues without advance prescription of their construction or meaning (Denzin and Lincoln, 2000). As such, my research question is also open, allowing me to develop understanding based on issues important to participants, rather than beginning with a more defined, or narrower research question.

Related to the discussion of existing knowledge is Bryman's (1984) justification for the use of a qualitative methodology. Bryman's (1984) 'qualitative research as preparation' rationale focuses on the unstructured nature of qualitative research and how qualitative research's lack of specified hypotheses is likely to stimulate new avenues of research that quantitative methods might not capture. In this sense, qualitative research is used as a precursor to the use of a framework associated with a natural science approach, i.e. quantitative methodology.

Bryman's (1984) argument about qualitative research as preparation in part reflects this study's aims. Although this project looked to conceptualise dream fulfilment and provide insight into how dream fulfilment is experienced by charity users, this PhD is also positioned as the first phase of a larger project that will quantitatively measure the impact of dream fulfilment, using the findings discovered during this initial qualitative phase.

Thus, the current study generates and presents a theory that could be used by DCT, or another dream or wish fulfilment organisation to further examine constructs perceived to be important by service users of such organisations. While there is some research that supports current understanding of the impact of dream and wish fulfilment, there is at present no theory conceptualising the impact of dream and wish fulfilment organisations on children and families. This study was therefore conducted to develop an understanding of dream fulfilment that could be used in future studies that look to quantitatively measure the impact of dream fulfilment on ill children and families.

1.3 The structure of the thesis

It is useful to note, prior to continuing with my introduction that this thesis is structured slightly differently to that of a traditional thesis. This is due to my use of the grounded theory method. Utilising a grounded theory method means that I do not engage in a detailed examination of the literature prior to presenting my methodology or findings chapters. Rather, I use my findings to generate a discussion of the relevant literature, which is presented later in the thesis. A detailed discussion of the use of the literature in grounded theory research is outlined in section 3.8. Prior to moving on to discussing methodology, I provide a brief overview of the children who use the charity whose dream fulfilment intervention is the basis of this thesis.

1.4 The characteristics of families using Dreams Come True

In this section, I provide an overview of the types of dreams that have been requested by children and families using DCT in the last 20 years. I additionally examine the characteristics of families who used the charity, such as gender of the dream recipient and what conditions children have. In presenting this information I aim to provide a broader understanding of what Dreams Come True do, show the reader who might be using the service, and more generally, provide insight into what the charity's service looks like, and how it is used.

The data I present here are for context only. In accordance with grounded theory methodology, my sampling strategy was not based on service user characteristics. However, the service user data presented in this section is useful in understanding where my findings sit, and the wider context surrounding them. So as to provide this background information, I analysed data from DCT's database over a 20-year period, February 1994 – February 2014. Over this 20-year period, the charity completed 4,407 dream requests. Nineteen records were excluded from this total, due to missing data (on child's health condition, age or type of dream fulfilled, for example). My findings are described below.

1.4.1 Gender

Male children received a dream more frequently than female children (55% male; 40% female; 5% not recorded).

1.4.2 Age of child

For the purposes of analysis, the child's age was categorised into five groups: less than one year old, one to five years old, six to ten years old, eleven to fifteen years old, sixteen to twenty years old, and twenty-one years old and older. The eleven to fifteen age group was the most common age to have a dream fulfilled (N=1214, 28%), followed by the six to ten age group (N=1212, 27%). Sixteen children across this sample had a dream fulfilled at younger than one-year-old. Mean, mode and median age at dream fulfilment were calculated as twelve, 8 and twelve respectively. Figure 1 shows this below.
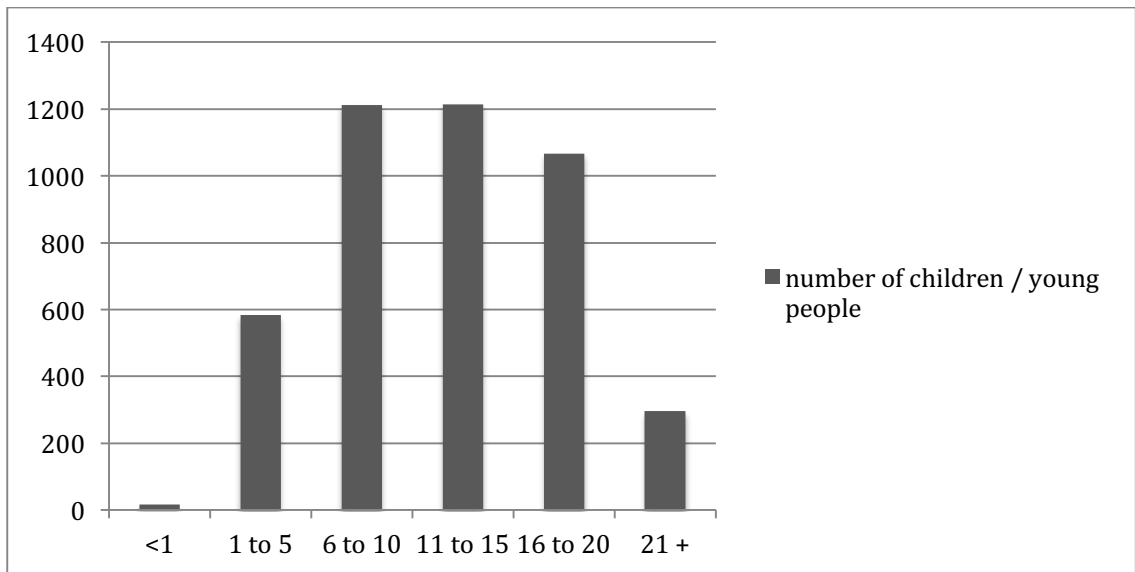
Figure 1. Age of dream recipients

1.4.3 Health condition of child

The Association of Children's Hospice and Royal College of Physicians and Child Health (ACT/RCPCH) categories were used to classify the children's health conditions. Rather than providing an exhaustive list of diagnoses, this system describes four archetypes of disease (Wood, Simpson, Barnes and Hain 2010) and provides a concise way of conceptualising the diagnosis and prognosis of conditions:

1. Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during phases of prognostic uncertainty and when treatment fails.
2. Conditions in which there may be long phases of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible.
3. Progressive conditions without curative treatment options, in which treatment is exclusively palliative and may commonly, extend over many years.
4. Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not considered progressive.

A fifth category was added for this audit to accommodate referrals whose diagnosis was unclear from the records, or where the condition was not life-threatening. This fifth category included conditions such as viral meningitis (which is not usually considered life-threatening). It also became clear that some conditions, either due to errors in recording, or being so rare that it was difficult to find any information on them would not fit with the ACT/RCPCH system either, thus being entered in a new category five.

Five hundred and thirty-one different conditions (including those with unclear diagnoses) affected the 4,388 children and young people who used this charity from February 1994 – February 2014. These conditions were mapped onto the previously described ACT/RCPCH categories. Table 1 shows the numbers of children affected by conditions within each category, and the percentage of children and young people in each ACT/RCPCH category.

Condition category	N (%)
1: life-threatening but treatable	1292 (29%)
2: intensive treatment, anticipated premature death	547 (13%)
3: progressive without cure	216 (5%)
4: neuro – disability, untreatable	1085 (25%)
5: Miscellaneous	1248 (28%)

Table 1. Condition of dream recipients

Category one was primarily comprised of children with cancer (N = 1,062; 81% of category one; 24% of the total number of ill children). Muscular dystrophy (N=326, 59% of category two; 7% of the total number of ill children) and cystic fibrosis (N=163, 29% of category two; 4% of the total number of ill children) were two of the most common conditions making up category two. Category three (N= 216; 5%) was made up of conditions such as Rett syndrome (N= 41, 19% of category three; 1% of the total number of ill children) and Batten disease (N= 29, 13% of category three; <1% of the total number of ill children). Category four was comprised of children and young people with conditions such as cerebral palsy (N= 637; 50% of category four; 14% of the total number of ill children). Category five contained a mixture of diagnoses and accounted for 28% of the whole sample (N = 1248), examples include autism (N= 177, 14% of category five; 4% of the total number of ill children) and Down's syndrome (N= 146, 12% of category five; 3%

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of the total number of ill children). Eight children and young people had no diagnosis specified.

1.4.4 Type of dream

Dreams were categorised into Disneyland trips (France or USA), holidays (Europe, UK and worldwide), specialist equipment (for example, adapted swings, electronic eye gaze computers, electric wheelchairs, and sensory equipment) and 'meet a hero' dreams (for example, meeting an actor or sporting hero). These categories were constructed by the dream-fulfilling organisation as a way of classifying dreams. The most common requests were: equipment (N=1261, 29%) and trips to Disneyland (n=1214; 28%). Non-Disneyland holiday experiences (N=1033; 23 %) were the next most common type of dream fulfilled. Twenty percent (N=880) of children and young people received a dream of meeting a celebrity in a meet a hero dream.

1.4.5 Deprivation

A score of deprivation was assigned to each record on the basis of postal code. Deprivation was calculated using the indices of deprivation measures from each of the UK's four countries (English Indices of Deprivation, the Welsh Index of Multiple Deprivation, the Northern Ireland Multiple Deprivation Measure and the Scottish Index of Multiple Deprivation). The indices of deprivation are measures of deprivation for every lower layer super output area (LSOA) and local authority area in England, Northern Ireland, Scotland and Wales and are based on indicators such as employment, crime and health (UK Data Service, 2012). Although the four indices are not based on identical criteria they offer broad comparators. These indices were split into ranked quintiles (1 being the geographical area with highest deprivation and 5 being the lowest). Analysis identified that those using the service were most likely to live in the least deprived fifth of the United Kingdom (N=1563, 38%). Across the sample 4% (N=149) of children and young people receiving the service lived in geographical areas with most deprivation (see Table 2). Postcodes that could not be assigned a deprivation code were excluded from the analysis of deprivation data (N=328).

Deprivation quintile	N (%)
5 (least deprived)	1563 (38%)
4	1208 (30%)
3	779 (19%)
2	361 (9%)
1 (most deprived)	149 (4%)

Table 2. Dream recipients and deprivation.

The data presented here are interesting, in that most families who used the charity lived in the least deprived areas of the UK. Further analysis could be conducted to facilitate further insights. However, analysis of the charity database is not the purpose of this study, with the data presented in this section on gender, age, condition and deprivation for context only. The data provide insight into the types of dreams provided by DCT, and an overview of the characteristics of families using the organisation. I now move on to explain the research process undertaken in this study, and the subsequent structure of the reminder of the thesis.

Prior to discussing methodology, I briefly discuss my position as an embedded researcher with dream fulfilment charity DCT, and some of the challenges this presented.

1.4.6 On being an embedded researcher

As discussed, this study was funded by children's charity DCT. DCT had not previously been involved in conducting or funding research. As part of my funding arrangement, I worked one day per week as part of the organisation. As such, I spent time with team members, occasionally sitting in on fundraising meetings, writing charity grant applications, and hearing about past and future dreams.

As much as I enjoyed this aspect of my PhD, my attachment to the funder had two implications for myself as a researcher. Firstly, many family members perceived me to work for DCT, and secondly, my relationship with the organisation meant that I felt under a certain amount of pressure to produce findings which would cast the funder in a positive light.

My attachment to DCT was useful in recruitment, in that family members trusted the organisation, which meant that I recruited relatively easily. However, perhaps as a result of my affiliation with the charity, I found that some family members might have not understood my position as an objective researcher. Although my information sheet made my position clear, and I clarified with families my objective status as a researcher as much as possible, it was my perception that some families still perceived me to work for Dreams Come True. Although this was at times frustrating, it was not the case with all families who participated.

Additionally, as an embedded researcher within DCT I sometimes felt under pressure to produce positive findings. I was particularly aware of the charity's sensitivity to findings not perceived as positive. On occasion this felt difficult to manage.

These implications will be discussed further in my reflections section (section 10.3.2) but it is useful to highlight them here, so as to be transparent about the nature of my relationship with DCT and its potential impact on this thesis.

Chapter 2: Conducting research with children, and with seriously ill children

This chapter presents an overview of the literature on conducting research with children and young people. This section emerged essentially, as a response to the way in which historically, children's voices have been mostly absent from social research. Children's voices have been absent at least in part because of perceptions of children based on age (Mason and Hood, 2011; Oakley, 1994).

> *"Structural prescriptions made on the basis of age have constrained children's agency and silenced their voices…while research on children's issues has commonly been associated with forms of policymaking that have embedded children in families and schools"* (Mason and Hood, 2011, 490).

Mason and Hood's (2011) argument summarises the sociological literature on children and research, which suggests that children have historically been excluded from research due to their age, and their position as minor within society (Alanen, 1988). Although perceptions of children are beginning to change (Prout and James, 1990), there are still some challenges to involving children in research that need to be considered so that children feel safe, respected, and involved in the research process. This chapter presents some of the theoretical and methodological issues and implications of conducting research with children, and with seriously ill children and young people. I situate my examination of children and their research involvement in a brief discussion of how the social milieu has affected the ways that children are conceptualised, and how this has translated into their participation in research.

My discussion begins with Punch's (2002) work on childhood and research which poses the question, is research with children the same or different to research with adults? This question is important as one's response informs subsequent methods used as part of the research process. For example, if research with children is no different to research with adults then the same methods, such as interviews, can be used to engage children. However, if there are differences between children and adults then researchers must consider alternative methods of doing research with, and engaging children in research. However, before examining Punch's (2002) question further it is perhaps useful to define what childhood means in a research context.

In defining childhood I present the different ways in which children and young people are conceptualised by the academic literature, and how they are treated in society in terms of their rights, their perceived competence and their voice that society allows. I then return to Punch (2002) and discuss how my understanding of childhood led me to the choices I made about how I involved children within this study.

2.1 Defining childhood

Legally, the United Nations' (UN) convention on the rights of the child (1991), states that a child means every human being below the age of eighteen. Although wishing to move away from conceptualising children by age alone, this is perhaps the most concrete definition of what it means to be a child. Although individuals under the age of 18 are legally considered children, individuals over the age of 16 are presumed to have the capacity to consent to research participation (General Medical Council). The UN do not describe the basis on which 18 constitutes the end of childhood, nor do the General Medical Council provide rationale on why individuals of 16 years old are presumed to have the capacity to consent to research. However, the literature on child development and cognition in part, reflect 16 to 18 years as a general indicator of the end of childhood (Borgers, Leeuw and Hox, 2000; Arnett, 2000).

As part of this literature on childhood, influential theories of cognitive development, such as Piaget's (1930), suggest that intellectual development evolves as age increases until 16 years, when cognitive capacities become fully developed (Arnett, 2000). Young children however live in the here-and-now, where egocentric perception, emotion, action and general cognitive activities are still partially fused (Piaget, 1930). Perhaps due to this egocentric perception, children under seven years are perceived not yet able to imagine, or reason (Piaget, 1930) or appreciate different personal positions (Buchanan and Brock, 1989). Kortesluoma, Hentinen and Nikkonen (2003) write that for research purposes this means that between the ages of two and six, children may not be able to answer research questions accurately due to not having the linguistic flexibility or vocabulary.

As much as explanations of childhood based on chronological age are useful, researchers (Bluebond-Langner et al, 2010; Alderson, 2000) argue that variations in development make it difficult to use age as a predictor of understanding within childhood. Bluebond-

Langner et al (2010) perhaps put it most succinctly, writing that, "children do not develop evenly. Some children, for instance, can be described as socially immature but gifted in math. These variations make it difficult to speak of a certain age or stage at which a particular minor or cohort of minors have or do not have the cognitive capacity for decision making." (Bluebond-Langner et al, 2010, 332).

Children's differing experience is another important factor to consider when thinking about childhood and research. To illustrate, I return to Bluebond-Langner (1978), who gives the example of the six-year-old who, after many rounds of chemotherapy, potentially has more experience and understanding of a condition than a nine-year-old beginning the same treatment. The older child may not be a more competent research participant yet, in a research capacity context the nine year old would be assumed to have a greater and broader understanding as a result of their age. The example used by Bluebond-Langner (1978) highlights how experience and understanding might be more useful than chronological age when thinking about what a child may be able to bring to a research situation. The essence of such arguments is that children are different from other children, just as Piaget (1930) might argue that children are different to adults, based on their cognitive capacities.

I, like theorists and researchers such as Bruner (1960), Vygotsky (1978) and Bluebond-Langner (1978) argue that assumptions of childhood based on age alone ignore the importance of social aspects of childhood developments, social aspects being cultural, environmental, based on language or class, or gender. Social considerations are particularly relevant to my study as research suggests that many seriously ill children and young people miss out on normative childhood experiences (Schwartz & Drotar, 2009; Last and Grootenhuis, 1998; Pinquart, 2014), with some children having difficulties with psychosocial adaptation as a result of long-term illness (Mattsoon, 1972). As such, the children and young people in my study might be different to well children based on their experience of illness and living within illness environments. The next section moves on to discuss the way in which thinking about children has progressed, taking into account the social and environmental contexts in which children sit.

2.2 Children as competent social actors

As a response to the over-reliance on age in conceptualising childhood, in the early 1990's the 'sociology of childhood' emerged as a critical discipline within the fields of psychology and sociology. This paradigmatic shift (Prout and James, 1990) in the conceptualisation of childhood recognised the political and cultural constructions of childhood such as geography and class. Additionally, it recognised children as active in the construction and determination of their own lives (Mayall, 2000). The sociology of childhood movement, shifted perceptions of childhood away from understandings based solely on chronological age.

Prout and James (1990) write that a key theme in the new social study of childhood is children's competence as social actors. This means looking beyond perceiving children as incomplete (Mascollo, 2014; James and Prout, 1997) and of childhood as a purely biological phenomenon (Holloway and Valentine, 2000). Perceiving of children as competent social actors represents a shift towards seeing children as agentic and active.

What this means for research with children, is that rather than children being passive participants in research studies, children should have a stake in the production of academic knowledge (Smart, Neale and Wade 2001). Recognising children as subjects rather than objects entails "accepting that children can speak in their own right, and report valid views and experiences" (Alderson, 2000, 243). Although this study was not a collaborative or co-constructed piece of work in that children were not research collaborators, I align this study to Smart et al (2001) and Anderson's (2000) approaches to research with children. I thus take account of children "not solely or mainly as legitimate objects of adult socialization but as moral interpreters of the worlds they engage with, capable of participating in shared decisions on important topics' (Mayall, 2002, 8).

A range of studies evidence the argument that children are competent research participants (Coad et al, 2015; Bluebond-Langner, Belasco, and Wander, 2010; Bluebond-Langner, 1978). Competent in this context meaning, "that the young person is sufficiently able to: understand the relevant information; retain the information; weigh the information in order to make a reasoned choice; and make voluntary and autonomous decisions" (Alderson, 2007, 2281).

Examples of children as competent as research participants are suggested by Alderson, Hawthorn and Killen's (2006) study which found that children with diabetes aged three and four years refused sweets that their friends were enjoying, and Mason and Falloon's (2001) study where children made and articulated nuanced analyses and observations on childhood abuse. The studies cited here reflect Alderson's (2007) criteria for research competence, in that the studies show that children are able to understand information (Mason and Falloon, 2011), make autonomous decisions, and make reasoned choices (Alderson et al, 2006).

Embedded within discussions of children, capacity, and research are conversations about the social status of childhood (Punch, 2002; Mayall, 2000; Johnson, 2001). These social issues have implications for research and are discussed next. Bluebond-Langner (1978) begins my discussion on how the social status of children impacts upon research with children. Bluebond-Langner (1978) explains that although a child may be capable of understanding what it means to participate in research, and be cognitively capable of participating, that same child might also accept decisions about participation, without protest due to the influence of his or her parents. This is because of the imbalance of power that exists between children subjects and adult researchers (Morrow and Richards, 1996; Punch, 2002).

Hill (2006) adds that environment is also important, in thinking about how a child participates in research. Hill (2006) writes that children's behaviour in schools for example is affected by the expectations and customs of that institution. Expectations of behaviour shape how children perceive external researchers. For example, "outsiders are often treated like teachers (e.g. being called 'sir' or 'miss') and communication patterns in the classroom (e.g. putting hands up to be 'allowed' to speak)" (Hill, 2006, 83). Hill's (2006) example shows how power is held by adults, as adults control the customs and expectations of institutions like schools.

Mayall (2000) demonstrates the impact that such power imbalances have on children's' perception of research in a study into children's rights and the sociology of childhood. Mayall (2000) interviewed nine year olds about research participation and reported that,

> *"children regard themselves as subordinate to adults;*
> *that children accept their low status vis-à-vis adults;*
> *that children think they have rights to protection and to*

provision…but find that these are not always respected;
that children are often not believed, [and] often wrongly
blamed; and they are not always accorded respect for
their moral competence" (Mayall, 2000, 253 – 254)

Mayall's (2000) findings support arguments like that of Punch (2002) who proposes that children are used to adults being in positions of power and that, "they are not used to being treated as equals by adults" (Punch, 2002, 324). The literature thus suggests that children's social position as minor within their families (Bluebond-Langner, 1978), and as part of an adult-centred society (Punch, 2002), mean that there are important differences between children and adults. These differences being focused on power (Morrow, 1998) and social positioning. As such, the literature suggests that there are differences in doing research with children. And, these differences lie not just in differences in understandings of language or cognitive ability as researchers such as Piaget (1930) might argue, but in differences in power and respect.

I therefore now move onto outlining the methodological considerations researchers working with children might take into account, while at the same time reflecting on the idea that what might work for one child, or one cohort of children might not work for another.

2.3 Methodological considerations in researching with children and young people

Weithorn and Campbell (1982) assert that including children's voices is not the same as suggesting that young children can ultimately consent to research, however it does mean that they can, and should, be informed and consulted as part of the overall process of consent. There are a number of ways in which researchers can do this, ensuring that children are included and engaged as part of the research process as much as possible. Some of these methods are outlined here. Issues around assent and consent are outlined in section 2.5.

2.4 Participatory methods

Grootens-Weigers et al (2015) argue that researchers must find ways of doing research with children in ways that support understanding and engagement, and in doing so "confront generational issues" (Mayall, 2000, 121). One way of doing this is to use

participatory methods. Participatory methods aim to explore the views of children and young people (and other populations perceived as vulnerable) in an appropriate way, a way that reduces power, is fun, is sensitive to language or cognitive differences and difficulties, and that is rapport building. Participatory approaches to research, such as drawing (Ewing, 2007), the use of puppets (Gibson et al, 2010), photography (Darbyshire, Macdougal and Schiller, 2005), and tools such as Talking Mats (Germain, 2004) have been found to support the rights and voices of children, allowing their thoughts, experiences and feelings to be accessed, rather than adult versions or perspectives. A core principle of participatory methods "is the generation of knowledge, rather than its extraction, through a coming together of academic and local knowledge. The process should be experienced as transformative, based on principles of social justice, non-hierarchical relationships and reciprocal learning" (Greene and Hogan, 2005, 253).

Participatory methods have been found useful in providing insight into children and young people's lives. This is because Gibson et al (2010) write that most young children find direct questions difficult, and as such require researchers to enter the world they, the children, are familiar with. Using dolls as puppets facilitated these researchers' (Gibson et al, 2010) research engagements with their young (children under the age of five years) cohort. Participatory methods have been found to be helpful in studies on young male masculinity (Blackbeard and Lindegger, 2015); health research in adolescents (Hingle et al, 2013); and in exploring eating behaviours in obese adolescents (Lachal et al, 2012).

2.5 Assent

In addition to supporting children and young people's engagement with research processes is the growing acceptance that children and young people should be involved in research participation (Alderson, 2007; Grootens-Weigers, 2015; McHale et al, 2007). The National Research Ethics Service (http://www.hra.nhs.uk) also suggest that although evidence is limited, many children are happy to participate in research, and, as researchers we should be asking children and involving children in research decisions.

Child assent is defined as agreement to participate (Miller and Nelson, 2006). Although children and young people under 16 cannot legally consent to research, good practice dictates that children and young people should still be given the time, space, respect and adequate information to decide whether or not they wish to participate in a research study (Diekema, 2006; Ramsey, 2006; Kinscherff and Latham, 2014; Alderson, 2007).

Kinscherff and Latham (2014) state that the assent process should be about more than requesting a signature from children. Rather, "an adequate informed consent [or assent] requires that: the individual who is offering informed consent has been provided sufficient information to allow a reasonable person to make a considered decision about the professional services involved; the individual demonstrates that they have a sufficient understanding of the information offered so that they can actually make considered decisions; and the individual has been afforded a meaningful opportunity to ask questions or express concerns" (Kinscherff and Latham, 2014, 1). It is also important to respect children and young people's dissent to research participation (Leiken, 1993). This means that researchers should listen to children and young people, regardless of whether their parents or guardian give consent for them to participate in a research study.

2.6 Adapting the process of consent for children and young people

In response to Kinscherff and Latham's (2014) statement on adequate informed consent, Grootens-Weigers et al (2015) write that although researchers have tried, or might want to engage children in an assent process, "disclosure to children is seldom adequate, due to the use of too difficult language or due to a general absence of information material specifically designed for children" (Grootens-Weigers et al (2015, 518). Grootens-Weigers' (2015) argument is evidenced by studies such as that of Ondrusek et al's (1998) that found that the young children (under nine years) in their study did not fully understand the meaning of the research and so could not meaningfully assent. Additionally, O'Lonergan and Foster-Harwood's (2011) study found that 76% of children participating in their clinical trial did not understand the potential risks involved in participating.

As such, other methods of explaining research concepts to children are necessary. Such resources such as comic strips and pictures (Grootens-Weigers et al, 2015) are available so as to help explain concepts involved with the consent process such as withdrawal and randomisation. Grootens-Weigers et al's (2015) work using images, shows that comic strips, which themselves were developed with children, helped children engage with and understand concepts associated with informed consent and assent. This full understanding of what it means to participate in research is important because without it, children and young people may be consenting to something they do not feel comfortable with, or have their information used or published in a way they later regret.

2.7 Additional considerations in working with seriously ill children and young people

Age appropriate assent processes and participatory methods are some of the ways in which traditional, or adult research methods can be adapted to ensure children and young people understand and engage with research. However, in addition to involving children, this study's sample involves seriously ill children. This additional consideration of illness leads me to ask, is doing research with ill children different to doing research with well children?

I begin my discussion with Bluebond–Langner (1978), proposing that research with ill children is different to research with children who are well. This is partly because in most studies of children and childhood, children's views and experiences are explored with the underlying idea that childhood will lead to adulthood and, this understanding cannot be applied to the study of terminally ill children. Bluebond-Langner (1978) continues, asking of researchers "how can anyone use a model that presumes a future that presupposes adulthood, for children who will never reach adulthood, particularly when everyone associated with these children is acutely and painfully aware of this fact?" (Bluebond-Langner, 1978, 6). I agree with Bluebond-Langner's (1978) argument, that we as researchers cannot conceptualise seriously ill children, particularly those with life-threatening conditions, in the same way as well children. In the same way as children are different to adults, children with serious conditions have different prior experiences and possible expectations of the future compared to children who are well. I subsequently look to the literature on doing research with seriously ill children, and how best to engage with and include their voices as part of this study.

My initial examination of the literature on doing research with ill children suggests that many researchers do not seek out the voices of seriously ill children and young people in their work. Within the literature, experiences of paediatric illness are often told from the perspective of a parent or guardian, rather than the ill child him or herself (Montoya-Juarez, 2013; Darlington et al, 2013; Vickers and Carlisle, 2000). And thus, decisions about ill children's bodies, children's services, their conditions, their (dis)abilities and their rights are often then dictated by adults. This is perhaps because the literature appears to focus on the challenges, difficulties, barriers, and burdens of working with seriously ill children (Tomlinson et al, 2007; Davies et al, 1995; Rolls and Relf, 2006; Liben, Papadatou and Wolfe, 2008).

Although I include the voices of seriously ill children and young people within this study, I acknowledge the challenges of working with seriously ill paediatric populations. Such challenges to participation are outlined in Tomlinson et al's (2007) systematic review paper 'challenges to participation in paediatric palliative care research'. Although Tomlinson et al's (2007) review is limited to examining papers on paediatric palliative care from parent perspectives it is helpful in providing an overview of the challenges involved in doing research with seriously ill populations.

The challenges identified by Tomlinson et al are: the potential vulnerability of the research participants which includes the risk of coercion, the burden of participation, the potential that the child is unaware that he or she is dying, and the possibility that parents have not yet come to terms with the inevitability of their child's death. I subsequently examine each of the issues outlined by Tomlinson et al (2007), prior to showing in my methods section how I addressed each one as part of this study on dream fulfilment.

2.8 Seriously ill children and family members as vulnerable

Although children and young people themselves are considered a vulnerable group, palliative care patients are considered particularly vulnerable as they often experience pain, fatigue, other physical symptoms, and emotional distress (Pessin et al, 2008). Families with ill children might also be considered vulnerable because of the high level of stress associated with receiving a diagnosis (Dixon-Woods et al, 2001). Concerns are additionally centred around the heightening of vulnerability in family members throughout the research process, as research participation might cause them to "relive traumatic experiences through the retelling of stories" (Stevens et al, 2010, 496). Two concepts contributing to this vulnerability, and highlighted by Tomlinson et al's (2007) review, are the child's awareness of his or her condition and family member adjustment.

2.9 The child's awareness of his or her condition

Knowing how much children and young people understand about illness has both ethical and theoretical implications (Myant and Williams, 2005). For example, by inviting children to be involved in a study that examines the impact or experience of life-threatening illness, underlines, or names participating children as seriously ill. There is a possibility that an ill child may not fully comprehend the extent of their condition, but become aware through

involvement in research. Tomlinson et al (2007) write that children's potential unawareness of condition or condition seriousness is a cause for concern.

The meaning of conditions like cancer to children depends on a variety of individual and family characteristics. These characteristics include the child's developmental level, previous childhood experiences, the context of the illness, and family relationships (Hymovich, 1995). Although, Tomlinson et al (2007) write that children's unawareness of their condition is concerning, other studies suggest that ill children are aware of their conditions.

Studies, such as those conducted by Easson (1970), Spinetta (1974) and Kastenbaum and Aisenburg (1972), report that the terminally ill child is aware of the seriousness of his or her condition. Thinking specifically about conditions that could lead to death, Speece and Brent (1984) reviewed children's understandings of death concepts (irreversibility, non-functionality and universality). Looking at age, they report that an adult understanding of the key components of death was found in children four to twelve years to older (Speece & Brent, 1984).

As discussed, "age is not necessarily predictive of what children know" (Bluebond-Langner, Belasco, and Wander, 2010, 331). As an example Reilly et al (1983) found that children with previous experience of death appear to understand more than children without this experience. Additionally, Bluebond-Langner et al (2010) explain that it is difficult to determine how any child views illness because children present different understandings to different individuals on different occasions. Dying children can also signal their awareness and distress indirectly (Beale, Baile and Aaron, 2005).

Although ascertaining how much children know about their conditions can be difficult, research suggests that children do have an understanding and an awareness of themselves and their conditions. Sahler et al (2000) suggest that most children with life-threatening conditions, even those as young as three years old, pick up cues from the physiological changes in their bodies and, as Bluebond-Langner (1978) also found, the reactions of parents and hospital staff. Children and young people therefore have at least some understanding of illness.

Beale, Baile and Aaron (2005) share children's questions about death from their practice and research with children, such as, "Is it going to hurt?" "Will I be able to breathe?" "Will

an angel come and take me away?" (Beale, Baile and Aaron, 2005, 3629). These researchers reflect that with these questions the children are asking them if they are going to die and show a surprising awareness of the fact that the children realise they are seriously ill, or going to die.

2.10 Parental and family member adjustment to a child's condition

Another point highlighted by Tomlinson et al's (2007) review of challenges to paediatric palliative care research is doing research with parents who are not adjusted to a child's condition. I briefly look at the literature around this point, prior to discussing how my methods reflect such considerations in the methods section of this thesis.

Being confronted with a childhood diagnosis of cancer, for example, causes various emotional reactions in family members (Grootenhuis and Last, 1997). Research suggests that parents of children with life-threatening conditions can experience high levels of psychological distress, which has significant effects upon aspects of life such as employment and relationships (Wallander and Varni, 1998; Mastroyannopoulou et al, 2006). High levels of parental distress have been found both at the time of the diagnosis (Sloper, 1998; Kupst, 1992), and over the years post diagnosis (Sawyer at al, 1993). Siblings too, are at risk of developing psychological disturbance (Black, 1998), although evidence from meta-analyses show that only a minority experience clinical symptomatology (Barlow and Ellard, 2006).

Although family members of children with life-threatening conditions show distress and adjustment issues, research also suggests that participating in research can be helpful and, if conducted in a sensitive and appropriate way, research participation can be a positive way for individuals in distressing situations to feel that they are helping others. The experience of research participation in seriously ill children and family members is detailed in the section below.

2.11 The potential burden of research participation

The literature on research with children with life-threatening conditions and their family members suggests that discussing end of life issues with terminally ill patients can be considered distressing and harmful (Emmanuel et al, 2004). However, few studies show

exactly how seriously ill individuals and their family members or caregivers experience research participation. Additionally, there is little literature that reflects on why research with children with life-threatening conditions, and their family members is not being conducted, and if the absence of research in the field is because of the potential challenges identified by reviews such as Tomlinson et al's (2007).

Although there is little evidence that conceptualises the potential burden of research participation, two studies have recently been conducted which examine the experience of seriously ill adults' participation in research. These are studies by Pessin et al (2008) and Hynson et al (2006). Both studies found that adult participation in research was helpful and positive. Pessin et al (2008) issued questionnaires to adult research participants with less than two months to live, so as to understand their experience in a research study. These researchers found that 75% of participants reported no burden, with 68% finding participation beneficial. Factors frequently identified as beneficial were, "the social interaction (75%), sense of contributing to society (57%), and the opportunity to discuss their illness (47%)" (Pessin et al, 2008, 627). Hynson et al (2006) conducted a similar study, but with bereaved parents. This group of researchers found too that participating in research was a positive experience for the bereaved parents in the sample. Positive aspects of the experience were the timing of the research interview, the researcher's approach and the interviewer's skills. These studies underpin the notion that participation in research can be a positive and beneficial activity.

Although useful in contradicting arguments which suggest that individuals in distressing situations should not be engaged in research, both studies cited involve adult participants. As discussed, the seeking of parental views in conceptualising children's experiences of research appears the norm. As such there is an absence of literature exploring the perceptions of seriously ill children who have participated in research.

Although there is an absence of research specifically examining the experience of seriously ill children's research participation, researchers such as Bluebond-Langner (1978), Gibson et al (2013), Malcolm et al (2012), Forsner, Jansson and Soerlie (2005), and Boyd and Hunsburger (1998) have successfully involved seriously ill children and young people in research in the past without any reported burden. Additionally, Broome, Richards and Hall's (2001) paper on age-based understanding of research concepts in children, reports that participation in their study helped children and young people with cancer feel that they were helping others and feel a sense of control over their condition.

Thus, "while little is known of how families with sick children perceive research participation, the contention that bereaved families are negatively affected by research is not supported in recent research" (Hynson et al, 2006, 805). In fact, there is some evidence, as highlighted by this discussion, to suggest that participation in research can actually be a useful and positive activity for ill children and their family members.

2.12 Conducting research with children with impairments

Before concluding this section, I want to discuss the methodological considerations that the literature identifies in conducting research with children with impairments. As my analysis of DCT's database suggests (section 1.4), many children with impairments or long-term, non-life-threatening conditions use the charity. Thus, in addition to considering what good research with children, and children with life-threatening conditions might look like, I examine here if there are additional methodological considerations in conducting research with children with impairments.

Nind (2008), in her paper on methodological challenges in conducting qualitative research with individuals with disabilities, identifies a range of issues that should be considered when doing research with these groups. Such considerations include adapting the consent or assent process, utilising communication tools, providing appropriate time for information to be understood, and recognising power imbalances between the researcher and the researched.

Nind's (2008) recommendations are reflected in the literature. Wickenden and Khembhavi-Tam (2014) for example conducted successful research with children with impairments using photo elicitation; Murphy and Cameron (2008) supported young people in making decisions using Talking Mats; and Shaw et al (2011) discuss how by keeping interviews short, and ensuring interviews take place in comfortable, and non threatening locations, researchers can engage children with impairments in research. Cocks' (2008) study reflects Shaw et al's (2011) discussion on place of research by showing how she reduced power imbalances by interacting with children with impairments in spaces usually occupied by children.

This short overview of the literature suggests that conducting research with children with impairments is similar to that of conducting research with ill children, and children

generally. This is because there are crossovers in how illness and impairment manifest. For example, a child with cerebral palsy might have difficulty with muscle weakness and so find it difficult to speak. Similarly, a child with speech impairment might have difficulty answering questions in an interview. Thus, a visual interview method, in a comfortable space would be appropriate for both children in such situations. A child without illness or impairment might too prefer to engage in an interview using a participatory method.

I therefore take from the literature that essentially, researchers should make decisions about how to engage children in research based on each individual child, rather than making assumptions based on age, condition or impairment. As such, researchers should not make assumptions about an individual with impairments based on their impairment alone. Shaw et al (2011) support this argument, concluding that carrying out qualitative research with children with impairments is largely a matter of following good qualitative research practices in general.

2.13 Conclusion

This section on conducting research with children, with seriously ill children and with children with impairments highlights some of the sensitivities and issues that need to be considered when conducting research with these groups. Research with children, well or ill, might mean adapting language or changing the way that an interview with a healthy adult might be conducted to suit the child or young person. The most important part of this being that children and young people's voices are heard within research, and that children and young people's involvement in research is on their terms as much as possible. Children and young people should be given the space, time and appropriate information to help them understand research processes, and be allowed to make decisions about participation themselves. If children and young people are ill, then researchers should be aware of the issues that affect conducting research with ill children, such issues being, a child's awareness of their condition or their family's adjustment to their illness.

Although research with seriously ill children and families is potentially challenging, "there is an urgent need to improve the care of children with palliative care needs, and their families" (Hynson et al, 2006, 805). Research, being an essential aspect of this process of improvement. As there is such a need to conduct research in this field, there are guidelines and support available for researchers doing research with seriously ill children, young people and their family members.

Recommendations suggested by Gysels et al (2013) in the MOREcare recommendations for ethical issues and end-of-life care research provide guidance; Hull (2000) provides guidance on conducting research with children; and Addington-Hall (2002) provides methodological advice on conducting research with palliative care patients. I consider the recommendations provided by each of these papers in my study on dream fulfilment. Details of how I applied such guidance can be found in my subsequent methods section in chapter 4. I now move on to outline grounded theory methodology.

Chapter 3: Methodology

This chapter outlines grounded theory methodology and shows how it was used to answer the research questions presented in section one, 'what is the impact of dream fulfilment on children and young people with life-threatening and long-term conditions and, what is the impact on their families?'

I discuss the process of choosing a methodological approach best suited to responding to the aims of the research and detail how grounded theory methodology was used to inform the methods that were then utilised within this study. The subsequent sections introduce grounded theory, discuss its emergence and subsequently detail grounded theory methods.

Prior to discussing grounded theory I want to briefly attend to the idea that grounded theory can be conceptualised as both an approach to methodology, and as the final product of an examination of data, i.e. theory (Rennie, Phillips and Quartaro, 1988). This is confusing and as such, I will be clear on my use of language, highlighting to the reader when I use grounded theory to refer to the method, and when I use grounded theory to refer to my findings. However, throughout these initial discussions of methodology and methods it can be assumed I use grounded theory to refer to the way that grounded theory informs the research process.

3.1 Grounded theory methodology

Grounded theory is a qualitative methodology, and like most qualitative approaches is concerned with the way in which the people being studied understand and interpret their social worlds (Bryman, 1988). In this section I outline the core concepts of grounded theory before describing its philosophical underpinnings and history.

Grounded theory is a methodology that seeks to construct theory about issues of importance in people's lives (Glaser, 1978, Glaser and Strauss, 1967, Strauss and Corbin, 1998). Grounded theory begins with general research questions, rather than tightly framed, pre-conceived hypotheses (Charmaz, 1990).

> *"Most qualitative approaches stress*
> *collecting copious amounts of data before delving*
> *into the analysis; researchers using such approaches*

> *often complete their major analytic work long*
> *after they have left the field. In contrast, grounded*
> *theorists use their emerging theoretical categories to*
> *shape the data collection while in the field as well as*
> *to structure the analytic processes of coding, memomaking,*
> *integrating and writing the developing*
> *theory…the 'groundedness' of this approach*
> *fundamentally results from these researchers' commitment*
> *to analyze what they actually observe in the*
> *field or in their data."* (Charmaz, 1990, 1162)

As Charmaz (1990) illustrates, sampling in grounded theory is not driven by attempts to be representative of population, but rather, is driven by concerns emerging from provisional analysis (Clarke, 2003). In this sense, grounded theory is emergent, with the generation of theory being the principal aim (Charmaz, 2008).

This brief introduction to grounded theory will be built on later in the thesis, with detail extended to each of the concepts introduced in this section. I now move on to discuss grounded theory's emergence and development, as Suddaby (2006) writes that grounded theory is best understood historically. Thus, in this next section I discuss the emergence of grounded theory, and some of the debates contextualising grounded theory's history.

3.2 The emergence of grounded theory

Grounded theory emerged as a formal method of qualitative enquiry in the 1960's, when sociologists Glaser and Strauss worked together researching dying in a hospital. Glaser and Strauss' grounded theory method combined the depth and richness of Strauss' qualitative research background and Glaser's training in quantitative survey research (Walker and Myrick, 2006). Together these researchers developed a systematic and iterative research method for collecting and analysing data, and generating theory. Although sociologists were already conducting fieldwork with the goal of developing theory and writing about social process (Morse et al, 2009), there is a trend in the literature to categorize Glaser and Strauss as first generation, or classic grounded theorists (Birks and Mills, 2007).

Grounded theory is so named because its aim is to produce theory 'grounded' in data collected from participants on the basis of the complexities of their lived experiences in a social context (Fassinger, 2005). Glaser and Strauss' (1967) theory is derived inductively, through an iterative process of data collection, coding, conceptualizing, constant comparison and theorizing (Cutcliffe, 2000; Fassinger, 2005). Additionally, the extant literature in classic grounded theory is not examined until the researcher is in the field, and codes and categories have begun to emerge (McGhee, Marland and Atkinson, 2007). Grounded theory is appropriate when the study of social interactions of experiences aims to explain a process, not to test or verify existing theory (Lingard, Albert and Levinson, 2008).

The development of classic grounded theory challenged the arbitrary division of theory and research, the prevailing view that qualitative methods were impressionistic and unsystematic, the separation of data collection and analysis phases of research, and the assumption that qualitative research only produced descriptive case studies (Walker and Myrick, 2006; Charmaz, 1996 and 2014). Grounded theory methods echo pragmatist and symbolic interactionist assumptions (Fassinger, 2005; Clarke, 2003; Charmaz, 2015). Pragmatism being a philosophy which views reality as fluid and open to multiple interpretations, and symbolic interactionism, a theoretical perspective influenced by pragmatism that assumes society and self are constructed through interaction (Charmaz, 2006).

3.3 Symbolic interactionism and grounded theory

Symbolic interactionists assume that human beings create the world they live in. They do this by acting on things in terms of the meanings such things have for them (Charmaz, 2006). Like Charmaz, Denzin (1992) writes that meanings come from interaction, and are shaped by the self-reflections a person brings to their situation. A symbolic interactionist perspective is therefore one that is theoretically focused on the acting individual (Klunklin and Greenwood, 2006). Klunkin and Greenwood (2006) write that what this implies is that objects possess no inherent meaning. Society is constructed through the interactions of individuals and groups. Meaning is derived from how others act toward objects, and these meanings are represented symbolically in action and in language.

Symbolic interactionism as a perspective helps researchers to understand the complex world of lived experience from the point of view of those who live it (Schwandt, 1994).

Grounded theorists use symbolic interaction as a perspective to uncover the ways that actors under investigation create and enact meaning. It is a theoretical framework that informs the way that data is conceptualised and understood.

Grounded theory as a method has been developed and adapted since its formal emergence in the 1960s. However, symbolic interactionism continues to underpin and work as a theoretical framework for grounded theory as the method evolves and develops away from its classic roots. It is this variation of the classic formulation of grounded theory that will be discussed next.

3.4 Approaches to grounded theory

As discussed, grounded theory emerged from the collaboration of sociologists Glaser and Strauss, who in 1967 wrote the Discovery of Grounded Theory. This section further examines grounded theory's classic roots, and the way in which the method has shifted and evolved since Glaser and Strauss first developed and wrote about grounded theory.

As a research method, "grounded theory is often heralded as revolutionary in the history of the qualitative traditions. Yet, at the same time, it is the most frequently discussed, debated, and disputed of the research methods" (Walker and Myrick, 2006, 547). The debates and dispute referred to in Walker and Myrick's (2006) quote are methodological in nature, and began when Strauss and Corbin (1990) released their version of grounded theory. Strauss and Corbin's (1990) development of the classic grounded theory is often referred to as Straussian grounded theory.

Although Strauss and Corbin's (1990) approach to grounded theory adhered to the same basic research processes as classic grounded theory, i.e. the gathering, coding, sampling, and categorizing of data (Walker and Myrick, 2006), nuanced differences in the utilization of such processes reflected different methodological assumptions.

In the first instance, Straussian grounded theory advocated an alternative coding process to Glaser and Strauss' (1967) original method. Glaser and Strauss' (1967) classic version of grounded theory was very much focused on emergence. Emergence being, the generation of codes and categories directly from data. In classic grounded theory codes and categories were thus "not selected prior to data analysis…and often labelled from words found in the data themselves" (Kendall, 1999, 744).

Like classic grounded theory, Strauss and Corbin's (1990) adapted method also saw coding as an important part of the method. However, Corbin and Strauss (1990) advocated using a coding framework as part of the coding process. This coding framework included questions that particularly novice researchers could ask of collected data. While Strauss and Corbin's (1990) adapted coding framework was perhaps useful to novice researchers, it is argued that in using preconceived frameworks to analyse data, researchers are forcing categories of information, instead of allowing categories emerge naturally (Kelle, 2005).

In addition to prescribing a coding framework, Strauss and Corbin's (1990) method advocates for an earlier review of the literature, than Glaser and Strauss' (1967) classic method originally advises. Strauss and Corbin (1990), propose techniques where prior understandings, ascertained from the literature are deliberately used to question the data. Classic grounded theory, and Glaser's (1998) later work however, rejects prior reading, giving reasons related to the distorting effects this may have on analysis (Heath, 2006). Furthermore, Glaser points out that, "as discovery and emergence are at the heart of the grounded theory method, relevant literature cannot be known at this stage" (Heath, 2006, 520).

While Glaser and Strauss (1967) acknowledged that their classic method of grounded theory represented only the beginning and, that it was appropriate for the methodology to evolve and develop (Cutcliffe, 2000), Glaser (1992) argued that Straussian grounded theory was not grounded theory at all. Glaser (1998) instead proposed that Strauss and Corbin (1990) did not extend understanding of grounded theory but had gone on to develop another method, that being full conceptual description.

Thus, the methodological differences in processes between classic and Straussian grounded theory run deeper than differences in coding processes. The variations in approach represent wider debates about the nature of knowledge. Glaser and Strauss' (1967) approach to grounded theory is arguably objectivist in its foundational assumptions (Oliver, 2011; Ong, 2012; Charmaz, 2000) in that it is about the pursuit of a generalisable theory explaining an objective reality (Glaser and Strauss, 1967). Classic grounded theory implies that reality – and the methods used to produce it – is independent of the observer. Core processes and problems reveal themselves, rather than being defined by actors or analysis (Charmaz, 1990). Researchers are also considered neutral observers (Oliver, 2011), and passive (Charmaz, 2014) rather than co-constructors of knowledge.

Strauss and Corbin, although never directly identifying the paradigm that underpins their method (Mills, Bonner and Francis, 2006) come closer to what I would argue is a method with pragmatist, rather than objectivist foundations. Strauss and Corbin's (1990) version of grounded theory acknowledges an active researcher, who has a part to play in constructing categories and generating theory. Thus, Straussian grounded theory shifted the method closer towards the approach to grounded theory which I found myself most closely aligned with, that being Charmaz's (1990, 2006, 2015) constructivism.

The next section of this chapter introduces constructivist grounded theory, before moving into a more detailed exploration of the approach.

3.5 Constructivist grounded theory

Charmaz's (1990; 2006; 2015) constructivist grounded theory is a 21st century form of the grounded theory method. Charmaz positions enquiry in its historical, cultural and social location. Charmaz's approach to grounded theory additionally acknowledges the perspectives and positions of the researcher, as well as the researched (Charmaz, 1990; 2006).

Constructivist grounded theory reflects the basic beliefs of constructivism as a paradigm of inquiry. Guba and Lincoln (2005) write that constructivism is ontologically relativist, epistemologically transactional and methodologically dialectical (Guba and Lincoln, 2005). This means that a constructivist grounded theory assumes an active, not neutral observer whose decisions shape both process and product throughout the research (Charmaz, 2009). Realities are assumed to be multiple and layered, not unitary and self evident (Pidgeon and Henwood, 2003).

Constructivist grounded theory additionally views the process of categorization, i.e generating themes, as dialectical and active (Charmaz, 1996). And, Charmaz's constructivist grounded theory challenges the belief that there is an objective truth that can be measured or captured through research enquiry (Crotty, 1998).

Constructivist grounded theory brought new concerns into view such as reflexivity and representation of research participants. Before the constructivist turn, "grounded theorists like many qualitative researchers, had not examined their assumptions about data

collection, themselves as observers and writers, and the situated nature of their studies"
(Charmaz, 2015, 404). Such methodological considerations are important, and impact
upon the way I have used constructivist grounded theory in this study.

Charmaz's (2015) constructivist version of grounded theory additionally treats grounded
theory strategies as tools for researchers to use and adapt to fit their empirical problems.
As such, Charmaz's approach to the method is less prescriptive than classic or Straussian
versions.

Breckenridge et al (2012) write that Charmaz's constructivist grounded theory values the
inductive creativity of the classic methodology, yet also resonates with the current
popularity of constructionism within social research. I agree, and as such, extend detail to
this, and my additional reasons for choosing Charmaz's approach to the method. In
presenting my rationale I discuss constructivist grounded theory and examine its
components further.

3.6 Choosing constructivist grounded theory

In this section I present my rationale for using Charmaz's (1990, 2002, 2006)
constructivist version of grounded theory. In doing so I discuss and extend detail to this
approach to grounded theory. My initial argument for utilising constructivist grounded
theory was based on Berger and Luckman's (1967) writing on the sociology of knowledge.
Berger and Luckman wrote that,

> *"What is 'real' to a Tibetan monk may not be 'real' to an*
> *American Businessman. The 'knowledge' of the criminal*
> *differs from the 'knowledge' of the criminologist. It follows*
> *that specific agglomerations of 'reality' and 'knowledge'*
> *pertain to specific social contexts, and that these*
> *relationships will have to be included in an adequate*
> *sociological analysis of these contexts."* (Berger and
> Luckman, 1967, 15)

Berger and Luckman (1967) adopt a relativist ontological position (Guba & Lincoln, 1994).
This means that concepts such as truth and reality should be understood as relative to a
specific social context (Bernstein, 1983). Berger and Luckman's (1967) examples led me

to think about the potential social contexts situating the children, young people and family members in my study. My participants' lives were likely to be, at least in part situated in illness, bereavement and disability. Thus, my participants were likely to have different sets of knowledge to my own. Social constructionism as an ontological lens acknowledged this difference, and allowed me to explore the relative meanings, constructions and relationships in my participants' worlds.

Charmaz's constructivist grounded theory recognises individual and social differences. The approach additionally acknowledges that individuals experience their different constructions as reality, and that such constructions are neither fabrications nor inventions (Charmaz, 1990). Rather, "people's constructions reflect their understandings of their experiences as well as the diverse situations in which they have them" (Charmaz, 1990, 1161). It was the beliefs, assumptions and ideologies (Cresswell et al, 2007) and understandings and perceptions of reality (Charmaz, 1990) that I wanted to capture as part of this study on dream fulfilment. Therefore, a constructivist approach to grounded theory was appropriate.

In addition to the recognition of participants' constructions as realities, Charmaz's (1990, 2006, 2008) constructivist version of grounded theory recognises an active and involved researcher. Constructivist grounded theory's relativist epistemology assumes that neither data nor theories are discovered, but are constructed by the researcher as a result of his / her interactions with the field and its participants (Thornberg, 2012). Charmaz (1990) writes that the relationship between the researcher and the data result in discovering or creating categories. As such, the discovery process consists of the researcher actively creating categories and constructing the analysis. Therefore, "how the analyst uses the method and which questions he or she brings to the data shape the results." (Charmaz, 1990, 1165). Charmaz (2015) adds that the awareness of multiplicity of perspectives and multiple realities sensitizes grounded theorists to look beyond the surface and to study what happens among diverse research participants. As such, "grounded theorists are poised to construct useful theories…that offer conceptual handles on specific issues and may generate persuasive changes in policy arenas" (Charmaz, 2015, 406).

The constructivist approach to the generation of knowledge, which assumes an active researcher, examining the construction of participants' multiple realities, contrasts with the positivistic approach to knowledge. That being, that the investigator and the investigated

are independent entities. This positivistic approach, concerning objective or passive researchers is reflective of classic, and arguably Straussian grounded theory approaches.

As discussed in my section on the emergence of grounded theory, Glaser and Strauss' (1967) grounded theory is argued to assume an objective external reality where the researcher is viewed as a neutral observer who discovers data in an objective and neutral way (Denzin and Lincoln, 2002; Hallberg, 2006). Mills et al (2006) additionally argue that Strauss and Corbin's (1990) work could be conceptualised as post positivist as it relies on terms such as *recognizing bias* and *maintaining objectivity* when describing the position the researcher should assume in relation to the participants and the data.

I thus take a constructivist perspective to the construction of knowledge, as I, like Charmaz (1990) and Crotty (1998) argue that meaning does not lie dormant within objects waiting to be discovered, but is created as researchers interact with and interpret their participants experiences, stories, views and opinions.

Following on from my last point is Charmaz's (1990; 1996; 2003) flexible approach to the research process. Charmaz (2006) proposes that grounded theory methods can be used to study uncharted, contingent, or dynamic phenomena. Constructivist methods also allow for new properties of the studied phenomenon to appear that, in turn, shape new conditions and consequences to be studied. Charmaz's flexible approach to the research process allows researchers to follow data, and to adapt to and change questions as dictated by collected data. Although it could be argued that Glaser and Strauss' (1967) and Strauss and Corbin's (1990) method are also directed by data, constructivist grounded theory is less restricted by coding frameworks (Strauss and Corbin, 1990; 1998) or on the focus on the discovery of reality (Glaser, 1978). Coding processes in constructivist grounded theory are detailed in the following section on the methodological components of grounded theory.

Additionally, Charmaz's conceptualisations of research findings are also different to previous approaches to the method. Rather than traditional definitions of theory, such as those purported by Glaser and Strauss (1967), i.e., that theory must predict and explain behaviour, this thesis' presented theory emphasizes understanding rather than explanation. In line with social constructivism Charmaz's (2006) interpretative theory allows for indeterminacy, rather than causality, and patterns and connections rather than linear reasoning. Breckenridge et al (2012) write that rather than looking for one main

concern, constructivist grounded theorists should, as Charmaz (2003) proposes seek to construct a "picture that draws from, reassembles, and renders subjects' lives" (Charmaz 2003, p. 270). My research question was broad, and as such I anticipated finding more than one main concern within my data. As such, a constructivist approach worked as it allowed me to present findings that represent processes and understanding of dream fulfilment rather than a theory based around one core concern.

My final argument, which follows on from, and related to my previous discussion in this section is about the way in which constructivist grounded theory allows for the exploration and examination of research participants' views, experiences and voices. Charmaz (2006) encourages researchers using constructivist grounded theory to give voice to their participants so as to incorporate the multiple voices, views and visions of all involved in the research process. Giving voice to participants is especially important within this study as seriously ill children and young people have historically been excluded from participation in research, due to perceptions of vulnerability (Tomlinson et al, 2007).

I chose a constructivist approach to grounded theory as it encourages reflection, it acknowledges the researcher and the participant as co-constructors of knowledge and it supports researchers in understanding and exploring perceptions and constructions of phenomenon. I continue to discuss constructivist grounded theory in my next section, which looks at the components of constructivist grounded theory. I discuss such components, prior to detailing how constructivist grounded theory was utilised in my methods section.

3.7 Methodological strategies in constructivist grounded theory

I now look at the methodological components of grounded theory, prior to discussing how grounded theory was utilised in my methods section. I begin this section with a discussion of the literature debate in grounded theory. I include my use of the literature as part of the methodology section of this thesis, as the literature review in my grounded theory study was a part of the research process, rather than being a precursor to it. Grounded theory researchers generally avoid the literature until investigations are finished and grounded theories are in place. Once a theory is developed, existing theories are evaluated and those that fit the grounded theory are integrated with it so that it may be further enriched and elaborated (Rennie, Phillips and Quartaro, 1988). However, there are nuanced differences in the timing and place of the existing literature within grounded theory

approaches. Such differences are methodological in nature. I briefly discuss such perspectives before presenting my own use of the literature with respect to place and time.

3.8 Theoretical agnosticism (the literature debate)

In their original publication, Glaser and Strauss (1967) explicitly advised against conducting a review of the literature prior to entering the field. Arguments against conducting an early review of the literature were; to prevent generating a focus from the literature rather than from the emerging data; to prevent recognised or unrecognised assumptions; and to prevent the researcher being constrained, contaminated or inhibited (McGhee et al, 2007). An early literature review was seen as potentially stifling the process of developing a grounded theory and thus something that could detract from the quality and originality of the research. Francis, Mills and Bonner (2006) argue that this perspective situates the data as an entity separate from both participant and researcher and, as such is reflective of positivistic underpinnings. Thornberg (2012) agrees, writing that classic grounded theory's reliance on pure induction and realist concept of data is "very similar to the naïve empiricism that characterises positivism" (Thornberg, 2012, 247).

Although classic grounded theory advocates against reviewing the literature prior to entering the field it is important to note that Glaser and Strauss (1967) did not suggest a complete abandoning of the literature. Focused reading in a classic grounded theory study occurs when emergent theory is developed (Heath and Cowley, 2004). Thus, the fundamental issue in classic grounded theory is when, and not if, engagement with extant knowledge should occur (Dunne, 2011).

In Strauss and Corbin's (1990) adapted approach to grounded theory, both use of the self and the literature are early influences (Heath and Cowley, 2004) on data collection and theory generation. These researchers believed that both personal understanding from past experience and the extant literature may be used to stimulate theoretical sensitivity (Strauss and Corbin, 1990). Theoretical sensitivity is a concept that includes the researchers level of insight into the research area (Mills, Bonner and Francis, 2006). Strauss and Corbin (1990) also believe that reviewing the literature prior to data collection provides a secondary source of data; contextualises the study; provides rationale; supports the researcher in becoming aware of rather than numb to unhelpful

preconceptions (Maijala et al, 2003); and promotes clarity in thinking about concepts and possible theory development (Henwood and Pidgeon, 2006).

Like Glaser, Charmaz (1996; 2006) advocates for delaying a formal academic literature review. Charmaz (1990) agrees with Glaser and Strauss' (1967) *tabula rasa* view of enquiry, writing that "reading and integrating the literature later in the research process is a strategy to prompt exploring various ways of analysing the data…delaying the literature review decreases the likelihood that the researcher will already be locked into preconceived conceptual blinders upon entering the field and interpreting the data" (Charmaz, 1990, 1163). Like Glaser (1978), Charmaz (1990) is clear that that this means delaying the literature review, not overlooking or failing to use it.

Although, thus far in the research process I have adhered to Charmaz's (1990; 1996; 2006) methodological processes, I take a different approach to that what Charmaz advocates with respect to the literature. Rather than delaying the literature in its entirety I used the perspective of Henwood and Pidgeon (2003) and Thornberg (2012), which is that of theoretical agnosticism. Theoretical agnosticism is about treating all extant theories and concepts that one already knows, or might encounter as provisional, disputable and modifiable. This approach does not advocate that the researcher ignore theories, but rather, avoids the imposition of specific frameworks which may cause the researcher to view data through a specific theoretical lens (Dunne, 2011). Henwood and Pidgeon's (2003) stance demands that researchers subject our ideas and early theoretical interpretations to rigorous scrutiny. This means that grounded theorists must think critically, question their underlying assumptions and assume a curious and skeptical attitude to the extant literature, *throughout* the study (Thornberg, 2012).

Pragmatically, theoretical agnosticism as an approach to the literature works for this project. Firstly, because I have previous experience of working in a children's hospice and have witnessed seriously ill children and young people receive dreams and wishes from organisations like Dreams come True. As such, I had expectations of what I might find in my data. Additionally, prior to beginning my PhD, or considering my grounded theory approach I briefly reviewed the literature and found scarce, but existing discussion on dream fulfilment. It would be difficult to have ignored this existing understanding prior to, and while, collecting data. Theoretical agnosticism acknowledges that extant theories and concepts might aid researchers in drawing attention to potentially relevant features

(Thornberg, 2012) and thus I critically examined the papers that were published in the field during the duration of my PhD.

Methodologically theoretical agnosticism as an approach to the literature does not reflect my utilisation of Charmaz's constructivist grounded theory. Theoretical agnosticism is epistemologically different to constructivist grounded theory's *tabula rasa* approach to the literature, in that my prior exposure to the substantive literature means that I entered the field and began interpreting data perhaps blinded by what Charmaz (1990) calls preconceived conceptual ideas. I recognise my departure from Charmaz's constructivist methodology, but my exposure to the literature prior to the study beginning, could not be avoided, or unseen. I also argue that due to the few papers on the subject, my understanding of dream and wish fulfilment was limited prior to data collection or analysis.

The existing literature thus played a role in the development of the findings presented in this thesis. However, in line with Henwood and Pidgeon's (2003) stance I remained critical and curious about this literature. I read more widely when my categories were developed. In line with Charmaz's constructivist grounded theory, the literature was then used to situate my findings, and look at how my theory was both similar to and different to existing understanding of dream and wish fulfilment.

3.9 Iterative nature of grounded theory

Prior to discussing grounded theory process further, it is useful to reiterate that the strategies presented in this chapter are used iteratively throughout grounded theory research processes. Ideas from data collection and analysis are explored through sampling. New data is then analysed further, so as to check initial hypotheses in participant experience. Once categories are established the literature can be reviewed, and findings situated and contextualised. This iterative process is a major strength of the grounded theory method; because analysis and data collection proceed simultaneously, a researcher can follow up on ideas as he or she creates them. Thus researchers can use the method to examine an issue thoroughly rather than to rely on previously collected data, which may address the issue incompletely (Charmaz, 1990).

Grounded theory's iterative method follows data, and as such data also dictate when data collection should cease. The literature (Guest et al, 2006; Morse, 1991) suggests that data collection ceases when the researcher has collected adequate data to fully account

for and explain developed categories. This stopping point is called theoretical saturation and it is the endpoint of theoretical sampling, grounded theory's sampling strategy, outlined previously. Theoretical saturation is the product of grounded theory's, theory driven and iterative process of data collection (Charmaz, 2014). Theoretical saturation is described in detail later in this section, alongside other grounded theory processes. I begin with sampling.

3.10 Sampling

Grounded theory as a method utilises a theoretical sampling approach. Theoretical sampling is a specific type of non-probability sampling (Mays and Pope, 1995) that is driven by evolving theory (Strauss, 1987). Theoretical sampling involves starting with data, constructing tentative ideas about that data, and then sampling theoretically so as to obtain data to help explicate the existing categories (Charmaz, 2006). It is part of an iterative methodological process involving data collection and data analysis, with each aspect informing the other.

The purpose of using theoretical strategy is not to establish a random or representative sample drawn from a population (Bowen, 2008). Rather, theoretical sampling works to identify specific groups of people who either possess characteristics or live in circumstances relevant to the phenomenon being studied (Mays and Pope, 1995). Sampling in grounded theory is thus driven by category development, and as such these samples are theoretically informed and relevant to the research question, rather than being statistically representative of a population.

Theoretical sampling involves making sampling decisions based on data and emerging analysis. However, at the beginning of a study researchers have no evolving theory on which to base sampling decisions on (Cutcliffe, 2000). Researchers therefore need theoretical 'jumping off' points from which to begin theory development (Thompson, 1999, 816). In grounded theory, such jumping off points are based on a researcher's sensitizing concepts. Sensitizing concepts is the name given to a researcher's background assumptions and disciplinary perspectives (Charmaz, 2006). Such assumptions and perspectives shape research topics and provide initial ideas to pursue. They provide starting points for building analysis (Charmaz, 2003). Breckenridge and Jones (2009) however warn researchers that pre-existing knowledge can guide the researcher in

identifying a starting point for data collection, but that such knowledge should be awarded no relevance until validated or dismissed by the formulation of the emerging theory.

The 'jumping off' point for this project, and subsequent data directed sampling strategy is detailed in the methods section, in section four.

3.11 Coding

Coding is the process of defining data. And, unlike methods of analysis that apply preconceived coding frameworks to data, grounded theory coding is about creating relevant codes as data is studied. Coding is "an iterative, inductive, yet reductive process that organizes data, from which the researcher can then construct themes, essences, descriptions, and theories." (Walker and Myrick, 2006, 547).

Line by line coding is recommended during the initial coding phase (Charmaz, 1990). Line by line coding is about asking questions of data such as what is going on; what are people doing; how do context and structure support actions and statement? (Charmaz, 1996). Charmaz also recommends that researchers initially code their data using gerunds (2007). Coding with gerunds, that is, noun forms of verbs, such as revealing, defining, feeling, or wanting, "helps to define what is happening in a fragment of data or a description of an incident. Gerunds enable grounded theorists to see implicit processes, to make connections between codes, and to keep their analyses active and emergent." (Charmaz, 2008, 164)

Additionally, Charmaz (2012) prompts the researcher to remain active within the whole process - emphasizing the importance of action, with actions being embedded into codes, and eventually categories. Coding is "about categorising segments of data with a short name that simultaneously summarizes and accounts for each piece of data" (Charmaz, 2006, 43).

Murray and Chamberlain (1999) write that focused coding is about the process of developing initial codes into more general categories. This stage of the process is about deciding what codes make the most analytic sense, and which categorize data most completely. Focused codes can then be used to both synthesize and explain larger segments of data (Charmaz, 2006). These larger segments of data, explained by codes that explain data most succinctly are the basis of categories. Such categories are

developed through constant comparison and memo writing. More detail on raising codes to conceptual categories follows.

3.12 Raising codes to concepts

Charmaz (1996) writes that raising codes to conceptual categories is about explicating the properties of a category. By this, Charmaz means taking a code, and defining and analysing it. This is done through identifying properties and characteristics, and specifying the conditions under which a process or relationship arises. The code in effect, moves beyond a description of an event or a topic and becomes conceptual. The category at this point, also becomes linked to, and integrated within other categories. Raising a code to the conceptual level, "first means deciding that the term reflects a significant process, relationship, event or issue. Second, it means explicitly deciding to follow up on it, in making connections between it in subsequent data collection. Third it means making connections between it and other conceptual categories" (Charmaz, 1990, 1169). Making connections between categories is conducted through the process of constant comparison and memo writing. Both processes are described later in this section.

Prior to discussing memo writing and constant comparison I present an example from my data of how I developed a series of codes into a conceptual category. I provide this example, as the process of categorisation can appear vague. I use my category of agency to illustrate the process of raising codes to a category. Agency is a developed category about the perception of responsibility that young people felt in choosing a dream. It started as a series of codes describing control and choice. Through comparing codes about control and choice with each other, and looking at the contexts that control as a code described, I began to define the meaning and condition of the perception of choice. I called my category agency, and by adapting my interview schedule to include questions around choice and control, was able to extend meaning to my category. Further comparison and questioning of my data helped me define the conditions of the category. The constant comparison and memory writing aspects of the constructivist grounded theory process are discussed next.

3.13 Constant comparison

Constant comparison is a central aspect of the grounded theory methodology and an aspect of the grounded theory research process agreed upon by Glaser and Strauss (1967), Strauss and Corbin (1990), and Charmaz (1990; 2006; 2014). It is, as the name suggests about the comparison of interviews and concepts and processes found within data, to each other. Basinger et al (2015) explain that constant comparison involves repeatedly assessing similarities and differences within the data, such as within participants' experiences and between participants' narratives. Charmaz (2007) recommends that researchers compare interview statements and incidents within the same interview, and compare statements and incidents within different interviews. She recommends that researchers compare earlier and later interviews, as well as observations of different times and places. Strauss and Corbin (1990) argue that making comparisons assist the researcher in guarding against bias as you are constantly challenging what you think about the data, with the data. The purpose of constantly comparing existing data with new data, and established codes with newer codes is to begin the process of raising descriptive codes to conceptual categories.

3.14 Memo writing

In addition to constant comparison, memoing is a way to help researchers define categories. As a strategy, it is most commonly associated with grounded theory, yet it is not specific to the method (Birks and Mills, 2008). Memo writing supports the development of theory through reflection and exploration. It is about looking at the data from different perspectives and reflecting on established thoughts and ideas in a kind of self-dialogue. Glaser (1978) suggests that a memo could be a sentence, a paragraph, or a few pages, with the aim being to develop the properties of a category.

Although there does not appear to be a right or wrong way to construct memos to support theory development, I used Charmaz's (2006) guidance on memo writing. Charmaz (2006) suggests prompts such as, 'what is taken for granted?' And, 'what connections can I make?' to develop ideas and fullness of categories. Examples of my written memos, and the way in which they contributed to my research process are detailed in section four. The function of memo writing is to contribute to category and theory development. As such,

finished memos can be kept as a kind of audit trail, or tossed out (Charmaz, 1996), as the memos themselves are not important. Memo writing's role is, like many aspects of constructivist grounded theory, about process.

3.15 Theoretical saturation

As discussed, theoretical saturation is the endpoint of theoretical sampling. It refers to the point in data collection when no new additional data are found that develop aspects of a conceptual category (Francis et al, 2010). In grounded theory saturation does not refer to the point at which no new ideas emerge, nor is it about witnessing repetition of events or stories (Charmaz, 2006). Rather saturation in grounded theory means the point at which "categories are fully accounted for, the variability between them are explained and the relationships between them are tested and validated and thus a theory can emerge" (O'Rielley and Parker, 2012, 192). Charmaz (2006) adds that theoretical saturation is where further data no longer prompts new distinctions or refinements to emerging theory. Conducting research in this way means that data collection ends when the aims of the study have been fully addressed.

For clarity, theoretical saturation in this discussion is about the saturation of categories, rather than saturation of generated theory. This is due to the literature's focus on categorical saturation, and the absence of literature on the saturation of actual theory in grounded theory research. I highlight the literature's focus on the saturation of categories with the following extracts,

- Theoretical saturation, in effect, is the point at which no new insights are obtained, no new themes are identified, and no issues arise regarding a *category* of data (Strauss and Corbin, 1990).

- When one *category* is saturated, nothing remains but to go on to new groups for data on other *categories*, and attempt to saturate these *categories* also (Glaser and Strauss, 1967).

- Saturation of all *categories* signifies the point at which to end the research (Morse, 1995).

- Theoretical sampling allows researchers to 'saturate' their theoretical *categories*. Saturation occurs when researchers find no new properties of these *categories* (Charmaz, 2015).

While not wishing to pick fault in the work cited above, I reference it to show the lack of discussion on saturation of generated theory. I thus continue my discussion of theoretical saturation with a focus on categories. I return to theory generation in the following section.

Although theoretical saturation is the most commonly mentioned justification for a stated sample size in qualitative research (Emmel, 2013) and cited as a key feature of qualitative work (Morse, 1995), there is little literature on how saturation might be determined; no practical guidelines for estimating sample sizes (Guest et al, 2006); and no tests of adequacy for estimating the sample size required to reach saturation (Morse, 1995). This makes it difficult for novice grounded theorists to estimate the number of individuals required for a grounded theory study.

In light of the apparent lack of guidance on what constitutes saturation in qualitative research, Guest et al (2006) conducted a study to find out how many interviews might be needed to get a reliable sense of what constituted thematic exhaustion, or saturation. Thus, these researchers conducted a series of interviews in which they documented theme identification. Guest et al (2006) documented theme progression until 60 interviews had been conducted. In doing so, these researchers reported that 92 per cent of all codes were identified after 12 interviews and 97% of the 'important' codes (operationalised as the number of individuals expressing the same idea) were identified within these 12 interviews. Guest et al (2006) thus conclude that 12 interviews is sufficient for a qualitative study.

An additional attempt to elicit guidance on sample size in qualitative research, Mason (2010) analysed 660 PhD studies that referenced saturation as a justification for sample size. Mason's (2010) results showed that the mean sample size constituting saturation was 31. While interesting, this average included a range of sample sizes from one up to 95. This wide ranging distribution means that Mason's (2010) study is relatively meaningless in terms of guiding novice researchers towards a widely used or normative sample size.

However, Mason's (2010) finding of 31 fits with Adler and Adler's (2012) advice of sampling 30 participants, reported in the National Centre for Research Methods' '*How many qualitative interviews is enough?*" expert voices paper (Baker and Edwards, 2012). Adler and Adler (2012) suggest 30 as this number offers the advantage of moving beyond a small number of people without imposing the hardship of endless data gathering. Within the same paper, Ragin (2012) suggests 50 cases for a doctoral thesis.

While such advice is helpful, the 'How many qualitative interviews is enough' paper is not based on grounded theory studies, and for the most part is not concerned with saturation. However I include this discussion here as there is little other literature to draw upon in this section on sample size and saturation. Guest et al (2006) and Mason's (2010) studies are useful in that they make explicit some of the sample sizes representing saturation within qualitative research, providing a sense of guidance and example.

Although a novice researcher like myself would prefer more guidance on how to achieve theoretical saturation, it is apparent that there are good reasons for the difficulty in establishing a set of guidelines around theoretical saturation for grounded theorists. Charmaz (2006) for example, suggests that a small study might achieve theoretical saturation more quickly than a study that is aiming to describe a process that spans disciplines. A smaller study might be assumed to require less data to generate a helpful theory than a larger study and will therefore have a smaller overall sample size. Charmaz also writes that uncritical or limited analytic treatment can also lead to early saturation of categories.

In addition to methodological influences, Flick (2012), as part of the expert voices paper, reports that there are a number of other, outside determinants that influence the question of sample size. These include the time given to conduct a research project, recruitment, and the institutional demands of ethics committees. Flick (2012) thus acknowledges that while methodological and epistemological considerations should in practice be more important in answering the 'how many' question, external factors also play a role in determining sample size.

Flick's (2012) experience make it clear that theoretical sampling in grounded theory is not as clear cut as Marshall's (1996) advice on sample sizes: this being that "an appropriate sample size for a qualitative study is one that adequately answers the research question" (Marshall, 1996, 524). However, although I was constrained by time, and by difficulties

retaining some participants in research due to illness, I reached saturation with my developed categories through the utilisation of the grounded theory research processes outlined in this chapter. I conducted 62 interviews in total, in 21 different families. I reached theoretical saturation with some categories sooner than others. Saturated categories were put to one side while I focused on collecting additional data to refine the properties of others. My sampling process is detailed in full in section four as part of my application of methods section. I now move on to discuss theory generation in grounded theory research.

3.16 Theory generation

Theory generation is arguably the point of grounded theory research. Grounded theory, i.e. the result of a grounded theory study, refers to a "theory that is generated in the course of the close inspection and analysis of qualitative data" (Henwood and Pidgeon, 1992, 103). Although the literature acknowledges that theory generation is the outcome of a grounded theory research project (Wacker, 1998; Myrick and walker, 2006; Glaser and Strauss, 1967; Charmaz, 1990), many researchers claiming to use grounded theory methods do not present an eventual theory (Templeman, Robinson and McKenna, 2015; Plakas, Cant, and Taket, 2009; Mossin and Landmark, 2011).

The lack of theory in grounded theory research is however not surprising given the little published work on the process of generating theory in a grounded theory project. And, the absence of developed theories that show explicitly how raw data was transformed into such theories, through the application of grounded theory research strategies. Charmaz (2015) agrees, writing that,

> "Many researchers identify grounded theory as their
> analytic approach, but do most engage in theory
> construction? No, relatively few researchers have
> taken grounded theory into explicit theory
> construction despite numerous claims to having
> done so. More accurately, grounded theory has
> been invoked to explain conducting qualitative
> research. Some researchers align themselves with
> grounded theory because they engage in inductive
> inquiry…simultaneously, grounded theory has
> become a general method of analysis, and its

> *strategies have been diluted and generalized as*
> *they have become routine practices in qualitative*
> *research"* (Charmaz, 2015, 402)

Although the literature is lacking a wide ranging discussion on theory generation, there are a number of grounded theorists that recognise the absence of discussion of theory generation, and who have made attempts to close the gap (Charmaz, 2015; Scott, 2004; Whetten, 1989).

Prior to examining the process of theory generation in a grounded theory study, it is useful to first highlight what a theory is. Glaser and Strauss (1967) argue that the jobs of theory in sociology are, to enable prediction and explanation of behaviour, to be useful, to be useable in practical applications, to provide a perspective on behaviour, and to guide and provide a style for research on particular areas of behaviour.

Glaser and Strauss' (1967) definition of theory is helpful. However, such a definition is reflective of classic grounded theory's objectivist underpinnings in that it assumes that reality can be discovered, and thus, through the generation of theory, that reality can be predicted. Such an objectivist definition of theory, while useful does not reflect Charmaz's assumption of multiple and layered constructions of reality. This thesis is a constructivist one, and as such, I look to Charmaz for an alternative definition appropriate to my study's methodology.

Charmaz's conceptualisation of theory emphasises understanding rather than explanation. The constructivist perspective views theory as abstract and interpretative, rather than linear (Charmaz, 2006). Charmaz's (2006) constructivist theory, "assumes emergent, multiple realities, indeterminacy… truth as provisional, and social life as processual" (Charmaz, 2006, 126). My discussion of theory generation thus utilises Charmaz's (2006) description of a grounded theory, theory as its definition.

As discussed, theory generation is the end point, and destination of a grounded theory study. However, in my review of the methodological literature on grounded theory, I perceive there to be a focus on data collection, data analysis through coding, memoing, constant comparison and theoretical saturation. Theoretical saturation being where discussion of grounded theory strategy appears to end (Fassinger, 2005; Bowen, 2008;

Mills et al, 2006). Statements such as, "the theory emerges through a close and careful analysis of the data" (Lingard et al, 2008, 459) being an example of how theory generation in grounded theory is explained. Although not my intention to critique the work of others, it is frustrating to be a novice grounded theorist, with little literature or support available in how to actually move past data analysis and generate a grounded theory.

However, there are a small number of grounded theorists who do discuss theory, and theory generation. Charmaz for example has recently written a paper on just this. Charmaz's (2015) paper on theorizing in grounded theory (a response perhaps to the absence of discussion on theory generation), proposes an engagement in abductive reasoning as the crucial part of theory generation. Abduction is the process by which useful explanations are developed from observed facts (Richardson and Kramer, 2006). As such, abduction is the appropriate method for making sense of new situations Cunningham (1998).

Charmaz (2015) suggests that the most helpful way to engage in abduction is to "expand the range of theoretical possibilities and subsequently confirm which hypothesis offers the best theoretical account for the data." (Charmaz, 2015, 406).

So, theory generation is partly about developing potential explanations and checking them in subsequent data. In this sense, Charmaz's (2015) advice on theory building in a constructivist grounded theory is similar to what Whetten (1989) calls propositions. Whetten (1989), writing on theory building in management suggests that in building a theory, theorists need to consider the who, where, when, what, how and whys of a phenomenon. Propositions are the relationships that link the developed categories. These propositions should be tested in various situations. Although my approach to theory is not about testing, or discovering truth, Whetten's (1989) suggestion of thinking about the who, where, when, what, how and whys of a phenomenon, and the relationships between those questions, are useful in generating potential theoretical accounts of data. These potential theoretical accounts can then go on to be checked, or confirmed in subsequent data as Charmaz (2015) suggests.

Asking questions of data (Whetten, 1989) is similar to what Scott (2004) and Scott and Howell (2008) might call a coding matrix. A coding matrix "identifies the relationships and interactions of the categories with the others, and also describes how the consequences of each category are understood" (Scott, 2004, 120). The matrix supports researchers in

defining the properties and processes of categories through the asking of questions. Like Whetten's (1989) how, what, why questions, Scott (2004) recommends questions such as how does the category occur? Scott and Howell (2008) write that asking when, where, and why questions identify contextual conditions and boundaries. Asking how a category occurs identifies actions and interactions among the categories, including the notion of processes over time. These researchers propose that asking such questions provides depth and understanding consequences, which aids theory development.

Coding matrices, while useful appear inflexible and prescriptive, when looked at with a constructivist lens. They also reflect Strauss and Corbin's (1990) prescriptive approach to the grounded theory method, which also emphasised coding frameworks.

However, Charmaz (2006) too suggests that researchers ask questions of their data to support the generation of theory. Rather than asking prescribed questions as part of a coding framework (Strauss and Corbin, 1990) or matrix (Scott, 2004), Charmaz (2006) suggests questions such as "what does the data suggest?" or "from whose point of view?" In identifying relationships and processes, Charmaz (2006) suggests, "How does the participant act while involved in this phenomenon?" (Charmaz, 2006, 212). In line with constructionism, Charmaz's (2006) questions look for understanding, rather than explanation.

Defining the theory generation process is difficult, and in developing my own theory, and writing this section of the thesis I have a greater understanding of why researchers perhaps avoid, or limit their discussion of theory generation in grounded theory. However, by developing hypotheses and checking them with participants, asking questions which examined process and understanding, using constant comparison and memo writing, and being reflexive throughout my data collection and analysis helped me to develop my theory, which is presented in my findings chapter.

My next section is about transparency and credibility in qualitative research.

3.17 Credibility in qualitative research

Morse et al (2002) argue that without rigour, research is worthless, becomes fiction and loses its utility. Therefore, a great deal of attention is given to improving or judging the quality of qualitative research (Seale, 1999). However, determining the credibility of

qualitative research remains a contested area (Cutcliffe and Mckenna, 2002), this contestation primarily being about whether qualitative methods should be assessed by the same criteria as quantitative methods (Mays and Pope, 2000).

Whether qualitative research should use, and be judged by the same constructs as the natural sciences is epistemological, and concerned with the nature of knowledge within the rationalistic (quantitative) and naturalistic (qualitative) paradigms. The consensus view amongst qualitative researchers (Guba and Lincoln, 1994; LeCompte and Goetz, 1982; and Seale, 1999), is that the nature of knowledge in each paradigm is different, and requires paradigm-specific criteria for establishing rigour (quantitative) / trustworthiness (qualitative). It is important to note that this rejection of validity as a marker of quality does not mean that qualitative research should not be subject to any judgement at all, but that criteria appropriate to qualitative enquiry should be used to judge qualitative research.

Recognising that qualitative research is different to quantitative research and therefore "assessed from an internal logic of its own method, not by inappropriate application of external criteria founded in other methods" (Charmaz, 1990, 1164) means substituting new criteria for validity and reliability to reflect interpretivist conceptions (Seale, 1999). Guba and Lincoln (1994) for example advocate that trustworthiness should replace reliability and validity. Seale (1999) too proposes that qualitative researchers should be concerned with credibility rather than truth-value.

Emerging from discussions about how to evaluate qualitative research are a series of guidelines, constructed by various researchers with an interest in evaluation in qualitative research. Such guidelines include Elliott, Fischer and Rennie's (1999) guidelines for qualitative research in psychology; Guba and Lincoln's (2001) guidelines for constructivist evaluation; Patton's (1999) quality and credibility in qualitative analysis paper; and Mays and Pope's (2000) assessing quality in qualitative research guidelines. This section of the thesis demonstrates how I have utilised such guidelines, and incorporated techniques to enhance the quality, trustworthiness and credibility of my research. The first concept discussed is negative case analysis.

3.17.1 Negative case analysis

Negative case analysis, also known as disconfirming evidence or deviant case analysis, is the search for data that disconfirms established categories (Cresswell and Miller, 2000). It

is the seeking out of informants whose experiences might not confirm an emerging hypothesis, or whose experiences might refute an emerging theory (Schrieber and Stern, 2001; Guba and Lincoln, 1985). In engaging in this process, the researcher incorporates and accounts for the maximum variety of meanings and behaviours related to a phenomenon (Schrieber and Stern, 2001).

Although negative case analysis is a way of providing a credibility check, the search for negative cases is embedded in grounded theory methodology. Charmaz (2006) writes that researchers often use negative cases to provide alternative explanations for their developing theory, and that such negative cases are actively sought out by researcher so as to challenge and refute developing theory.

Individuals, or cases, that refute emerging conceptualisations, force the researcher to think abstractly and develop concepts and explanations that account for the fullest range of data (Henwood and Pidgeon, 1992; Schrieber and Stern, 2001). Negative case analysis encourages alternate explanations and refinement of theory (Charmaz, 2006), and in doing so, increases a study's reach and exploratory power (Strauss and Corbin, 1998).

As well as exploring alternative explanations for data collected, Mays and Pope (2000) report that the search for negative cases reduces error in qualitative research, and therefore increases the credibility of research reports. Lincoln and Guba (1985) agree, making negative case analysis a part of their 'trustworthiness' criteria: a strategy outlining methods to ensure rigour in qualitative research.

Multiple researcher analysis is the next aspect of my check for credibility. Unlike negative case analysis, this is not embedded within the constructivist, or rather any approach to grounded theory. However, I utilise it to maximise transparency, and like negative case analysis, to challenge and develop emerging understandings of data.

3.17.2 Multiple researcher analysis

Multiple researcher analysis or second person coding is a research strategy that works to bring varied perspectives to qualitative research. It is about researchers with previously analysed data, asking other researchers to review their analysis for discrepancies, overstatements or errors (Elliot, Fischer and Rennie, 1999). The literature concerning

credibility in qualitative research (Patton, 1999, Barbour, 2001, Morse et al, 2009, Lincoln and Guba, 1985) proposes that the objective of multiple researcher analysis is about substantiating findings through mutual confirmation.

Primary definitions of multiple researcher analysis, such as those around checking and confirmation of findings are reminiscent of the positivist paradigm's concern with truthfulness and objectivity. Such definitions do not fit well with the social constructivist paradigm that this study sits within. Other arguments however, as to why multiple researcher analysis is a useful part of a grounded theory research process sit more comfortably within the constructivist paradigm. Elliott et al (1999) for example, recommend using the technique for comparing varied qualitative perspectives. Rather than the independent assessment of a second researcher looking for agreement (Pope and Mays, 1995) or consistency of findings (Madill, Jordan and Shirley, 2000), the purpose of multiple researchers from this perspective, is to explore alternative insights, leading to a deeper understanding of phenomenon.

To access these alternate insights, Barbour (2001) recommends that researchers do not individually code entire datasets, but independently code one transcript, to facilitate discussion and refine coding frames. Patton (1999) asks researchers to consider differing logical possibilities and then check if these possibilities can be supported by data. He stresses that this is not a matter of looking for clear cut yes or no answers, rather, considering the weight of evidence and looking for the best fit between data and analysis (Patton, 1999). I show how I conducted multiple researcher analysis within my theory generation in the following methods chapter.

3.17.3 Respondent validation

Respondent validation, like negative case analysis is both a procedure outlined in the literature on enhancing credibility and an integral part of the grounded theory method. Respondent validation, also known as member checking, is a research phase during which a provisional report is taken back to a participant and subjected to the scrutiny of the persons who provided the information (Lincoln & Guba, 1985). Morse (2002) proposes that respondent validation is about confirming, making sure and being certain. Lincoln and Guba (1985) describe member checks as the most crucial technique for establishing credibility in a qualitative study.

Respondent validation as a strategy of checking and refining is built into each interview, rather than being a one-off procedure. Rather than presenting transcripts or interpretations back to the participants from which the reports emerged, grounded theory methods assert that researchers present developing categories to new participants (Charmaz, 1990). Interview schedules are adapted as theory is adapted and refined by both participants and researchers (Charmaz, 1996). As such respondent validation is built into the process of collecting research and refining findings throughout the process of collecting data. In this sense, theory is co-constructed as it is constantly adapted and refined by both researcher and participants.

As such, the aim of respondent validation is not to make sure, or be certain (Morse, 2009). Rather respondent validation is part of a process "which generates further original data, which in turn requires interpretation" (Mays and Pope, 2000, 51). And Charmaz (1996) asks researchers analysing interview transcripts to see emerging perspectives as one among many, with issues or themes emerging from data being checked for relevance with further participants, developed further, and held up against other potential explanations before earning its way into a final set of results. Charmaz (1990) states that researchers can and should test reported theories through standard logical-deductive verification procedures, such as member checking.

Negative case analysis, multiple researcher analysis and respondent validation were used to maximise transparency, challenge my personal biases as a researcher, and refute developing theory. As discussed, grounded theory as a method builds in checks of credibility, such as negative case analysis and respondent validation. However, I added multiple researcher analysis to additionally challenge and refute my developing theory and potential biases. It is hoped that by making such processes transparent the grounded theory that I present in my findings section will be considered credible and trustworthy.

My discussion on credibility concludes my methodology section. I thus move on to show how I applied the methods discussed here in generating my grounded theory.

Chapter 4: Methods

This section describes the application of constructivist grounded theory methods in the generation of a theory conceptualising the impact of dream fulfilment. It details why and when families were interviewed, and how I generated codes and categories guided sampling. I discuss ethical amendments to my research process and show how I applied grounded theory strategies such as memoing and constant comparison to my data. I begin with data collection.

4.1 Identifying the sample

DCT hold a database which contains details of all children and young people who have had a dream fulfilled by the charity in the last five years. DCT randomly identified 50 families from the database using a random number generating internet tool. DCT staff accessed the database in order that data protection laws were not breeched and their users' confidentiality not compromised. The database contains information on: child age, family makeup (number of siblings for example), type of dream, date the dream was fulfilled, and the child's health condition.

4.2 Contacting families

The 50 randomly-sampled families were written to by DCT. The initial letter served to introduce the researcher and the study, provide information on the study in the form of an information sheet (see appendices A, B and C respectively) including what would be expected of them if they choose to be involved. It also outlined data protection and confidentiality. Families were asked to opt-into or opt-out of further research by filling in the relevant form (for 'Yes please' and 'No thank you' forms, please see Appendices E and F) and returning the form to me at the University of Stirling.

All research materials were scrutinised and commented on by members of three different families whose children have had dreams fulfilled by Dreams Come True. One of the families was bereaved. They confirmed that all the information provided was clear, transparent, and easily understood. The families provided feedback that led to changes in the wording of the documents in the appendices, and in particular advised that I should be

direct about using the term death/dead when referring to the potential for a child to have died (rather than synonyms such as 'passed away'.)

4.3 Selecting the sample

From those families who returned an opt-in form indicating interest in a research interview, I invited three families to participate in the first tranche of data collection. This sample was based on my sensitizing concepts, which as discussed are background ideas from which researchers begin sampling (Charmaz, 2003).

I selected families based on my sensitizing concepts. These were the child's age at the time of their dream, the time since the child's dream, and the child's condition (life-threatening or long-term). These concepts were based on my own experience working in a children's hospice. I also included a bereaved family in my initial sample so as to examine the impact that dream fulfilment had on families, after the dream-recipient died. The initial sample of three families therefore comprised a mixture of families who represented a range of age groups, conditions and whose dream happened between one and five years previously. Table 3 details my initial sample.

Family	Condition	Dream	Time since dream	Family members interviewed	Individual or family interview
1	Autism	Disneyland	< 6 months	Mum, dad, dream recipient (age 7), sibling	Family interview
2	Cancer (in remission)	To meet a dragon	1 year	Mum, dream recipient (age 12)	Individual interviews
3	Genetic condition (deceased)	To meet a giraffe	> 3 years	Mum and dad. Dream recipient had been 5 at the time of dream	Family interview

Table 3: Initial Sample.

Interviews were my primary method of data collection. Interviews were chosen as they permit an in-depth exploration of a particular topic or experience. They allow researchers to go beneath the surface of a described experience; request more detail; restate points to check for accuracy; and ask about feelings or actions (Charmaz, 2006). After gaining consent and assent (please refer to section 2.5 for a detailed review of ethical

considerations and procedures) from family members, interviews were conducted with dream recipients and family members.

A semi-structured interview schedule was followed initially. However, in line with grounded theory's iterative process, questions were adapted for subsequent interviews, based on analysis emerging from previous interviews. Interviews were arranged at a time best suited to participants, and I ensured participants knew that I could be flexible with interview timings. This was in line with MOREcare recommendations for ethical end of life research (Gysels et al, 2013). I also ensured that interview questions were adjusted to compensate for varying developmental stages (Krisjanson et al, 1997), and that familiar examples were used to help younger people understand concepts such as confidentiality. I used a word search game to help children and young people understand concepts such as consent (Appendix D).

Tomlinson et al (2007) explain that parents of dying children are most likely to refuse to participate in studies if they see the research as too involved or burdensome. Thus, time spent with the family was kept to a minimum. Interviews lasted approximately 45 minutes per participant. However, this was much shorter for some young children, or seriously ill participants.

Interviews were conducted as much as possible with only the participant and myself present. This was to allow family members to give more detailed accounts of phenomena (Gardner and Randall, 2012). Studies by authors such as Mauthner (1997) and Garth et al (2009) found that the opinions of children interviewed with their parents present were different from those gained when the children were alone. Speaking to participants alone however was not always possible, due to parents' interest in the interviews, and parents' wish to support children during the interview process. Although I asked parents to adopt an observer role in such situations, some children looked to their parents to fill in gaps or add detail to their narratives, and thus parents would became a part of the interview process. One telephone interview was conducted with a dream recipient.

I also attempted to interview adults alone. This was to avoid children hearing their parent or guardian's (potentially) upsetting thoughts, feelings or experiences, and for this to cause distress or upset. When organising interviews I asked if it would be possible to have another adult present to look after children for the duration of the interview. This

however was not possible for many families, and thus in some cases, children were present for their parents' interviews.

In addition to using interviews I trialled the use of the participatory communication resource Talking Mats© in this study. As discussed, Talking Mats is "a low tech communication resource which helps understanding and supports expression" (Murphy and Cameron, 2008, 232). Talking Mats has been successfully utilised in research with children with learning disabilities (Germain, 2004) and those with little or no speech (Brewster, 2004). The resource uses picture cards that participants can use to tell stories with. Participants are presented with a series of cards, and asked to arrange them on a black mat, creating as the name suggests a talking mat. Photos can then be taken of the arrangement and used as data and analysed further.

My aim with using Talking Mats© was not to use the tool's output to analyse data, but rather use the visual and creative aspects of the resource to stimulate communication with young children, and those with communication difficulties. However, the children in my study preferred to engage in traditional interviews, using their own photographs and dream mementos to facilitate communication. Talking Mats was offered as a resource throughout the first half of the research process, after which I accepted that the tool was perhaps not appropriate for this sample. I discuss this further in the reflective section of this thesis.

4.4 Coding

Interviews were transcribed, coded, compared to each other and, as Charmaz (2006) explains, evaluated to ascertain the fit between initial research interests and data emerging from initial interviews.

After transcribing and analysing interview data, the following codes were generated, feeling special, break from routine; sibling / parental relationships, change in environment, having something to look forward to, rules of illness, good amongst difficult, memories, remembering, positive experiences, spirituality, changes in eating, feeling important, Disney magic, having fun, family time, forgetting illness, recognition of illness, pushing boundaries, exploring, new things, feeling special, adventure, and remembering. The way that these codes were refined and used to inform categories is shown in figure 2.

Memos were also written to illuminate and connect codes. Memos are researchers' ongoing dialogues with themselves throughout the grounded theory study. Memo writing allows researchers to ask questions and define what is implicit and explicit within their data (Charmaz, 1990). An example of a memo written after these initial interviews was:

Illness acts almost like a member of these families. It seems absolutely central to the family system, dictating what the family does, what it can do / eat. Siblings are pushed outwards. The dream might change this. Dreams seem to replace illness at the centre of the family for this dream time, the dream, rather than illness dictated what happened in the family. The dream is positive. Can I find out how much the illness was a part of family life after the dream? (Memo)

Time since dream, or age of the dream recipient did not appear important and therefore these initial sampling directives were discarded. Type of condition however did appear important, especially to those families where a condition had led to the death of a child / children.

Initial coding from interviews one to three, led me to invite families four and five to interview. Families four and five were chosen as family four's details suggested that they could add to data on sibling relationships. Family five were also interviewed to extend understanding on dream fulfilment and bereavement. Families four and five are described in table 4 below.

During this period of data collection, I had arranged to interview an additional family, so as to add data to my understanding of life threatening illness, and dream fulfilment's impact on siblings. However, the family cancelled due to illness and I was unable to re-arrange the interview. Additionally, I had arranged to interview a further sibling as part of family five, but at the time of interview, the young person was not available for interview.

Family	Condition	Dream	Family members interviewed	Individual or family interview
4	Leukaemia	Holiday	Mum, dream recipient, sibling	Individual
5	Brain tumour (deceased)	Disneyland	Mum, dad, sibling	Individual

Table 4: Sample

I was however able to collect useful data from families four and five. Data from interviews four and five added codes such as; coping; planning; making memories; family; Disney as a normal childhood experience; having a break; dream as a milestone; kindness; grief; loss; limitations of dream; feeling normal; limitations of illness; memory objects; rollercoasters/ice cream as novelty; and focus. These codes are shown in figure two.

In addition to the creation of new codes, interviews four and five expanded and added detail to existing codes, which at this point were beginning to develop into preliminary categories. The category of continuing bonds emerged, beginning to explain the experience and impact of dream fulfilment in bereavement.

I used multiple researcher analysis at this point to search for perspective, as Barbour (2001) and Patton (1999) recommend. As a novice researcher I was concerned about missing an important or interesting concept. I also wanted to ensure that my bias as a researcher was not blinding me to seeing concepts within data. As such, I asked my two supervisors to read over one interview transcript each and develop preliminary codes. After coding, we met up as a group and discussed preliminary codes and possible categories. This process led to different analytic insights, alternative explanations and new questions that I could incorporate into interview schedules and put to my existing data. This was the first of two sessions.

Although multiple researcher analysis is not a part of constructivist grounded theory, using it as a research strategy supported my search for perspective (Patton, 1999), while ensuring my study adhered to credibility guidelines outlines in the literature (Mays and Pope, 2000, Guba and Lincoln, 2001) on qualitative research. Another example of a memo documented post interview five is as follows:

Memories from the dream and good times can be in physical form. Like dad taking his son's travel cushion from the dream on his hiking trips. He's carrying a memory of his son at a happy time. Could dad use another travel cushion instead? Probably. But in this way the deceased child and the dream is carried around. A hike - this seems like another time when a family could escape from 'normal' days, does the dream carry through to this in the form of a cushion? (Memo)

Codes continued to develop into categories through processes such as memo writing and constant comparison (see figure 2). At this stage in the grounded theory process preliminary categories were: continuing bonds, distraction, and validation. However, more data was needed to expand understanding of non-cancer conditions, extend and refine existing categories, and expanding the range of dreams in the sample to meeting a celebrity. Five families were therefore sampled to further understanding. These families are shown in table 5 below. Respondent validation, or member checking, the discussion of existing findings with participants, was utilised for purposes of credibility (Seale, 1999).

I chose to interview family six, as the family had four children. Again, I wanted to collect data on the impact of dream fulfilment and illness on siblings. However, when I arrived at the family home, I was only able to interview mum. The dream recipient and siblings were not able to be there due to illness and other commitments. I was however, able to develop my understanding of the impact of dream fulfilment on siblings in future interviews.

Family	Condition	Dream	Family members interviewed	Individual or family interview
6	Leukemia (remission)	Holiday	Mum	Individual
7	Epilepsy	Disneyland	Mum, dream recipient, sibling	Family
8	Cystic Fibrosis	Disneyland	Mum, dad, dream recipients (two siblings), sibling	Family
9	Rare genetic condition	Meet a hero	Mum, dream recipient	Individual
10	Genetic condition	Holiday	Mum	Individual

Table 5. Sample

At this point in my analytic process, I began to see patterns in my data and used existing codes to capture and explain what was going on in my data. I put to one side codes that were not useful in working to explain my data. However, I was also aware that coding is an emergent process, and so revised my codes, as I collected new data. By comparing

existing codes with new ones, and existing data with new data, I utilised the constant comparison method.

After my analysis (which included coding, constant comparison and the integration of memos), of interviews six - 10, existing categories were refined, and new categories were generated from my data. New categories developed from existing and new codes (see figure 2). New categories included empowerment (holding control and alleviation of guilt), validation (in families without a cancer diagnosis), and normalisation. Decentralisation of illness also moved from a series of codes such as 'feeling normal' and 'break from routine' to a preliminary category, to be further tested and extended through future interviews. An example of a memo at this point:

Being in Disneyland seems easy to families. Everything looks beautiful, it's polished, perfect. It's not real. Risks are calculated. It's passive. Is this 'unrealness' the attraction? It's the opposite of these families' actual lives. (Memo)

Again, theoretical sampling, based on preliminary findings was utilised to select families for the next set of interviews. At this point, rather than relying on the information sheet returned by family members containing basic information about the family and dream, a phone call was necessary to ascertain whether family members would be able to extend detail to existing categories. This decision to speak briefly to family members pre-interview was taken to ethics and approved. Subsequent families were thus sampled so as to extend, challenge and refine existing categories. Families 11, 12, and 13 are detailed in table 6 below.

Family	Condition	Dream	Family members interviewed	Individual or family interview
11	Genetic condition	Holiday	Mum, dream recipient	Individual
12	Cystic Fibrosis	Holiday	Mum, dream recipient	Individual (one phone interview)
13	Muscular Dystrophy	Holiday	Mum, dream recipient	Individual

Table 6. Sample

Families 11, 12 and 13 added detail and enabled me to refine preliminary categories. Validation (in non-cancer conditions) in particular was nearing saturation at this point, with family members discussing feeling isolated from support offered to those with a cancer diagnosis.

At this point in the data collection process it became apparent that family members who received equipment as a dream had not responded. Although making up 29% of DCT's service users, response to invitation was 0. Thus, my search for negative cases began.

I utilised theoretical sampling, inviting families who had received equipment as their dream to interview. At my request, DCT sent out invitations to 50 families who had received equipment as a dream. A small number responded, and interviews followed. Additional data were also sought on the celebrity dream in this next tranche of interviews. Interviews 14, 15 and 16 are shown in table 7 below.

In searching for alternative stories I broadened my overall theory. In doing so, I added depth to my findings, and enhanced the trustworthiness of my findings through utilising credibility techniques outlined by qualitative researchers such as Patton (1999) and Lincoln and Guba (1985).

In family 14, I had expected to interview the dream recipient and mum. However, during the course of the interview, dad, a grandparent, and an auntie came to the family home. They had shared in the dream experience and wished to be interviewed. Although unplanned, I conducted the interviews, and was able to further my understanding of the dream fulfilment process.

In family 15 I had expected to interview mum and the dream recipient. However, when I got to the family home, the dream recipient did not wish to be interviewed. Instead, I was able to interview dad for a short period of time. Such changes to interview schedules reflect some of the challenges of conducting interviews with families in family homes.

Family	Condition	Dream	Family members interviewed	Individual or family interview
14	Cerebral Palsy	Met a hero	Mum, dream recipient, (dad, grandparent, auntie)	Family
15	Cancer	Equipment	Mum	Family
16	Genetic condition	Equipment	Mum, dream recipient	Individual

Table 7. Sample

The meet a hero dream added detail to existing categories, mainly, validation (through nomination for a dream), the curation of memories and decentralisation of illness. Codes developing from interviews around equipment dreams were: equipment as a second choice, equipment highlighting disability, insurance limitations, illness as constraining, practical, equipment as integrative, long-term over short term, and normalising. An example of a memo at this stage is as follows:

It seems like dreams of equipment are not really dreams at all. They help, and they are useful. I felt like mum resented not being able to go on a proper holiday with her children. The equipment dream was good in the end, but having to choose that instead of a holiday didn't feel like choosing a dream. (Memo)

Memo writing and constant comparison raised codes to preliminary categories: equipment as a social response, equipment as practical and equipment as integrating.

A further two families who received equipment were interviewed to member check and refine findings. Going into member checking with participants I was very aware of the impact of myself as a researcher and the interview process on family members. I had read studies such as that of Forbat and Henderson (2005), and Punch's (2012) work on reflexivity. I was therefore careful to manage, or at least be aware of my participants' responses to being asked to comment on developed categories and theory. However, as discussed, respondent validation in a grounded theory study is slightly different to the way in which respondent validation is used in other qualitative studies.

Rather than presenting transcripts or interpretations back to the participants from which the reports emerged, grounded theory methods assert that researchers present developing categories to new participants (Charmaz, 1990). As such, I conceptualised respondent validation as being about using participant reactions to existing categories, to help refine my existing explanations and to further develop theory. To utilise this method, participants in my study were invited to refine and comment on my findings as I developed them. Participants were asked if the categories presented to them made sense (Cresswell and Miller, 2000) and whether such categories did or did not represent their experiences of dream fulfilment. The following questions extracted from interview schedules show how I used respondent validation to develop my categories of distraction and of agency respectively:

"Did you think about illness on your [dream experience]? Some families told me that dream experiences helped them forget about being ill"

"Some young people have said that it was important for them to choose the dream themselves. Was it important to you?"

In asking questions, such as those detailed above, I was able to check if my emerging categories of distraction and agency also reflected the experiences of participants that were interviewed subsequently. Building respondent validation into my data collection process meant that I was able to both check that emergent categories reflected participant experience, and further refine my emergent categories though the collection of more data. Respondent validation was thus about the adaptation of my interview schedule so as to check and add to my developing categories.

In this way my construction of categories and theory could be checked against participants' meanings of the phenomenon (Chiovitti and Piran, 2003) as I collected more data. As such respondent validation was a part of grounded theory's iterative process, one that generated further original data, which in turn required interpretation (Mays and Pope, 2000). Families 17 and 18 are documented in table 8 below.

Family	Condition	Dream	Family members interviewed	Individual or family interview
17	ENT condition requiring tracheostomy	Equipment (TV)	Mum, dream recipient	Individual
18	Genetic condition	Equipment (adapted smartphones)	Mum, dream recipients (two)	Individual

Table 8: Sample

Preliminary categories concerning equipment were developed into fully formed categories after analysis of families 17 and 18, reaching theoretical adequacy by the final interview (conducted by telephone). With equipment dreams saturated, a final three families who experienced non-equipment dreams were theoretically sampled. These families were sampled on the basis of pre-interview telephone screenings which indicated that families could provide further insight into existing categories such as continuing bonds, agency, decentralisation of illness, dream as social confirmation of illness and post dream support void. The way in which codes and categories were refined throughout the research process is shown in figure 2.

Family	Condition	Dream	Family members interviewed	Individual or family interview
19	Liver disease (deceased)	Equipment & experiential	Mum, sibling, auntie	Family
20	Autism	Disneyland	Mum, sibling	Individual
21	Cancer	Disneyland	Mum	Individual (phone)

Table 9: Sample

The last phase of my research process involved the generation of theory. Although relationships between my categories had been developing throughout my study, I used Charmaz's (2006) questions to generate further insights. Examples of such questions

were, "how does the participant act while involved in this phenomenon?" (Charmaz, 2006, 212).

Family members in final interviews engaged in the process of member checking, allowing me to make final edits to categories and developing theory. Final interviews also confirmed thoughts about categories that could be discarded, such as dreams being a platform for testing boundaries. My generated theory explains the processes suggested by the collected data, and further conceptualises some of the findings gathered at this stage in the following chapter.

THEORY

Dream fulfilment as
reshaping illness

Dream fulfilment as an
alternative milestone

FINAL CATEGORIES

Agency, Validation, Control,
Hope, Illness Decentralisation,
Memory Curation, Continuing
Bonds, Post-dream Support Void

INITIAL CATEGORIES

Empowerment, Guilt, Control, Distraction,
Integration, Normalisation, Agency, Validation,
Control, Hope, Memory Curation, Continuing
Bonds, Post-dream absence, Development of
attachments, Equipment dreams as utilitarian

REFINING INITIAL CODES

Disney as normal, break from life, milestones, grief, continuing
bonds, limitations of dream, limitations of illness, memory objects,
continuing bonds, focus, distraction, new spaces, pushing
boundaries, attachments, impact of illness, learning, dreams as safe
adventure, feeling important, fun, recognition, dreams as hopes

INTIAL CODES

Feeling special, break from routine, sibling relationships, change in environment,
positive future, rules of illness, good amongst difficult, ice-cream, memories,
remembering, positive experiences, spirituality, fun, rollercoasters, attachments, feeling
important, family, bonds, forgetting, recognition, pushing boundaries, new spaces,
feeling special, recognition, sadness, exploring, adventure, Disney dreams as normal,
missing out, being in hospital, dreams as goals

Figure 2. Coding and theory generation process

4.5 Conclusion

This section of the thesis has provided an outline of how data was sampled, and the rationale for interviewing some families over others. It is hoped that this will clarify the grounded theory process in part, showing how analysis (coding, memoing and constant comparison) and interviews inform each other in data collection and in theory generation. Negative case analysis, multiple researcher analysis, and multiple researcher coding were three strategies utilised to embed trust and quality into my research. The search for negative cases worked to expand my developing theory's reach. Sampling and analysing negative cases challenged my thinking and helped me become more critical of my existing findings. In a similar way, asking other researchers to voice their perspectives on my data made me examine other explanations and perspectives, other than my own. My potential biases were challenged as I looked at alternative codes and categories. Respondent validation too, supported my continual critique of my own perspective on data, and ensured that the views of participants were represented in my developing theory, rather than just my own. Lastly, I have aimed to be transparent and comprehensive in the reporting of my methods.

Chapter 5: The meaning of a dream

5.1 Introduction

This chapter is the first of four chapters reporting study findings. In this initial chapter I clarify what a dream meant to participants. In chapter six I move on to present the grounded theory of dream fulfilment and accompanying theoretical model. In chapters seven and eight I detail the eight categories encompassed by the grounded theory.

5.2 The meaning of a dream to families

Prior to presenting findings around the *impact* of a dream, I present an account of what dream experiences *meant* to the children, young people and family members as part of this study. I want to provide readers with a sense of understanding of how a dream was conceptualised by family members so that findings around the impression and impact of such a concept will be more fully understood.

DCT describe the dreams they provide as far-reaching and unique experiences that bring lasting joy and memories to ill children's lives. Examples from the DCT database include Disneyland trips, celebrity meetings and one-off experiences such as publishing a book of stories. A breakdown by category of the dreams provided by the charity and the characteristics of charity users can be found in section 1.5. While it is useful to have a pragmatic understanding of dreams provided by DCT, this section on meaning moves past description of dream categories. This section provides an insight into what a dream meant to children, young people and family members.

In conceptualising the meaning of dream experiences, I use the Cambridge dictionary (2015) definition of the word *meaning* for guidance on defining and presenting such a complex concept as a dream. The word *meaning* as defined by the Cambridge Dictionary (2015) is defined by, that what something expresses or represents. I use this definition of expression and representation to present my account of what a dream experience meant to the seriously ill children and young people and family members participating in this study.

To reiterate, this section on the meaning of dream fulfilment does not constitute my findings. This section on the meaning of a dream is presented as useful context to my subsequent grounded theory on the impact of a dream on children with life-threatening

and long-term conditions, and their family members. Although the answer to the question 'what is a dream' is complex and wide-ranging, this section clarifies as much as possible the wide-ranging meaning of a dream to family members as part of this study.

5.3 The selection of dream experiences

Interview data suggest that prior to finding out about DCT, many of the participants in this study had not formally considered what a personal dream or wish might be. Where the popular media suggest that individuals with life-threatening conditions actively consider their bucket lists (catalogues of experiences or achievements to accomplish prior to death) when terminally ill, the data gathered as part of this study do not suggest that ill children or their families curate such lists.

As such, thoughts about what a dream or a wish might look like began when health professionals suggested to families that due to the serious nature of their child's condition, they might be eligible to apply to a charity offering dreams or wishes. A new diagnosis or the deterioration of a child's condition also prompted individual family members to consider requesting a dream or a wish from a third sector organisation like DCT.

Interestingly, families with children with serious, but non-life-threatening conditions were mostly unaware of their eligibility for dream fulfilment, until being informed or nominated by a health professional. Conceptualisations of dream fulfilment for the majority of family members were therefore embedded in thoughts about illness.

Jayne – "so, what made you think about having a dream?"

Mum – "It's uhh, when the doctor gave me the [application] pack, when he diagnosed my child's condition." (Mum, family 20)

"I think I just found a form in the waiting room at the hospital in the parents' room in the children's ward and thought, actually that would be quite a nice thing to do." (Mum, family 2)

Because many family members had not previously thought about having a dream fulfilled, the meanings of such dreams were often shaped by interpretations of the application process. Prompts in application forms, for example, had the potential to shape family members' initial dream choices.

"I'd never heard about it, even though I was nurse myself, to be honest I'd never really thought about that kind of thing as we were hoping that [my son] would have a liver transplant and that he'd recover from that. We never thought about those kinds of things. And then, he deteriorated, and the doctors started to talk about transplantation. I was doing the job I'm doing here now [working with children]. I had a supervisor who told me about the charities, um, so she told me about it, and we applied, and she came out and spoke to my son. I think they had a box of four – like, would you like to meet your favourite pop star, or go on holiday…" (Mum, family 19)

"We got like three choices, so obviously my first choice was I wanted to go to London." (Dream recipient, family 4)

It is important to note that the extracts above portray interpretations of the application form. The application form itself does not present dream choices as tick boxes. Structured choices may have been presented to family members by health professionals, or as examples of types of dreams by staff at the charity. Nevertheless, some family members' dream choices were influenced by perceptions of established dream categories and restrictions.

5.4 Disney as a normative childhood experience

For other family members, the meaning of a dream was shaped by societal preconceptions about what a dream holiday should look like, or a sense of pressure to provide a certain kind of childhood experience. This was particularly the case for Disneyland dreams. A Disney dream therefore meant an opportunity to experience something that was perhaps considered a normative aspect of childhood.

Mum – "I think we went to the Magic Kingdom [Disneyland] because we felt we had to see it." (Mum, family 5)

"I think it's [Disneyland] the dream holiday for children and it's something, emm, we wanted them to experience." (Mum, family 8)

Jayne – "Can I ask why you chose the group [Disneyland] trip?"

*Mum – "There were lots of options, but I don't think I could have, well they gave us lots of examples but then they told us about this Florida trip and em, I couldn't particularly think of anything else that stood out for us, and the Florida [Disneyland] group just seemed ideal as a dream because it really is!" (*Mum, family 7)

For one family, the crossing off a list phenomenon was a concept relevant to the meaning of a dream. Rather than Disneyland, this was about a long-held desire to visit Italy. For family 13, a holiday to Italy meant achieving a desired experience prior to death. A dream fulfilled meant parental relief and satisfaction for having completed something so time sensitive. Family 13 were driven to choosing their dream for reasons other than normative ideas of childhood, but felt a similar sense of obligation to achieve it, due to the pressure of time.

"It made us extremely happy that we were able to spend that time together. Because as each month goes by he gets older and older and I think the urgency was there, do you know what I mean? So when we got back we were like, 'ahhh, at least he's achieved that.' Because I mean, going to Italy, that was something he was always wanting to do and because we planned it, we were relieved that he's done it. And if anything happened we're happy to have done it" (Mum, family 13)

5.5 Dreams as learning and development experiences

While some dreams were shaped by time or social pressures, many other dreams were about individualistic desires to experience a passion or new learning experience. The

following data extracts show how dreams worked to inspire learning and interests. For some families children and young people, dreams represented opportunities for travel and exploration of interest.

"I wanted to see the musical Wicked. I was really into, before I was ill, really into musical theatre, and I went to theatre school, so I wanted to go and see Wicked…something that was a bit different." (Dream recipient, family 4)

Jayne – "So, can you tell me a bit about why you chose this dream?"

Dream recipient – "I was studying classics in college, it was about the Romans, so I wanted to go to Italy." (Dream recipient, family 13)

Dad – "He [dream recipient] was always really fascinated with giraffes, stories about giraffes, if there was a giraffe...I mean it stems from watching Disney films I suppose, doesn't it, when you're very young."

Mum – "I mean, he did like animals in general."

Dad – "He liked touching animals…he really liked when you were able to hold a guinea pig or a rabbit." (Mum and dad, bereaved, family 3)

As families 3, 4, and 13 suggest, dreams were ways that children could enrich their lives with new experiences, thus developing their interests and learning. Dreams represented a potential opportunity for growth and learning.

5.6 Dreams as an otherwise unattainable experience

"I kind of wanted to do something that, you know my mum and dad couldn't afford to do" (Dream recipient, family 4)

The dream for the young person in family 4 was a chance to experience something outside of usual financial constraints. For this young person, a dream was about the opportunity to experience something otherwise unattainable. The unattainable aspect of the experience was a characteristic that appeared to be important in differentiating the dream experience, from other enjoyable experiences. Mum in family 3 also discussed the otherwise unattainable aspect of the dream.

"If we hadn't had funding we would never have even be able to think about going somewhere like that [America] unless we'd have I dunno, won some big prize or something. So it was really good to be able to have done something like that because it was just not something we'd ever have conceived of ourselves" (Mum, family 5)

The charity also organised dream experiences that would have been otherwise difficult to facilitate regardless of a family's financial situation, such as the meeting of a hero / celebrity.

Mum – "We had two experiences, we had the meet and greet and then we went to the concert that night"

Dream recipient - "We got one to one time with them, they came in and they sang…and then they talked to us for a little while and we got pictures with them and stuff" (Mum and dream recipient, family 14)

Some families therefore conceptualised a dream experience as something that was otherwise unachievable.

5.7 Dreams as safe adventures

Additionally, dreams were conceptualised as safe adventures by parents of ill children. Dream experiences were considered safe because of the planned and protected aspects of the trips. Families were informed that DCT plan trips using familiar tour operators, and ensure, as much as possible, the safety of holidays.

"Something that was important was trust, the thing with having a child with Muscular Dystrophy was that you just worry, and knowing that DCT had helped with the booking, and the van and the tours, that all helped you know, I trusted them." (Mum, family 13)

Additionally, permission from a GP or consultant for their child to go on a dream trip or holiday (a requirement from the charity) helped parents perceive a dream as a protected and safe experience.

"You know you're safe, because the safety checks are all there and stuff, all the paperwork has to go to the consultant, and you know he has to give permission. He knows it's safe for her to go, so as a mum you've got nothing to worry about." (Mum, family 4)

Group trips to Disneyland were also accompanied by nurses who added to perceptions of safety and trust.

"I looked on their website and they said they did a group trip or a single family trip and I thought 'no it'd be really nice to be amongst others and have that support' and the kids can make some friends, and it'll be totally organised we won't have to worry about anything and I imagine for some families, having the nurses there would be a big plus." (Mum, family 8)

Again, this support was reassuring, adding to parent perceptions of dreams as fun and exciting, yet safe and organised. The trust, permission and medical support aspects of the experiences positioned dreams as safe, yet somewhat passive adventures. To parents, with children whose dreams were to travel or go to Disneyland, dreams meant protected and safe fun.

5.9 Dreams as pragmatic

Other dream choices were shaped by more practical concerns. These dreams were constrained by the child's health and the family's financial circumstances. The young person described in this following extract requested a television, due to his first choice of a Disneyland trip not being viable.

Jayne: "What was the original dream?"

Mum: "Florida, to Disney. That became a bit of a poisoned chalice really…um, we, we just couldn't get insurance, and it was a long protracted thing trying to get the insurance. We missed two or three of the holidays [group trips] because we couldn't get insurance, or he wasn't safe enough to travel, and em…in the end you ask for something else don't you!" (Family, 18)

For this family, like many others, sourcing affordable holiday insurance was difficult. Although DCT paid for the dream experiences, families were expected to meet insurance costs. For families with a child with complex conditions, this was expensive. Thus, families who were unable to afford this additional cost were not able to choose travel as part of their dream experience.

Additionally, some children's' illnesses prevented overseas travel due to the complex nature of these children's conditions. The complex nature of illness as well as difficulties paying for travel insurance influenced the choice of dream for family 18, and, as the following extract suggests, for family 16.

"We can't go on holiday with him really because of all his medical needs, and we can't fly, because he can be on oxygen sometimes and he's got a chronic disease and various others, sort of tracheostomy and other things and he wouldn't be able to fly and airlines are like, 'don't come on our planes!' So, we could have gone under the tunnel, but the insurance for going abroad is quite high. But when we costed it, it was going to cost more than I would ever spend on a holiday. But I was thinking I don't want to pay £3000 for a holiday, and I just thought, it became too complicated and I just thought, I felt embarrassed, and I said, 'actually do you mind if we don't do this?' " (Mum, family 16)

Families 16 and 18 requested equipment, as first choice dreams of travelling to Disneyland (family 18) and Euro Disney (family 16) were both too expensive and too difficult, due to illness. The data thus suggests that some dreams of equipment could be conceptualised as utilitarian dreams. Equipment dreams responded to the constraints of illness, as family 15 suggest.

"You have to live within the constraints you live within. You live within the disease, whatever that disease is, you live within that. Whether it is leukaemia or whatever, you manage the best you can within that" (Mum, family 15)

For three out of the four families who chose equipment as a dream in this sample, equipment was chosen instead of a holiday in response to the realities of illness and family financial situations. The meaning of a dream to these families was therefore a

balancing of reality with experiences that engaged children and young people and enhanced environments. Equipment dreams could therefore be conceptualised as utilitarian, or pragmatic dreams rather than aspirational or adventure dreams.

5.10 Choosing a dream

My final point on the selection of dreams is around the choosing of a dream. DCT's application form is user and child friendly. The application form asks dream recipients to draw a picture of the dream they would like to experience. This participatory process is to ensure that, as much as possible dream experiences are at the request of children, rather than parents or caregivers. However, for many families in my study with seriously ill children, the ill child or young person was not able to choose their dream without support. These families had children with communication difficulties due to disabilities, or other conditions that prevented them being able to choose a dream independently. Thus, the parents of ill children chose many of the dream experiences discussed as part of this study. Although choices were made based on ill children's interests or learning, this may have impacted upon the way that children, young people and other family members understood and experienced the dream experiences.

As the data suggest, the meaning of a dream is wide-ranging and complex. The idiosyncratic nature of some dreams also made it difficult to come to definitive conclusions about meaning. For example, to some, a dream represented exploration, and to others it was choosing a piece of equipment that could support children in illness. However, there were threads of meaning that ran through the interviews and connected different kinds of dreams. These threads were that dream experiences presented opportunities for children and young people to achieve, learn, grow and accomplish in some way. Dreams were also ways in which ill children and young people's lives could be enriched, in a way most appropriate to the child and their condition. With this understanding of what a dream meant to children and family members in mind, I move on to explaining the impact that dream fulfilment had on ill children and their families' lives.

The experience and impact of dream fulfilment will be presented as part of a grounded theory model in the next chapter. Chapters seven and eight subsequently detail further description of findings.

Chapter 6: A theoretical model of dream fulfilment

This section moves on from looking at perceptions of meaning, to what this thesis sets out to do; to conceptualise the impact of dream fulfilment on ill children and their family members' lives. The following set of chapters detail my generated theory of dream fulfilment, present an accompanying theoretical model of the dream fulfilment process, and discuss the categories generated from my data. In this chapter I outline the generated theory. My theory has two components and I introduce them as part of this chapter. In chapters seven and eight I extend detail to my generated theory by introducing the categories that informed my theory.

The grounded theory I present has two components. The first being that of *dream fulfilment as an alternative milestone*. The dream fulfilment as an alternative milestone component of the theory is about the way in which the actual dream experience was conceptualised as an alternative to social milestones in childhood, that were missed due to illness. Dream fulfilment as an alternative milestone is primarily about the dream experience itself.

The other component of the generated grounded theory is about the way in which dream fulfilment as a process redefined perceptions of illness. This component of the theory is called *reshaping illness*. This component of the theory explains the impact of the processes of the dream fulfilment experience, from nomination to the dream fulfilment experience itself. The dream fulfilment process shifted children and family members' perception of illness impact. This was due to the dream fulfilment process providing instances and experiences where illness did not underscore family life. The process of dream fulfilment, from nomination or application, to the dream itself, provided periods of hope, of agency, distraction and of normalisation.

Feeling validated, in control and distracted from illness meant that the ill child's condition did not have the same meaning, or impact on family life during the dream fulfilment process. Illness was decentralised. This shift in perception of the impact and meaning of illness facilitated a shift in the way that children and family members perceived of themselves. With illness not defining and dominating family routines, children and family members' were able to think about themselves differently. With the perceived impact of illness lessened, ill children and family members were able to define themselves in ways

other than illness. The dream fulfilment process facilitated a positive shift in perceptions of self and family.

Although it is unclear how long the positive impact of the dream fulfilment process lasted on participants' sense of selves, the dream experiences themselves remained as milestones in family lives. These milestones marked time, were used as points of reference, and as facilitators of happy memories.

My theory is therefore that dream fulfilment is an alternative milestone event in family life. The wider impact of this alternative milestone being that it reshapes perceptions of illness. My theory is presented as a theoretical model in figure 3 and discussed further in sections 6.1 and 6.2.
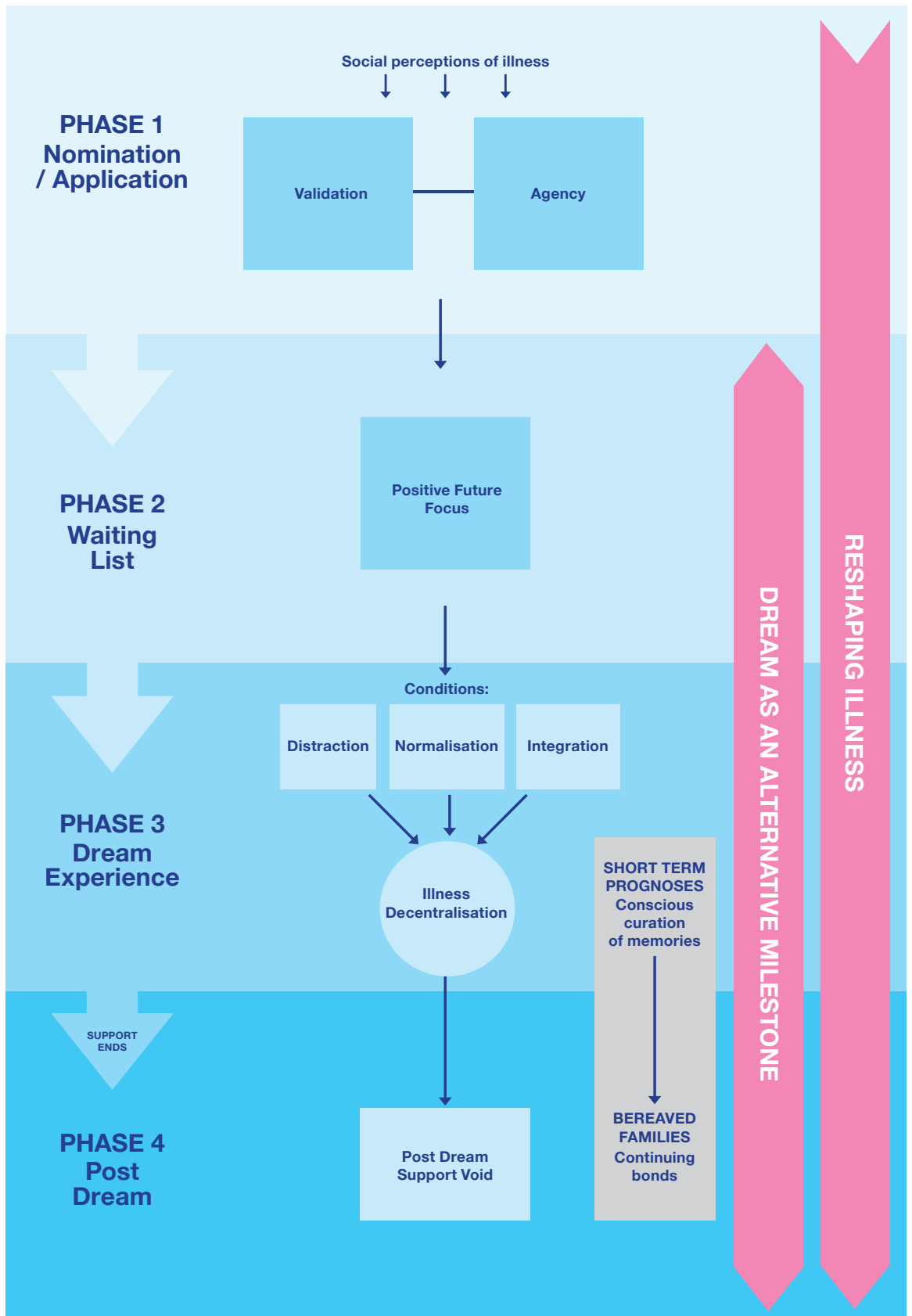
Figure 3. A theoretical model of dream fulfilment

6.1 Dream fulfilment as an alternative milestone

The dream fulfilment experience was a meaningful event in the lives of every family in my sample. Dream experiences were meaningful because the experiences allowed for travel, for family experiences, for the meeting of other ill families on group holidays, and for learning or fun.

I theorise that dream fulfilment experiences were alternative milestones because many of the children and young people in this study were reported to miss out on what were considered normative childhood experiences, or what the anthropological literature might call rites of passage experiences. These normative childhood experiences, or rites of passage were occasions such as the finishing of school or a first holiday with friends. These social activities were missed due to medication side effects, hospitalization and other illness-related restrictions. The dream experience was conceptualised as an appropriate, accessible, child-friendly experience that could in part, replace the milestone events that family members felt that their ill children were missing due to illness.

I use the word experience to describe the dream fulfilment intervention, as each dream was experiential in nature. Although receiving a piece of specialist equipment might not be immediately conceptualised as an experience in the same way that a holiday might, the impact of equipment on a child or family created positive and important moments. Experiences facilitated by a piece of equipment, such as a time when a family could play a computer game together as a result of an adapted screen, were conceptualised as positive and important experiences in family life.

In addition to the actual dream experience itself being conceptualised as a milestone experience, after the dream and especially in bereavement, families reflected on the dream as a positive marker in their child or sibling's life. Dream experiences put a positive milestone moment in amongst many difficult ones. Dream experiences provided important instances where illness did not underscore family life. They provided periods of hope, of distraction and of normalisation. Dream experiences provided opportunities for memories to be made and photos to be taken, in a similar way as other milestone moments might be encapsulated. Families later used these positive markers of the child's life to remember their child and sibling in a happy and fun environment. As such, my theory conceptualises dream fulfilment as an alternative milestone in children and family members' lives.

6.2 Dream fulfilment as reshaping illness

As well as being conceptualised as alternative milestones, dream experiences were additionally, and perhaps more importantly meaningful because of the shift in perception of self that the dream fulfilment process facilitated. It is useful to provide a brief overview of the categories that inform this theory prior to discussing this further. The eight categories that explain my conceptualisation of the dream fulfilment process were: validation, agency, positive future focus, illness decentralisation, memory curation, and continuing bonds.

The theory connecting and encompassing these categories is that of a positive shift in how ill children and family members' perceived of themselves as being ill, as a result of the process of dream fulfilment. I consider dream fulfilment a process because although the dream experience culminated in a milestone event (such as a dream trip to Disneyland), the impact of dream fulfilment began when family members were nominated for the experience, or when family members found out they were eligible for charity support. This process is illustrated in figure three.

The categories explaining the process of dream fulfilment show how dream fulfilment, from the initial planning and anticipatory phases of the process to the dream itself, helped families feel a sense of control, a sense that they were important, a feeling of hope, and during the actual dream, a sense of normality. Such positive perceptions of the experience were important to participants' sense of selves as they often felt defined by illness.

Families felt defined by illness because of the impact of their, or their child or sibling's condition, on wider family life. This impact stemmed from treatment processes, long periods in illness environments, anxieties about uncertain futures and by routines dominated by illness. Family member perceptions of themselves as individuals and as whole families were also shaped by their interactions with others. These interactions with those outside of immediate families and illness environments often felt exclusionary. An example of this sense of exclusion being that family members felt they had to apologise for their ill children in public. Thus, perceptions of exclusion, powerlessness, the lack of hope, and lack of control over futures were reinforced by interactions with peers, and statutory and third sector services.

Additionally, children felt powerless. As such, family members' sense of selves were based on illness, and for many individuals, their sense of self was almost entirely shaped by, for example being a parent of a seriously ill child.

The dream fulfilment experience countered these perceptions of exclusion, powerlessness and hopelessness. By providing an opportunity for children to choose an experience and thus feel powerful, to be given money to plan a holiday and in doing so, to have hope, to be with a group of other ill families in a group excursion, to be distracted from illness, to be given a piece of equipment, and to feel recognised as important, all contrasted against so much of what families with ill children lived with, or had come to expect from services.

The process of dream fulfilment was perceived by families to be validating, agentic, normalising and as providing a sense of hope for the short-term future. As such, the process interrupted or altered established low perceptions of the self, and the family in illness. The process of dream fulfilment shifted these low or negative perceptions of the self to interpretations of the self as agentic, validated and towards a more positive sense of who they were as individuals, and as families. Although the alternative milestone aspect of the theory is partly about the replacing of missed milestones, the deeper importance of the milestone experience emerged from the positive impact that dream fulfilment as a process had on children and family members' perceptions of selves, and their wider families. It is unclear how long dream fulfilment's impact lasted on family member perceptions of self. But, memories from the dream remained helpful, post dream.

The theoretical model outlined in figure 3 presents a visual representation of the process of dream fulfilment, and shows how each of the categories fit into the overarching theory. The theoretical model describes the dream fulfilment process from application to post dream. The model is split into four phases explaining this process: nomination/application, waiting list, dream experience, and post dream. The phases represent timeframes perceived by families to be important. Each family moved through each phase, although experience of individual phases was slightly different, depending on characteristics of the child, such as age or diagnosis.

Phase one explains eligibility and the process of application for a dream. It includes the categories of agency, validation and social confirmation of illness. These categories are detailed in the remainder of this chapter. Phase two is about being on DCT's waiting list

and explains how hope for the dream helped family members conceptualise a positive future. Phase three presents data on the dream experience. Illness decentralisation is the primary process occurring here alongside memory curation. Phase four is about the post dream experience, represented by the categories of continuing bonds and post-dream support void.

Chapter seven uses the theoretical model to move through the first two phases of the dream fulfilment process. Chapter eight then discusses the last two phases, phases three and four. In these chapters I show how each category representing each aspect of the dream fulfilment process facilitated the shift away from a self-defined by illness, towards something additionally shaped by positive interactions, travel, by celebrity meetings, integration and fun.

Chapter 7: Dream fulfilment, phases one and two

Phase one describes the application phase of the dream fulfilment process. The categories validation and agency are relevant in this phase.

7.1 Validation

Validation explained the way that eligibility for dream fulfilment acknowledged and recognised family members' experiences of having and living with complex, long-term and disabling conditions. Validation was relevant to family members of children with ACT/ RCPCH conditions two, three, four, and five, i.e. conditions such as cystic fibrosis, muscular dystrophy and spinal cord injuries. Dream recipients with conditions described by ACT/ RCPCH category one, i.e. cancer, and their family members' experiences are not explained by validation. Family members living with children and young people with conditions such as cystic fibrosis, cerebral palsy and other disabling conditions felt that societally, their illness experiences were dismissed and perceived as lesser than those in category one, namely cancer.

Mum – "It's been horrendous, it's been tough and I have to say that DCT didn't really affect her brother, it was more dad and I just being really pleased that there was a, a recognition that people care and have some understanding of the pressures, and it made you feel less alone with it."

Jayne – "Yep...yep, I mean, that is something that's come up in my previous interviews... could you tell me a bit more about that, if that's ok?"

Mum – "Yeah (long pause). I suppose it is that recognition, and for us, with something like [my daughter] and her cystic fibrosis, because it's so little understood, and um, gets relatively little attention it was nice to see that as a condition it was um, yeah, I suppose, the impact was understood, it's, there's a lot of stuff out there about children with cancer and god knows that's awful, but you say, 'oh my child's got cancer' and people say 'oh god that's awful.'"

Jayne – "People understand [cancer]?"

Mum – "Yeah, and there is a lot of support out there. But if you say my child has cystic fibrosis people say (in light tone), 'oh what's that?' so that's quite confusing. People think,

'is it cerebral palsy and what is it?' Um, and in a way it [dream fulfilment] is recognition of the seriousness of the condition, which for us was good."

Jayne – "That's really interesting."

Mum – "Yeah, I mean one of my nephews had leukaemia and I had breast cancer but there is a huge amount of awareness and fundraising. And you feel very left out of that. I talk to people when I'm fundraising [for cystic fibrosis], but they say 'oh no I give my money to the cancer trust', like you know, that it's great that they give to them but it's like, that's a serious charity, and that's a serious condition. So that's what the dream was about for us, that there is somebody out there that gets it." (Mum, family 12)

Parents of children with disabilities, progressive conditions and long-term behavioural difficulties reported feeling excluded from services, based on their child's diagnosis. They felt that cancer as an illness was prioritised, and that services were set up to cater for it as a priority condition.

Parents perceived this bias more than children, this difference in perception perhaps being in part about the age at which social identity develops. It may also have been about children not having developed the language to express their feelings about complex concepts such as validation. This is not to suggest that children or young people did not feel validated, but that they perhaps could not articulate it.

Parents of children and young people without cancer felt validated through being recognised and considered by a charity like DCT. Part of this was about children with non-cancer conditions being given access to the same service as children with cancer. Again, this was because parents felt children with cancer were usually prioritised. A condition-specific divide in the conceptualisation of dream fulfilment between families with cancer and non-cancer diagnoses thus emerged from the data. It is this lack of cancer diagnosis, which both defines this category and explains the experience of validation through dream fulfilment in families of children without a cancer diagnosis.

The following extract is from one mum of a young person with communication and behavioural difficulties. It shows how she, like many other parents felt let down by statutory services and found having a child with a long-term condition isolating and excluding:

"He has autism, severely autistic, he's uh, at 18 months he was diagnosed with autism, so, as you know with autism, it's not very easy, it's quite hard, he struggles a lot. He went today in the bus, and the transport says, 'we really need to talk to you', he's always playing in the bus, banging on the glass, this and that. And they say, 'tomorrow we're not coming'. Monday is the worst day, Tuesdays are hard, Wednesdays are ok, by the time he settles it's Friday and then it's off." (Mum, family 20)

Contributing to this feeling of exclusion were third sector organisations who granted dreams and wishes to children and young people with life-threatening conditions, without recognising the illness experiences of children with longer term or other complex conditions. Most dream and wish fulfilment organisations in the UK have eligibility criteria that exclude seriously ill children with long-term conditions and disability.

"I'm not asking like a big holiday or anything but other charities just say that 'it's not life-threatening or a proper disability'. Most of them they don't recognise, you know…the charity [Rays of] Sunshine, they straightaway refused." (Mum, family 20)

The statement 'not a proper disability' highlights how neurological and disabling conditions were perceived as being trivialised by some organisations within the third sector. This was difficult for this mum, whose son's condition was all consuming of her time and energy.

Sitting outside of charity eligibility criteria added to existing feelings of exclusion experienced by families with long-term conditions. Parents of children and young people with long-term conditions spoke of feeling isolated and stigmatised due to their child's condition. This was due to embarrassing or unsocial behaviour, limited wheelchair/ equipment access to social spaces, and general tiredness accompanying having a child or young person with a long-term or disabling condition.

"When you're out you're constantly thinking about, I've got to be aware or I've got to do this, or I can't do this because we've got that condition." (Mum, family 7)

Charity decisions, prioritising children with life-threatening conditions such as cancer, confirmed and reinforced pre-existing perceptions of the lower status attached to conditions such as autism and muscular dystrophy to the families in this sample. Such

exclusion criteria also worked to reinforce the perceived higher status of cancer within the third sector/ society.

"A lot of charities that we looked at are based on children, for example, children with cancer, being normal, you know what I mean, they're functioning normally, they can walk, they can talk, I mean, it's like your form, 'can we come and talk to your child?' I mean, you can try but you wouldn't get very far because he doesn't speak, and those assumptions are made." (Mum, family 16)

The perception of the prioritised cancer diagnosis within the third sector also highlighted the 'normalcy' of cancer as a condition for parents living with long-term conditions and disabilities. Parents of children with complex needs spoke of their disappointment in organisations that cater to children who are ill, but who functionally present as normal. The lack of recognition of functional and complex needs such as mobility and communication experienced by family 17 contributed to family perceptions of exclusion from the third sector.

Like mum in family 17, other parents experienced feeling misunderstood and unrecognised by services. An extract from family 20 adds to this context.

"There are so many conditions that they [doctors] don't understand, and even the council and local authorities, to be honest." (Mum, family 20)

The fulfilment of a dream thus gave recognition and validation to families. The charity examined here offers support in the form of a dream to both children with life-threatening and long-term conditions. Parents using this charity felt like DCT's wide ranging inclusion criteria signalled understanding of the pain, worry and anxiety they suffered as a result of their child's condition. Inclusion meant feeling recognised as equal to families of children living with cancer and other conditions perceived to be more serious.

"It [the dream] was an acknowledgement of a tough time." (Dream recipient, family 12)

The dream also worked to counter perceptions of exclusion emerging from having an overlooked condition. Like previous families a parent in family 18 talked about how they felt the condition affecting her children (spinal muscular atrophy) was overlooked. Again,

this was compared to cancer in its status. She felt that general acknowledgement of the condition her children had was lacking, and as a result felt isolated from support. The data show that DCT was able to provide a rare source of support for this family.

*"Because when they're ill, they can be ill for like, months on end, and, cancer is really recognised, whereas something like [genetic condition] is almost kind of, it just isn't recognised. I mean it is recognised, but there's not many support groups. There's not a lot of help really, for that sort of thing. Especially for a treat, there's nowhere else really where they can get a nice treat, something just for them." (*Mum, family 18)

Recognition and acknowledgement of illness were part of what validation meant within this finding. Such concepts were important to families because of the perceived contexts of exclusion in which family members of children with long-term and progressive conditions lived within.

In addition to personal feelings of validity stemming from charity eligibility, one young person with cystic fibrosis felt recognised and acknowledged through being nominated by someone outside of her family.

"It's thinking about it, it's just emotional, because it's, my neighbour nominated me because I'm so special, and, I could not thank him enough for nominating me, it was unbelievable." (Dream recipient, family 14)

This nomination communicated to this young person that her condition was worthy of attention, and that her illness experience was recognised. Although this young person went on to enjoy her dream, it was the nomination aspect of the dream fulfilment process that was important. Like eligibility for dream fulfilment, nomination validated this young person's sense of who she was.

Eligibility for the dream counteracted perceptions that families held about having conditions that were perceived to be less important than cancer. Eligibility for a dream meant that conditions such as cystic fibrosis and muscular dystrophy were attended to, and recognised as stressful and difficult, in the same way as cancer was perceived to be. Parents of children with such conditions felt validated by access to a third sector organisation who did not overlook or exclude their condition, but recognised it in the same way as conditions often perceived to be more serious in nature. In interviews with families with a child with a cancer diagnosis, family members did not talk about difficulties

accessing services, or services not being appropriate for their needs. They did not discuss feeling left out, or unimportant.

The category of validation, which represents families' perceptions and experiences of being eligible for a dream, was the beginning of the positive shift in self-perception illustrated in the reshaping illness aspect of my overarching theory. Agency is the next category to be discussed. Like validation it worked to shift perceptions of self towards something that felt more positive for family members. Agency was about choice and power in children and young people, and sits within the initial phase of the dream fulfilment process.

7.2 Agency

The category of agency describes children and young people's responses to the responsibility of choosing a dream. The act of choosing was important because of the lack of control children felt they held over their bodies in illness. Agency was about independence in choice. Agency was also about the alleviation of guilt associated with illness. Choosing a dream experience that benefited family members worked to help young people feel less guilty about the illness burdens they felt both responsible for creating and helpless in resolving. The opportunity to choose a dream countered feelings of helplessness.

The category is based on data from interviews with adolescents, rather than children. Many of the younger children I spoke to did not reflect upon, or articulate their feelings about emotions or concepts such as guilt. Similarly, children and young people with conditions affecting their ability to communicate, such as autism, did not discuss concepts such as agency or guilt at interview. This is not to say that younger children and young people with conditions affecting cognitive development felt no guilt, but there are no data in this sample to evidence their experiences or perceptions.

For two adolescent siblings, agency was about being given absolute control over a large amount of money.

"I was so happy, they gave <u>us</u> [my sister and I] £1000 to buy whatever <u>we</u> wanted. That was so cool." (Dream recipient, family 18)

The siblings described above needed support with mobility, feeding and from ventilation equipment. Therefore, an opportunity to choose and control something independently was empowering. Both young people in this family chose adapted smartphones as their dreams. These phones allowed them to communicate with others, be part of online communities and to play games independently. However, it was the choosing of the equipment that was important to these young people, evidenced by the emphasis on the *us* and the *we* in the quote referenced above.

In the next example of agency, a young person's diagnosis of cancer disrupted a family's planned and desired future of emigrating to America. A long chemotherapy period meant that this family missed visa deadlines, and was unable to move to America. They were also not able to claim back the costs involved in relocating, for example, for flights. For this participant and her family, illness meant losing personal control over a desired future. This young person's condition and its treatment period instead took control of future plans, which affected the whole family.

"I wanna live in America, 100%. So that [living in America] meant a lot to her [dream recipient]. And then to suddenly, have cancer and not go to America, to suddenly go, 'ok we're gonna go for three weeks' that meant something to her." (Mum, speaking on behalf of her daughter, family 6)

The opportunity to choose a dream of visiting America was important, as it renewed some of the power this young person had lost over her future in becoming ill. Dream fulfilment gave this participant a sense of agency.

One young person in this sample felt particularly affected by paternalistic medical practices, and also her parents' wishes. This participant had a short prognosis and a painful condition and wanted to die. Parents and medical professionals felt that this young person's life should be preserved, removing this young person's sense of control over her life and her future. Although perhaps unhappy, this participant appreciated the feeling of choice and responsibility presented to her in this phase of the dream fulfilment process. Choosing a dream for herself gave this young person a sense of agency.

"It felt really good to be able to do choose something like this, after all the time in hospital, all the time in bed, it was so good to decide to do something just for me." (Dream recipient, family 12)

It was the feelings of powerlessness that appear to situate the context of the findings presented in this category of agency. If young people hadn't experienced the lack of control that they did, through the intrusion of illness on their life, and the perceived lack of patient centeredness in their medical care, then perhaps the impact of this phase of the dream fulfilment intervention would have been different.

In addition to perceptions of choice and control, choosing a dream helped young people alleviate the feelings of guilt about their illness that they felt towards family members. Again, this created a sense of agency for the young people in this study. I return to the data to support this finding, beginning with the previously discussed young person whose move to America was interrupted by cancer. This participant understood the impact of her illness burden on her siblings and parents: from her younger sister feeling envious of the attention given to her, to her parents' anxiety, this young person understood how much her illness had affected the lives of the individuals in the systems around her.

 "I think she felt this guilt, that if it hadn't been for her, we would have all been there. I mean we could be living out there now couldn't we, we'd have been there and been like 'omg this life is wonderful', both of them, both my girls wanted to go." (Mum, speaking of her daughter, family 6)

Thus, this young person's choice of dream was one which involved her family. This participant chose to take her family to America on holiday, despite no longer being able to move there permanently. Choosing this dream helped this young person to feel in control of a part of her future and give her family a positive experience. It created a sense of agency.

Choosing a dream that benefitted others worked to relieve young people's illness-related guilt. A further example of dream fulfilment's role in the alleviation of this kind of guilt is presented below. This young person's interview suggested that this dream recipient used the dream to make up for the burden on her family she felt responsible for creating.

"They were just such a huge part of the treatment. My granddad used to drive me everywhere. I was going to hospital probably four times a week if I wasn't actually in hospital, so my granddad used to drive me all the time, so he was such a huge part of like the, my treatment. It was nice to give him something back as well, like give him a treat."

"Cos like, the whole year it was all based around me, like if I was in hospital [my siblings] just had to go to my Auntie and Uncle, or wherever… they just shuffled around and [my younger brother] was only nine so like, I was the centre of attention. I did get all the attention like, I didn't obviously want it, but then again I was only like 12 so I didn't like to be by myself in hospital so to get the dream and for that to be like, getting the whole family together, giving everyone a little bit of something, that was nice, it felt good."
(Dream recipient, family 4)

The young person in family four had a condition that meant she resided in hospital for extended periods. This meant one of her parents stayed with her in hospital and so was absent from the rest of the family, which affected her youngest sibling. This ill participant felt guilty for the impact that her condition and its treatment had had on her younger brother. She used the opportunity of being granted a dream to bring her parents, siblings and grandparents together in London. She chose something for her whole family, which helped her to feel better about her sense of self. Her feeling of being a burden shifted to a feeling of bringing happiness and fun to her family. This young person's sense of who she was shifted towards something more positive.

For another seriously ill young person, the opportunity to choose a dream and action it on behalf of his family was useful in shifting his perception of himself away from one who caused worry and pain, to one who could be perceived as positive. Choosing a dream was again agentic. The following extract from this young person's bereaved mum highlights the awareness her son had about his condition and how it affected others:

"The day before the scan, he started to get symptoms, he suddenly...he went over to my husband's brothers house and he came back and he said, emm, 'I have this pain in my neck' and, I think I was partly shocked and partly devastated. And he said, 'I'm so sorry, I didn't want to tell you', ummm, and, so the very next day I think, when he went for the scan, we went and got results and they said 'he's worse'..." (Bereaved mum, family 5)

This young person appeared to understand what his increase in pain meant, and what the consequences were for his family. Choosing a dream may have had a role in countering this feeling of guilt, as his bereaved sister suggests:

"He [dream recipient] was a very unselfish person. So he didn't really want something like a computer or a pet, or something like that. So his initial thought was that he wanted to do

something for his family because it was, uhhh, when was it…he had gotten ill the second time and there was a chance he could get ill again. So he just wanted to do something really nice" (Bereaved sibling, family 5)

This participant acknowledges her brother's unselfish nature, which perhaps contributed to his choice of dream. Regardless of this young person's nature, choosing a dream allowed for control over a final holiday, and a way to give his family something positive, at a difficult and distressing time. An opportunity to choose a dream meant having a sense of control and a sense of responsibility for individual and familial experiences. Choosing a dream was about agency.

Findings from this category suggest that in the early phase of the dream fulfilment intervention, choice was important to young people. Dream fulfilment at this nomination stage worked to counteract feelings of helplessness in ill, young people who felt they held little responsibility or control over their lives. It helped alleviate the guilt that young people felt because of the difficulties they caused their families. In this sense, agency like validation helped reshape perceptions of self, through a reshaping of the impact that illness had on young people's lives.

The categories of validation and agency explain how the initial part of the dream fulfilment process was experienced. Validation and agency counteracted perceptions of powerlessness and the feeling that children with non-cancer conditions were under prioritised. Validation and agency thus began the shift in facilitating ill children and family members in perceiving of themselves differently. This shift reflects increased self-esteem and a more positive perception of self. The subsequent categories described by the reshaping illness theory, and captured by the theoretical model show how the dream fulfilment process continued to support children and families in facilitating this shift towards a more positive sense of self. A self not defined by illness, and the negative impacts of illness on the self, but a perception of self that feels perhaps only momentarily, more normal.

The next section discusses phase two of the theoretical model. Phase two was about how being on the waiting list was experienced. Phase two encompasses the category positive future focused.

7.3 A positive conceptualisation of future

While a waiting list might conjure up images of frustration or delay, family members sitting on the waiting list as part of the wider dream fulfilment process were full of anticipation and hope. Positive future focus is therefore the name of the category characterising the waiting list period. The category positive future focus was primarily about hope and anticipation. Children and family members drew upon these feelings to think positively about their futures. As presented previously, families with seriously ill children often had chaotic and uncertain lives. Hope for a dream brought a point of focus to illness, which was useful to family members when feeling upset or distressed.

In some families the dream experience was used as an 'end point' to a particular period of treatment. The dream in these situations was used as a goal, representing the finishing of a process of treatment or the end of an extended hospital stay. Hope for the dream experience thus helped children and family members to visualise their dreams, and to distract their child from painful procedures.

The waiting phase of the dream fulfilment process also gave families an alternative timeframe to live within. This was especially relevant to parents with children with a short prognosis. Parents of children with short prognoses said that a dream experience gave their families something to anticipate and to work towards. Positive future focus as a category thus reflects the broader theory of dream fulfilment as an alternative milestone. Hope and anticipation for a dream as part of the category positive future focus shows how families with seriously ill children used alternative experiences and events as milestones, such as this dream within their children's' lives.

While the category positive future focus explains most families' experiences on the waiting list, the category does not describe children or family members who chose equipment, as this dream type did not have a waiting period in the same way as a holiday or event.

Family members used the dream to distract from difficult and painful procedures such as chemotherapy. It countered current distress and pain. The following extract shows how one mum of a child with cancer used hope for the dream to counteract feelings of sadness during treatment. Talking about the dream was used to make this young person feel special and hopeful at a difficult time.

"If she was feeling rubbish we'd talk about it, we'd talk about how she was going to meet the dragon, I remember talking about it with her, that she was going to meet the dragon. Yes it did, it gave her something to look forward to, to make her feel slightly better, at a time when she was feeling...feeling very not good at all" (mum, family 2)

Talking about the future dream experience with her mum, helped this young person distract or remove herself from the illness which otherwise dominated her family's life at this time. The young person in question's dream was to meet a dragon. She, as the following extract suggests, believed that the magical animal she was due to meet would cure her cancer. She had hope in this sense, for something beyond her treatment and illness. Although this young person looked forward to the dream, hope was also about becoming well.

"I believed that their [dragon] magic would help me to feel better" (Dream recipient, family 2)

Younger children might not have articulated a positive future focus in the same way as young people or adults in this category, but they too, felt excitement for their dream. In the following quote a five-year-old sibling remarked:

"It was really good, me and [my sibling] were very excited, tonnes and tonnes excited" (sibling, family 7)

For another young person, a dream of a holiday to America post-treatment worked to provide an experience to look forward to during treatment. This young person's illness meant that a pre-illness goal of moving to America was taken away from her. Having a dream experience to look forward to instead, presented an experience to work towards and look forward to while ill. Mum said:

"Just to go to America in itself was the, the best thing ever for her. It gave her a goal, something to look forward to… When we were waiting for the operation, there must have been somewhere around the hospital area which must coincide with one of the flight paths so she was constantly looking out the window" (Mum, family 6)

This young person was able to imagine being on a plane while in treatment, due to the hospital's proximity to an airport. She visualised escaping from her current world of chemotherapy, which included sickness and hair loss. Planning and visualising her holiday experience gave her a focus and a goal while in hospital.

"The impact of that holiday, made a massive different to [my daughter] because that was what was happening in her life before the cancer. And then the cancer just took a year out of her life really and this gave her a goal and something to look forward to. And um, when the initial treatment finished in the June, because it was six months of chemo and then within the next six months it was um, a treatment. But in tablet form so we didn't have to keep going backwards and forwards to the hospital. So this was kind of what she had to look forward to. So it was that in the January, so literally, it was uhh, it was brilliant."
(Mum, family 6)

Mum acknowledged the importance of having a goal during her daughter's long treatment processes, in the same way as a mum of this next family did.

"It just keeps you going I think. And we were still going through treatment and we're nearly out the other side, and it just keeps you going, you think 'we can do this.'" (Mum, family 4)

Like many in the sample, this family spent a long time in hospital. Mum spoke of the psychological toll that having no respite from illness took on her family. The dream in this waiting phase thus meant something to look forward and hope for. Mum referenced the family's usual optimism, which as a result of invasive treatments and long periods spent apart, was tested. The dream experience worked to give this family a positive future focus, something to 'keep them going'.

Families with a child with a short prognosis also used the dream as a focus and goal, in the same way that families with a child undergoing a structured treatment did. In addition, families of children with short prognoses conceptualised the dream as a kind of future. The requested holiday or event created a structured set of time that families could both situate themselves in, and hope for. This was important as some families discussed their child's lack of long-term future. Although dream experiences could not replace real futures for seriously ill children, dream experiences could provide alternative opportunities with which to look to the future as a family.

"When you've been all busy doing all this stuff, and they have had tough times and its something to look forward to and to…I suppose if you've got future things coming up so, yeah, we obviously didn't have the future." (Mum, family 8)

Dream experiences provided opportunities for escapist thoughts in young people with life-threatening conditions, and their parents and siblings.

The following extract shows how challenging having an ill sibling was for one young person.

Sibling – "Well he was ill for 5 years…he had one tumour which was about this big (makes shape with hand), at the back of his head here (points to upper neck). He had surgery on it, six weeks of radiotherapy, and then chemo, and then he...we thought he was getting better and then he had some scans, and then he got some symptoms back, and we were all trying just to think it was ok but we all knew it wasn't... And he had this crazily intense chemo and radiotherapy, which made him stay in isolation for almost a month"

Jayne – "Wow"

Sibling – "Which was very hard to see because he was in such a bad state (long pause)"
Jayne – "How are you doing?"

Sibling – "Yeah, I'm ok"

Jayne – "Just say if you'd like to stop"

Sibling – "I'm ok, after that, he was alright for a while, and we just kind of kept going, and we thought it might be coming back, and we'd scheduled this trip for July. I'm quite glad we didn't now because it would have been so hot…umm, but emm, we moved it forward because apparently he'd had some scans and they were a bit sceptical about them, and they were a bit worried that they couldn't read them, and they said, 'Wwe think there is going to be something there,' and we went in the May instead. And then when we came back he had another scan, and that showed that it was not clear and basically that he wasn't going to survive and that...that he was terminal. And then had basically palliative chemo and lots of steroids to kind of keep him on an even keel, to keep him from deteriorating, because the tumour that he'd had before was a kind of ball shape and they'd just been able to take it out, but this one. Because they could not do anything about it, they just had to leave it in. It was more of a patchy type growth, on the back of his brain, instead of just the one, and it inhibited one whole side of his body, so he couldn't walk so well, with one side and he had to use a crutch. I remember him writing on the white board in the kitchen, and to stabilise himself he had to get his hand, put it on the wall, and then

write, with his other hand, because he couldn't use the whole...one side of his body (breathes deeply...). So that would have been when his personality started to change too, so, really there wasn't that much change then, it was really later on because the tumour didn't start to affect him then. So yeah" (Sibling, family 5)

The extract shows how illness affected the family, and how difficult it was to have a sibling undergoing such treatment. Having a dream experience to look forward to was useful in giving children, young people, and families both support, and something to look forward to and distract from upsetting routines and environments.

Escape or distraction from such challenges may have been useful. However, rather than daydreams, these hopeful thoughts were based on actual future events, and were useful in metaphorically removing the self from an environment associated with illness. Dreams were positive futures that could be not just looked forward to, but desired.

"*It was so exciting. I looked forward to it so much, the thought of just being away from everything, from all the stuff that was in my life then. Ahhh, yeah, it was so nice to have something to think about and look forward to in the future." (*Dream recipient, family 12)

"*I mean God knows I got down too. I mean, just to think, this is what we'll be doing in a couple of months, let's go and have a look on the website to see the pictures of what we'll be doing. It helps buck you up at times when you're feeling, you know, pretty depressed."* (Mum, family 12)

Both mum and daughter in family 12 found escapist thoughts useful. Positive thoughts for the future dream were used to distract from, and cope with difficult situations in the present.

Many families in my sample used hopefulness as a coping strategy during the waiting list phase of the dream fulfilment process. The data suggest that conceptualising a positive future in the form of a dream was used to metaphorically remove or distract the self from distressing situations, to focus on an alternative time point, and as a way of feeling positive about a perhaps uncertain future. A focus on the dream also facilitated a shift away from a focus on the conditions and treatment situations which many children and families felt defined who they were.

In conceptualising a positive future, family members engaged in activities such as counting down the days, buying clothes, looking at websites and thinking about detailed aspects of the dream experience. Such activities were useful in helping family members visualise their anticipated dream experiences.

"We told him maybe just a month before, but he didn't …because he is limited, but he was excited and he was doing a countdown and he started doing that, and we got him a whiteboard calendar, and he started to learn the calendar because of this, this dream. And he now knows how to use the calendar; he was crossing off the days. So it was good as an experience altogether, you know?" (Mum, family 1)

"I remember counting down, I think it was in January I started counting down to August, and we were buying clothes and my dad's helping out to buy clothes and um, like, I remember my parents giving them dollars so yeah, it was really really good." (Mum, family 7)

Counting in this systematic way was part of visualising dreams. Making purchases and planning activities helped facilitate family members' positive future focus.

"We went shopping and she got things. We lived for that [dream] weekend." (Mum, family 14)

Thoughts about the dream also provided family members (mostly parents) living with a child with a serious condition respite from day-to-day thoughts of organising eating, travel, and other routines.

"When you have a very serious illness and spend a lot of time in hospital, they [ill children] need to focus on something, to look forward to something, to get excited about something, a plan. It's uplifting in itself. It's looking at the website, looking at the pictures, imagining going, thinking and planning ahead, you can't plan ahead in that stage in your life, but you know, for the next month or two months this is what we'll be doing, and when we get down time in hospital um, it's something you can really focus on." (Mum, family 12)

Anticipating the dream served as a distraction, and in situations where "you can't plan ahead" (mum, family 12), a dream provided a real chance to plan, prepare and conceptualise a positive future, in the short term.

Family members in the sample were on the waiting list for up to one year. During this phase of the dream fulfilment process, families experienced hope and a feeling of anticipation for a positive, albeit short term, temporary future.

The findings presented in this chapter perhaps parallel the way in which families without an ill child look forward to a holiday. Hoping for, and making plans for a future event might appear similar to the ways in which a family might prepare and look forward to a holiday. However, it was the contexts in which the category positive future focus sits that separates my findings from what might be considered a normal holiday, these contexts being life-threatening illness and disability.

Positive future focus shows how family members hoped for, and anticipated a positive future experience, in the form of a dream. The category explains how children and family members visualised themselves in new environments, away from illness. Positive future focus also shows how thoughts and longing for a positive future shifted thoughts away from illness. Thus, positive future focus, however momentarily, facilitated a shift away from a focus on the conditions and treatment situations which many children and families felt defined who they were.

This chapter has introduced the categories relevant to the first two phases of the theoretical model, discussed in chapter six. It has shown how the application phase of the dream fulfilment process impacted upon children and young people with life-threatening and long-term conditions, and their family members. Findings also show how experiences in the initial phase of the dream fulfilment process were influenced by social perceptions of illness, and how having a dream fulfilled changed the way that family members thought about themselves as ill young people, and as parents of ill children. Positive future focus additionally shows how the waiting list was experienced, and how hope and anticipation for future dreams were helpful in helping children and family members both distract from illness and imagine different or better short term futures.

Chapter 8 moves on to discuss the latter half of the dream fulfilment process. It details the dream and the post-dream aspects of the wider dream fulfilment process.

Chapter 8: Dream fulfilment phases three and four

This chapter introduces the categories encompassed by phases three and four of the theoretical model. Phase three of the dream fulfilment process explains the experience of the actual dream. This phase in particular is representative of the dream fulfilment as alternative milestone aspect of the overarching theory. Whereas the previous categories of validation, agency, and positive future focus explained the initial phases of the dream fulfilment process and the impact that the process had on family members' perceptions of illness and of themselves, the categories detailed here, relate to the actual dream experience.

Dream experiences were times when families were together, away from usual illness environments. They represented fun, newness and a momentary distraction from routine. In this way a dream experiences marked time with a positive event, and as such were conceptualised as alternative milestones.

Phase four is about the post dream period, and about the way that positive dream experiences contributed to the way in which families remembered children after they had died. Phase four also discusses the impact that coming to the end of the dream fulfilment experience had on family members.

8.1 Illness decentralisation

Illness decentralisation is the first of two categories relevant to the actual dream fulfilment experience. Illness decentralisation explains the process of family members' shift away from positioning illness at the centre of family function. During the dream experience behaviours related to dealing with their or their child's illness moved from dominating family members' lives to existing in the background. The dream experience worked to shift illness from its usual central position within the family system to a less centralised position.

Illness decentralisation occurred when families felt normal, when ill children were distracted, or when ill children were using equipment that helped integrate them into family life. As such, normalisation, distraction and integration are part of the category of illness decentralisation. Normalisation, distraction and integration facilitate and precede illness decentralisation by providing the necessary contexts for illness decentralisation to

occur. Illness decentralisation occurred when one or more of the categories of normalisation, distraction and integration were present. Normalisation, distraction and integration will now be discussed, and how each construct relates to the wider category of illness decentralisation.

8.1.1 Distraction

Distraction of the ill child was one way in which illness become decentralised. Due to ill children being distracted on dream experiences, families in this sample realised that they did not need to attend to the (usually central) illness of their child in the same way as they usually did. This shift in the prominence of illness allowed family members to move within, and develop their family systems in a different way. Distraction was therefore a category that facilitated illness decentralisation.

New environments such as those experienced during dream experiences to Disneyland and foreign cities and countries provided distraction for seriously ill children and their family members.

"It was just mesmerising being there, it's such a big place and it was just mesmerising." (Dream recipient, family 14)

Such experiences gave children new and different concepts to focus on, as an alternative to thoughts about illness or illness routines.

"You could just forget about everything there, it was beautiful the whole island was beautiful." (Dream recipient, family 12)

For another now deceased young person, a dream of meeting a favourite animal meant staying awake for longer than usual and focusing all energy on the dream experience. Although this young person was not able to speak, and had died by the time of interview, his parents spoke of their child's enjoyment of the dream and how he had focused so much on the experience at that moment in time.

"It was just really fantastic. I mean so much so that afterwards, you always used to know; just as we were leaving that, going back he just fell asleep didn't he, because then he knew that he'd just spent all his energy. And you could tell just wheeling him down, you could tell that there was something, because [dream recipient] couldn't talk, but you could

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sort of tell everything, and this giggling, gurgly sound he would always make when he was happy. When he'd had lots of stimulation. He, he would just think, 'oh, it's over!' He just wants to make sure that it is definitely over and then he would go just really soundly asleep. Bless him." (Bereaved dad, family 3)

Mum and dad enjoyed the dream also. The dream was a time that this family focused on something new and different. The exotic animal that this family met distracted the family for a period of time. Attention and energy were given to the animal, and the experience.

The finding of distraction was further explored using member checking with a young person from family five to discover more about the category. This young person said being able to forget about illness was important, and new places and situations facilitated this.

Jayne – "*Something I'm interested in is the idea of being on a dream and kind of forgetting about what was going on with your body, or the condition?*"

Dream recipient – "*Yeah, yeah, definitely. Because obviously I wasn't 100% better but I was you know, getting there and it definitely helped me forget, because it was just like being in a different world so it helped. You totally forget and I think because where were situated as well, like the hotel was absolutely fantastic and we were right bang in the centre of the city. Because I'd had my treatment, my lung capacity is quite low so to walk everywhere is quite a bit of a trek for me. So they just situated us perfectly in the place so it didn't feel like I was ill then, I think because you are just made to feel so special, and that everyone knew who you were and that you were part of the dreams come true that it was just like 'oooooh'!*" (Dream recipient, family 4)

The distraction of children on the dream led to other family members, and the child themselves forgetting about, or at least not focusing on conditions or illness for the duration of the dream experience. In a similar way, group trips provided a context for family members to shift their focus from illness.

8.1.2 Normalisation (of illness on group trips)

Normalisation of illness resulting from group trips and experiences was another way in which illness decentralisation occurred. Group trips involved many families with ill children

going away together for the first time. The collective nature of group trips normalised illness for families. In this way, illness shifted in family perception, becoming a peripheral rather than a central focus during the group dream experience. On group holidays, illness became less important due to each member of the group either living with, or having a life-threatening or long-term condition. Illness lost its focus. Situations that would usually have been embarrassing or difficult related to having an ill child were not embarrassing in the context of everyone having an ill child.

"I mean, everybody had some kind of disability or problem so it was easy to forget because everybody was in the same boat. Sometimes when you're out you're constantly got to think about, 'I've got to be aware or I've got to do this', or 'I can't do this because we've got that condition' but because we were all aware of each other's conditions and children and all together, everybody looked out for everybody. So it, it, perhaps if something did happen then it wouldn't have been a problem. We wouldn't have had to explain anything, because that just happens." (Mum, family 7)

Illness lost part of its stigma on group trips, due to its commonality.

"We had that common bond where we went there together ummm, so that's [illness] what, you know, is implicit but you don't necessarily talk about it." (Mum, family 8)

For another dream recipient, seeing a favourite band with other young people in similar situations was helpful.

Jayne –"So how many [families] were there?"

Dream recipient –"About 20 families. So maybe about 4 in each group, so there was a crowd of us, but we got one to one time with them, they came in and they sang"

Jayne – "Sounds really nice"

Dream recipient – "And then they talked to us for a little while and we got pictures with them and stuff"

Jayne - "What was it like have them sing to you? It sounds really special"

Dream recipient – "I started crying after the experience"

Jayne - "What was the concert like?"

Dream recipient – "Worse than meeting them! In a 'so bad it was good' way"

Jayne - "Can you explain it?"

Dream recipient – "It was quite like a shared experience because there were lots of other young people in wheelchairs there too so that was great" (Dream recipient, family 14)

For siblings, meeting other children who also had an ill sister or brother was normalising. For this sibling in family 20, the realisation that her experience was not in isolation was important.

"It was really worth it, all these kids there, it was huge thing, physically, and everything else, you are not alone in this world." (Sibling, family 20)

Mum's interview reiterated this point, suggesting that the meeting of others in similar situations was helpful to her daughter. Like others on the group trip, who spoke about illness being normalised, the meeting of other siblings of disabled children normalised this young person's experience. Feeling that something that was usually abnormal was perceived as normal helped family members to focus on other activities available on the dream. Illness shifted from its central position within the family system, to the background.

"There are so many siblings, she had chit chat with other siblings, and I could see, in the beginning of the trip, they were all a bit scared. But over time they became more confident with each other and realised, they weren't alone in this whole world. There are so many people, and everyone has different techniques for dealing with their disabled siblings. So its very hard for them, but on the holiday my son bonded with them all as well, because he looks at them all, and sees we're all doing this together, and we wait on each other." (Mum, family 20)

A group trip did not just normalise illness for the ill child, but it normalised the experience of living with illness for parents and siblings.

8.1.3 Equipment as integrative

Equipment as integrative is the final category that worked to facilitate illness decentralisation. This category explains the way in which specialist equipment such as an adapted screen for a computer facilitated a child's integration into their family.

Although equipment dreams were mostly chosen in response to difficulty paying for insurance, or difficulties travelling with an ill child, dreams of equipment helped children to communicate, play and integrate into their families and wider society. In this sense they worked to minimise the burden of illness within families. As such, illness decentralisation occurred in a similar way to families where children felt normal and were distracted.

Children who requested equipment for a dream often did so because insurance costs and illness environments related to children's conditions prevented travel. Limitations to travel, and difficulties leaving hospitals or specific environments meant that dream recipients could not choose holidays or meet a hero dreams. As such, some families in my sample perceived equipment as a second choice dream.

However, equipment dreams did work to help ill children communicate, play and learn. In this sense, equipment helped to integrate ill children into their familial and social worlds. Like normalisation and distraction, pieces of specialist equipment helped minimise the impact of illness on family life. For example, an adapted computer enabled a disabled young person to play a computer game with his non-disabled brother. This piece of specialist equipment helped minimise the effect of illness on family life. Equipment dreams helped include and integrate children, which in turn decentralised illness from the family.

For two dream recipients in family 18, Smartphones (mobile phones, with internet) provided opportunities for independence, and social integration.

Jayne – "what do you think is the most important part of having your phone?"

Sibling one: "Well mum and dad wouldn't let us go out without them, like, it's the independence, it's just, I just use it for everything really. Oh yeah and selfies [a photograph one takes of him/herself], lots of selfies!"

Sibling two: "I watch films and stuff, and like, I've got the PlayStation app so I can do that when I'm on the machines and stuff. It's all the social side of it, having contact with friends and stuff"

Sibling one – "I wouldn't know what to do without my phone, if I couldn't update my status."

Jayne – "what else?"

Sibling one – "Emm, hehe…I can't say too much because my parents are in the next room!"

(Dream recipients (siblings), family 18)

For these young people, both wheelchairs users with low muscle tone, a dream in the form of a Smartphone allowed them to socialise and interact with their peers on social media and through other online communities. A Smartphone also distracted from long periods attached to ventilating machines for example. Smartphones allowed these young people an independence they might otherwise not have had.

For the young person of family 17 a television added to this young person's social world, which had been restricted by illness.

"So in the end we got a big television for the bedroom, so that enabled him to have his friends around and be more independent. He couldn't go to anybody else's house because he had a tracheostomy [which needed trained carers to be nearby] and you know it um, it gave him a bit more independence because he had to be away from school" (Mum, family 17).

A television opened up this young person's space to his peers, allowing him to bring his social world into his own space. He was therefore able to maintain social links with friends throughout illness.

Like the siblings in family 17, a piece of equipment allowed this young person to establish and maintain connections outside of illness.

"His friend had one, and he wouldn't get off it, and it was something he could do himself wasn't it." (Dad, family 15)

For family 16 too, a touch-screen computer allowed the child in the family to develop skills and to play, independently. The child in family 16 had a serious condition, although it was not life-threatening. A dream of equipment was therefore an opportunity to enhance play and learning in the longer term.

"I mean it's a chance for him to grow, I suppose, in a sense, rather than something that you'd never get a chance to do" (Mum, family 16)

A dream in this sense, was about development rather than a one-off experience. The touch-screen computer adapted to this child's abilities, presented something both he and his family could use over time.

Additionally, the dream recipient from family 16 was able to use his adapted screen with his family.

"If we're all watching Dr Who, he can bring it in and he can watch one of his videos on it, and that means we can now all be in the same room at the same time, so because he's computer mad" (Mum, family 16)

Although the young person in family 16 was not engaged in the same activity as his family, it was important to mum that the whole family were in the same room, at the same time. The adapted piece of equipment meant that mum was able to spend time with her children at the same time, which was important. In this sense, the dream experience, facilitated by the adapted computer provided this mum with milestone moments. Although watching a film as a family may appear small compared to some of the more elaborate dreams, these positive family moments were special.

The sections above show how distraction, normalisation, and integration facilitated the primary process that occurred during the dream experience. This being illness decentralisation. Illness decentralisation was about the shift in illness from the centre of family function to the periphery during a dream experience. Illness was redefined, or reshaped during the dream experience. It became less important, taking on less of a prominent role within the family. Illness decentralisation thus facilitated a shift in self-perception, in the same way that validation, agency, and positive future focus did. The next section discusses illness decentralisation in more detail.

8.2 Illness decentralisation

As discussed, illness decentralisation occurred during dream experiences when children and family members were distracted on holiday or Disney trips, when children were learning, playing and integrating through specialist equipment, and feeling accepted and normal on group holidays. In such situations the ill child and the attention usually demanded by illness routines were removed from the centre of the family. Subsequently, thoughts about illness, and illness-associated behaviours did not dominate family life in the same way while on dream holidays and experiences.

"If you're at home, you end up doing everything, you do other things where as if you go away, it's, you're there for the enjoyment and that's it...doctors, hospitals, family, it all gets in the way, this and that and the other, in a way he [dream recipient] doesn't get a look in practically because you've got so many other things." (Mum family 13)

Mum's extract above suggests that routines associated with her son's condition were time-consuming. Although a medical appointment might have been time spent with her son, at interview mum acknowledged the difference between time spent with her son on routine things related to his illness compared to away from the usual constraints of illness. On holiday, mum was able to spend time with her ill son and family in a more enjoyable way. The dream experience thus became a milestone event, a time when illness related appointments, or other considerations were not overriding time spent with her son.

Likewise, for the mum of family seven, seeing her children happy allowed her to forget about the constraints of illness for the duration of the dream trip.

"We just felt so special. It was just a time when you could just forget everything, do you know what I mean. And for me, you could see the kids enjoying everything, and my mum and dad had had a tough time you know, to see a grand daughter so ill, and her chances of survival kept going down and down and down." (Mum, family 7)

For family one, a shift away from their usual environments facilitated a change in their ill child's eating behaviour:

Mum – "Oh, and something amazing happened, it was the first time he ate pizza! [My son] ate pizza for the first time in his life…cheese and tomato, but you know!"

The change in eating while on holiday also occurred in family 20, although for this family the change was momentary.

"My son is quite fussy, he likes Asian food and bread and curry and it has to be made by me. I said 'Oh my god, 10 days he has to learn' but oh my god, but from the first day, he ate white bread and cheese and cucumber sandwich. And he ate that, whatever they're offering there, he's eating. But when the holiday is over, no more sandwiches, back to normal." (Mum, family 20)

Another young person who met a dragon also adapted her usual behaviour while experiencing her dream. The dream recipient in family two had felt self-conscious about her bald head and hair loss since receiving chemotherapy. During her dream of meeting a dragon however she felt able to remove her hood. Self-consciousness was perhaps forgotten.

Mum - "It was just that, she had her hood up, always, and then when she met the dragon she took it down…she didn't really talk about it, it just was there and it happened…"
(Mum, family 2)

These changes may not have been permanent, but for the duration of the dream, changed the way that children with serious conditions behaved. These young people appeared to be caught up in the dream experience, and distracted from their usual behaviours enough to adapt and change to new situations and environments.
In addition to physical changes in behaviours in the ill children, data suggest that families on dream experiences were able to spend time together in a different way. Again, this was due to children having a different focus, and thus using less of their family's time and energy resources. For some children, being on a dream fulfilment experience was just fun, and a time to be away and think about different things.

Jayne – "What was your favourite part?"

Sibling – "The parades, you know when they walk down the streets"

Jayne – "What else?

Sibling – "The food" (Sibling, family 7)

For others, the experience was another way of feeling like illness did not matter as much, as environments were accommodating to ill families.

Sibling - "There was beach that we could take him on in a specially adapted wheelchair, and he usually could never go onto a beach" (Sibling, family, 19)

This different focus contributed to the way that the process of dream fulfilment facilitated shifts in the way that children and family members perceived of themselves. The dream facilitated time spent without illness.

Jayne – "can you tell me what you felt was the most important thing about the dream for you?"

Mum – "us having fun. You know, and the thing is, is...is because I keep forgetting that I have another one, you know?" (Mum, family 1)

"You know, she [sibling of dream recipient] felt that she had a special time. You know, it's like, even when we go to buy toys, in the shop. Usually he [dream recipient] goes for the things that are very expensive, but she is so kind, and so good that she would actually tell me, 'don't worry about me, buy whatever he wants, I can just go to the Pound Shop [discount store] and get something.' And when she went there, I told my husband, 'we save a little bit of money and whatever she wants'. It was her birthday in June, so and it was nearly May and June, you know? So my husband bought her silver necklace and earrings from Disney, you know? And this was her special stuff, and some stuff that he didn't want to go on, I left him with my husband and went with her, it was a little bit of me time for her, and she likes to draw so she went to the Disney studio and she did a workshop on drawing and she loved it. And the guy there said that she was a natural, so it's like I felt like I bonded more in a way with her, it was nice you know, the time with her." (Mum, family 1)

For this family, the dream experience meant that mum and her well daughter could spend a different kind of time together, with the focus shifting onto the young person without

illness. Family relationships were developed and bonds between family members strengthened. Again, distraction of the ill young person allowed this shift in family focus to develop.

The development of family relationships was also a consequence of the dream experience for family 20:

"I think the bonding with my kids, and that I could have that quality time with them, that's the main thing, and my kids, they were really happy, and most things were just out of my mind." (Mum, family 20)

The sibling of the dream recipient in this family reiterated this point in her interview, suggesting that it was the relaxing and supportive aspects of the dream that allowed her to develop attachments to and bonds with her family.

"It was good, for the family, what I feel you have your family, but if you get freshened up again with them, that makes a difference, these are my brothers, but when I am relaxed, and feel supported and have fun, then you get good memories, you want to go in the swimming pool and the lizards are there and jumping on you and it's just so funny!"
(Sibling, family 20)

For another family, the dream experience enabled siblings to spend time together. This time spent together was unusual, due to difficulty accessing environments outside of the home.

"It gave them [siblings] lots of conversation, something in common you know. They don't always get to do a lot of things together, because there are things that [dream recipient] can't do, or can't go to because of the [wheel] chair. So sometimes her sister has to go out and do things with other people, and vice versa, so it's just so much nicer that they were able to do it together, and share that experience" (Mum, family 14)

The dream experience thus gave these sisters the opportunity to spend time together; perhaps as they might if wheelchair access (a consequence of illness) was not a barrier.

The dream experience removed barriers caused by illness from the relationship for this period.

Family 14's experience shows how dream fulfilment experiences worked as alternative social milestones for ill children and young people. The dream fulfilment as alternative milestone theory is about how children and young people often miss out on social experiences, due to difficulty accessing new places, or side effects to medication. However, dream fulfilment experiences, in being chosen by the ill child, and at a time that suits them, facilitate new and social experiences. Thus replacing experiences they might otherwise miss out on.

The following extract also highlights the way in which equipment dreams allowed young siblings to communicate and be in each others' lives. Dream fulfilment thus decentralised illness for this family, as it did in family 14.

Dream recipient one – "We use facetime to speak to each other"

Dream recipient two – "We text each other. When she (sibling) is away or whatever, and when she's away I do, and like, you know, we send each other pictures"

(Dream recipients, family 18)

In addition to the development of within-family relationships, group experiences also facilitated non-family relationships. For a young person (a sibling of a dream recipient) described here by family 8's mum, a friendship between two young people, one with and one without autism, developed without illness being a barrier to the friendship.

"Maria made friends with a girl who was severely autistic ummm, but they just treat them on a level, they don't think behind the scenes, and I think yeah for them, it was an escapism, it was so full on with enjoyment and doing the next thing that they just weren't thinking." (Mum, family 8)

The data suggest that the usual meanings ascribed to illness appeared less relevant here than perhaps they would in an environment where autistic behaviours might be more visible or meaningful. With illness shifted away from its central position in family function, children and members felt they could move within and develop their family systems, without thoughts of illness at their core. The dream fulfilment experience, in a way, redefined perceptions of illness. Rather than defining family relationships and family

routines, illness became less important and less prominent in family life. As such, family members themselves were able to re-think and re-shape their own relationships and sense of selves, as ones that were not defined and dominated by illness.

The findings presented in this section highlight how new environments and changes in day-to-day experiences provided opportunities for shifts in self and in family function. A holiday or a new piece of equipment helped change the way that illness was experienced by family members. The distraction of ill children while on holiday allowed other family members to develop their relationships with one another. Group holidays facilitated the development of relationships by normalising illness. The normalisation of illness meant that family members were able to focus on their holiday, rather than their child or sibling's behaviours or difficulties. In a similar way, equipment helped to integrate ill children into wider social worlds by providing new opportunities for communication. Pieces of equipment helped reduce barriers to communication and supported the integration of ill children into families. Illness therefore lost its prominence during dream experiences (of which I include the use of equipment).

The data thus both support and reflect my theory of dream fulfilment as being facilitatory in shifting perceptions of self away from being defined by illness, and towards a more positive self image. The next category occurring during the third phase of the dream fulfilment process was memory curation.

8.3 Conscious curation of memories

In addition to illness decentralisation, the dream phase of the dream fulfilment process encompasses the 'conscious creation of memories' category. This category was created to describe the memory-collecting experience of families with ill children while experiencing a dream. It was particularly relevant to families with a child with a short prognosis. During dream experiences, family members purposefully took photographs, and internal snapshots of the dream experience to use in the future, if or when the ill child died. Family members with children or siblings with life-threatening conditions approached dream experiences with a 'collecting' approach to holidays, trips and events. In this way they consciously collected memories of moments, photographs and mementos. Such collected experiences and dream objects were curated as memories and later used in the post dream category, 'continuing bonds.' Continuing bonds will be discussed in the next section.

The linked categories of memory curation and continuing bonds describe the impact of dream fulfilment on families with a child with a life-threatening illness, particularly those with short prognoses. As such, continuing bonds is only relevant to bereaved family members.

For some families, family members were conscious of dream experiences being, for example, final family holidays. As such, dream experiences worked as opportunities in which family members could collect experiences, mementos and photographs. Holidays created spaces where families could be together, away from hospitals or other environments associated with illness.

"We were aware that [my daughter] was one of the people that wasn't going to do very well. She picked up a particular bug which we were told at that stage, was impossible to eradicate, so she was spending a lot of time in hospital so we were just trying to have as many good experiences as possible, while she was still able to do things." (Mum, family 12)

As a result of family members knowing that a dream might be a final family experience, dreams were conceptualised with a 'memory collection' approach to the experience.

For other families, dream fulfilment experiences presented opportunities to take photographs so as to commemorate positive experiences.

Jayne – "Can you firstly just tell me a bit about what it was like to go [on the dream]?

*Sibling – "Oh it was really good, I think emm, it seemed like it was better than a possession, a memory is better than a possession, like obviously we have photos and stuff so we can remember, especially like after like, it being like a lot of time in transplant and everything like, it was almost like a treat" (*Sibling, family 4)

Like mum in family 12, a bereaved dad from family four recognised the importance of a final family holiday. He spoke about how the dream experience facilitated opportunities to experience as much as possible before his child died.

"It [the holiday] certainly, lays down a whole host of experiences, which you can call back on. They knew this would be the last time he could, they knew he wasn't going to be ok. And they communicated that to us, but they said, just go, emmm, because the next scan showed signs of deterioration, and so the timing of it was very, very important, and in terms of 'cramming in' as much as we could get together as a family." (Bereaved dad, family 5)

Like previous families, the dream holiday for the dad of family 5 was experienced with a conscious approach to collecting or stocking up on positive experiences prior to his child's death.

Photographs were integral to the collection of dream experiences. In this next dream a young person met a famous pop band. The taking of photographs was an important part of this experience.

Dream recipient - "And then they [a famous pop band] talked to us for a little while and we got pictures with them and stuff."

Jayne- "What was it like have them sing to you? It sounds really special"

Dream recipient - "I know, it was fantastic, we were allowed to take pictures and things like that." (Dream recipient, family 14)

The dream recipient in family 14 felt well at the point of her dream experience. Family members could therefore be with, and capture through photography their child and her sibling in a positive environment and without pain. Family members knew that such consciously collected moments captured during the dream experience would be used as memories in the future, when or if the young person died.

"Because of the way she was at the time, the pictures were great, and will be great memories." (Mum, family 14)

Thus, dream experiences were conceptualised as special, and as one-off occasions that helped facilitate opportunities for photographs, mental images and other mementos to be collected.

"We've just got lots of lovely memories of him, and lots of lovely times, but they [dream experiences] are days you can pinpoint, and they are things that are different" (Bereaved mum, family 19)

This conceptualisation reflects the overarching theory, that dream fulfilment was an alternative milestone, and a kind of marker of time.

Most families in this category had used holidays to collect experiences and curate memories. However, for two families, dreams of equipment facilitated opportunities for families to spend time together.

"It was something we could all do together which was really important. And when you don't know how long you've got, and the clock is ticking, you have to think about these things" (Mum, family 14)

Like the category of validation, it was mostly parents and older adolescents who discussed actively engaging in this process of collecting memories during a dream experience. This may have been due to younger children being told less about illness or their smaller vocabularies limiting articulation of thoughts and feelings at interview.

A sibling of a dream recipient in family 5 cited awareness as a reason why her younger brothers were not able to articulate memory curation as a category. Age and experience were important to this older sibling's conceptualisation of dream fulfilment.

Jayne – "So going back to your other siblings, what do you think they thought about the dream?"

Sibling – "Well I think that because they were 11 and nine they were, they've always been a little bit too young to quite understand. Until recently, they've been...well the youngest [sibling] was six when [dream recipient] got ill, and they've always been like, not 100% aware. So the whole thing just kind of happened around them, been part of their lives, and they have never really known much different because they could never remember much different. But because I'm a little bit older and I can remember times when there wasn't...that [brain tumour], so I think going to America meant something, in a different way. It meant more to me as it was a time to be together because I could understand what that meant. Whereas they just got to experience the whole thing a lot differently from me because, they got to just enjoy it." (Bereaved sibling, family 5)

For this young person whose sibling had died, being able to recall a time without illness was important to the way that she conceptualised her family's final holiday. Her memory of being a family before her sibling's illness helped her be conscious of how important the family time was during the dream experience. Her younger siblings were perhaps able to enjoy the dream for what it was, rather than being consciously aware of the potential finality of the holiday, and the need for it to be remembered as such.

Findings explain how dreams were conceptualised as alternative milestones. These alternative milestones were points in time where positive experiences could be collected. Such experiences turned into memories post dream, and were used in the subsequent category, continuing bonds. The memories curated during dream experiences contributed to the way in which bereaved family members remembered deceased children. The way in which these memories were used will be explored and presented in the following category, continuing bonds.

Prior to presenting continuing bonds it is important to note that while dream experiences allowed for memories to be collected, so did other experiences. Although dream experiences were important, there were other planned and unplanned special moments too, which families captured consciously and which added to their banks of memories to be drawn from if / when their child died. Families' spoke of other experiences such as trips to friends' caravans and weekend breaks, in light of life-threatening diagnoses. Although such experiences might not have been as unique as the dream, data suggest that families additionally collected memories from these different situations for use if / when their child or sibling died.

The next section discusses the way in which the memories collected during dream experiences were used after a child or siblings death. The next category of continuing bonds is thus relevant to bereaved families.

8.4 Continuing bonds

The phrase 'continuing bonds' is a term used in the palliative care and bereavement literature, and is about the on-going relationship with the deceased in the resolution of grief. Positive memories, such as those emerging from dream experiences, contributed to the role the continuing bond played in family adjustment to bereavement. This category describes how parents and siblings in this sample engaged with memories of their

deceased family member so as to keep them in their life. In this way, the deceased child/ young person remained a part of their on-going life, through the retelling of stories, physical memory objects, photographs and art.

The memory and associated paraphernalia of the dream experience contributed, in part, to the stock of past experiences that family members could use as a part of their continuing bond with their deceased family member. It was the unusual or 'one-off' aspects of the dream experiences (due to being expensive or difficult to organise) that made them important in creating memories, which were then used in the development and maintenance of the continuing bond.

"It's taken us a long time, to even speak about him without crying, but I think, it's those extra special memories that are just something you wouldn't do, you know." (Bereaved mum, family 19)

"That it was lovely to get to do extra special things, and for them to be all about [my son], so yeah, it has helped [with grieving]." (Bereaved mum, family 19)

For two parents in family 3, whose children had both died, keeping toys and photographs visible in living spaces helped maintain their deceased children's presence in the house. Toys and photographs from this family's dream experience were presented in their home, held within glass cases, as if being preserved. The house was museum-like in its visual presentation, with the now deceased children at its centre. The dream experience of the family presented here was to meet a giraffe (animal changed). This was one of the favourite animals of one of their deceased children. The toys, books and photographs presented in this family space were connected to the dream experience in that giraffes featured heavily. The dream was thus an important element in the now deceased child's life, and the positive memories created through it were therefore meaningful to the bereaved parents.

"*So we just used picture aids, scrapbooks, they are all in the cupboard. We've also kept all their bits in cabinets, they're like glass cabinets with all the boys' things in them...because you know, we just put them all in there...you can see them, but they need to be sorted out more, you know, it's nice, the memories are really really good.*" (Bereaved mum, family 3)

The physical presentation of the deceased within the house was about more than remembering the deceased, but about maintaining these children's interests, personalities and experiences within the house. Data suggests that keeping memories visible around the house was comforting and reminded parents of the positive memories of their children. Another function may have been that displaying toys and memories meant that these bereaved parents were able to continue to be parents. Although deceased, these children were still very much present in the family space.

One family visited a holiday resort, which catered for families with seriously ill children, and while there, an animal was stuck on the ceiling for their ill child. They were also given small cushions to keep and take away. Both the concept of the hanging of the animal on the wall and the cushion were used by family members in continuing their relationship with their sibling/ son in bereavement. Such activities brought a sense of permanence to the bereaved sibling.

Sibling - *"It was everything, and it was uhhh, it was all centred around him as well, they have this one place where you have like, you write your name on an animal and then you place it on the ceiling and then it just stays there...they've had to build an extra building to put the animals in because there is so many of them."*

Jayne – *"Sounds lovely."*

Sibling – *"And we all got pillows from this pillow tree, I still have mine, it's all purple and green, really nice."* (Bereaved sibling, family 5)

This adolescent sibling found comfort in her brother's animal continuing to be in a special place after his death. The pillow she received as part of the experience also reminded this young person of her deceased sibling. Using memory objects and memories curated during the dream experience (and others) was one way in which the bond with the deceased was continued.

The importance of the animals and the pillow associated with it, were however not just useful to the siblings in the family. Conversations about the animals and the cushion were raised by each member of this family.

"The kids, they still use the cushion that they got from this tree which is inside the place where they put all the animals up. I don't know what the process is, or what they do but these pillows are important, and I guess these pillows are made somewhere and shipped to this place, and they need to be of a particular standard, and they are given to the children who want them, but they are still used by our children, they are all individualised, some are purple, I have adopted [my son]'s for the use of going on hikes because the size suits quite well." (Bereaved dad, family 5)

I spoke to family members separately, and each spoke of the importance of the pillow in their lives. Although dad justified his use of the pillow practically, it became a part of his life and his continuing journey without his son. Both the cushion and the associated animal were useful to the family. They gave a sense of permanence to the deceased young child/ sibling in the family's life.

The dream experience also facilitated a different kind of bond, for a bereaved sibling. The sibling from family four brought the memories from her holiday into her academic work. This suggests that this bereaved sibling was working to keep her brother in her life, and, as a part of this, used memories from the holiday in her art and writing practices.

"It was amazing, and our daughter, I don't know what she was like with you but she, she really talks about it [the dream] as, she described it in her schoolwork, her English GCSE coursework, she drew pictures of it in her art GCSE and, so it was, it was significant to her." (Bereaved mum, family 5)

Another way in which one family kept their deceased children in their lives was through the curation of a blog. Again, this blog was about more than the dream experience for this family, the dream and its resulting photos feature on the site. The blog in question began when this young person first became ill. It was a way of communicating updates to friends and family, but continued to be updated post-death. Recent posts, six months post death, contain memories and reflections on the deceased young person and his life.

In addition to the blog, each bereaved family interviewed in this sample used scrapbooks to remember the bereaved child. Family members were keen to use and show me these during interviews.

Family members used the scrapbooks as a way of remembering the deceased's identity, and the experiences they shared. Like the family who used glass cases to present their children within their home, these scrapbooks were kept in living spaces such as living rooms, on bookshelves or next to fireplaces. These memory books sat within family spaces and in this way, the deceased child remained part of the home.

"Here he was with the horses...he used to stick his tongue out didn't he, that was a sign that it was really good." (Bereaved dad, showing me a scrapbook, family 3)

The scrapbooks, blog articles and pillows linked to dream fulfilment and other positive experiences contributed to the way in which families remembered and reflected upon their deceased. Recalling and using memories from experiences such as these enabled family members to maintain and develop the bond they had with their sibling or child.

The next and final section of this chapter introduces the category post dream support void.

8.5 Post-dream support void

This section discusses the final category contained within the theoretical model, post dream support void. Post dream support void highlights the feeling of loss that family members felt after the dream experience was over.

As the theoretical model (figure 3) shows, the process of dream fulfilment has the potential to have a lengthy trajectory. Data suggest that from application to the actual experience, the process can take in excess of one year. Throughout this process, the ill children and their family members in my sample experienced agency, validation, hope, perceptions of normality, and distraction.

Once the experience was complete, data suggest that some family members felt a sense of loss. This was because the dream experience provided opportunities for anticipation, hope, and focus. Once the dream was complete some families felt a sense of emptiness. This stemmed from the gap that was left in place of anticipatory thoughts about the dream, or the experience of the dream itself. Prior to the dream experience ending, thoughts about the dream, or the dream itself had occupied space and time in family lives. Data also suggest that the removal of the support that was given to families, over the

relatively short period was difficult for family members to adjust to. Post dream support void was mostly due to the lack of focus or anticipation that had been so dominant in the run up to dream experiences. Family members felt a sense of flatness after the dream, knowing that the experience was finished, and that their period of support had ended.

The category post dream support void was relevant to all types of dream, apart from equipment. This was due to equipment being a dream that could be used multiple times. Additionally, equipment dreams did not have the period of anticipation preceding them, or the finality of the experience being over, that came with holiday or travel dreams.

The extract below suggests that children felt low after returning from a dream experience. Although perhaps a normal response from a child post-holiday, it shows how some children felt after returning from a dream experience.

Jayne – "How did you feel when you got back from America?"

Sibling – "Sad."

Jayne – "Oh, why?

Sibling – [long pause]

Jayne – "Because you weren't there anymore?"

Sibling – "Yeah." (Sibling, family 7)

For another young person, a dream experience in family 12 had worked to provide a sense of incentive to a dream recipient who was finding it difficult to stay positive about her condition and her treatments. Once the dream was over, mum felt she needed to source the next experience to maintain worth in her ill daughter's life.

"It was difficult to find other things to keep her motivated after that, to keep her going." (Mum, family 12)

Like the dream recipient's sibling in family 6, members of family 12 felt a sense of loss, post dream. To maintain the feelings of anticipation and hope another experience inciting hope and distraction needed to be found.

Mum in family 1 felt well supported by the charity throughout the dream fulfilment process. As the process model demonstrates, the dream was part of a larger experience: preceded by feelings of validation and hope. However, after the actual dream experience, mum was left wishing for additional support.

"Sometimes I feel selfish, like I want more from DCT, that they are so nice and did so much and maybe they can do more?" (Mum, family 1)

Although mum acknowledges her selfishness here, her interview adds to the data which suggest that post dream, family members felt a sense of having less to do, or look forward to. The dream experience was an important event, which was difficult to then move away from and make the shift into a reality without dream events or experiences to hope for, or focus on. Mum's words here could additionally reflect that actually she needed more support than she was getting from statutory services for example. DCT temporarily filled a gap in support but their involvement had had to end, leaving a sense of loss.

One reason the shift into reality might have been difficult was because family members would not be able to repeat the dream experience, due to financial constraints.

"Now I can see, he dreams about that, whatever he's asking, he's always asking, when are we going back? When are we going to Disney in America? Because it's very expensive" (Mum, family 20)

The support that had previously given respite to family members from their often-chaotic lives was no longer in place once the dream was complete. In addition, family members knew that they would not be eligible for a similar experience again. This was harder for some families than others, particularly those who acknowledged the restrictions of their financial situations.

It is unclear from the data how long this sense of absence lasted.

Although collected memories and dream stories were useful in the time after the dream, some family members still felt a sense of loss post dream. Data presented in previous chapters suggest that family members felt hopeful, distracted, focused and safe during their dream experiences. Thus, when the dream experience was complete, some families felt an absence in their lives. Post dream, a feeling of returning to reality was experienced, which was difficult to adjust to. Where thoughts about the dream had previously helped distract and focus from illness, there was an absence of something to look forward to, or experience. This post-dream sense of loss, in addition to other concepts presented here, will be contextualised and discussed in the discussion chapter. Prior to discussing my findings, I present a brief overview of the theory and categories presented in chapters five, six, and seven.

8.6 Conclusions

Study findings presented in sections five, six and seven suggest that dream experiences were conceptualised as alternative milestones in dream recipients and family members' lives. Additionally, the processes surrounding the dream experience facilitated a positive shift in individual and familial perceptions of self. This was due to the dream fulfilment process providing instances and experiences where illness did not underscore family life. The process of dream fulfilment, from nomination or application, to the dream itself, provided periods of hope, of agency, distraction and of normalisation. Feeling hopeful, agentic and validated through the dream fulfilment process shifted perceptions of the self away from feeling ignored, excluded and unsupported as a result of being ill. The positive experiences and interactions that family members had during the dream fulfilment process were important in shaping individual and familial sense of selves. Although it is unclear how long the positive impact of the dream fulfilment process lasted on participants' sense of selves, the dream experiences themselves remained as milestones in family lives. These milestones marked time, were used as points of reference, and as facilitators of happy memories.

The next chapter uses my theory to examine existing understandings of milestones and markers within individual and familial self-narratives. The chapter also looks to the literature for potential explanations as to why the process of dream fulfilment was so affective. Related to this I look at what other process have been found to facilitate positive shifts in perceptions of self in illness. In line with grounded theory methodology, my

discussion chapter provides an overview of the literature, relevant to my generated grounded theory.

Chapter 9: Discussion and literature

I include the theoretical model of dream fulfilment at the beginning of this chapter as a reminder of my theory, and the way in which my findings are connected.
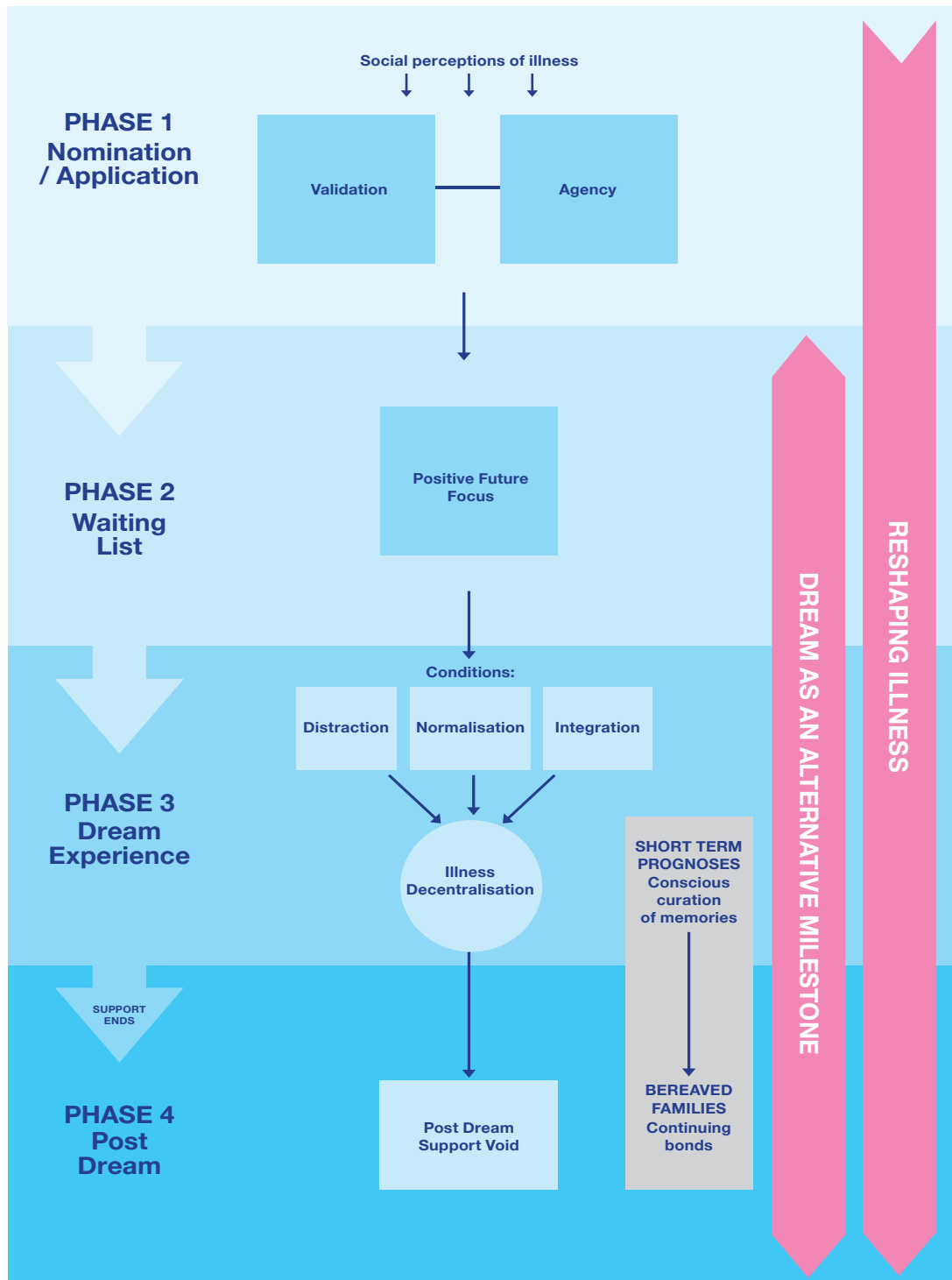
9.1 Introduction

This chapter situates the grounded theory generated from the data within a broader theoretical landscape. It makes comparisons between findings presented within this thesis and the extant literature, and shows how and where my findings are novel, and where they fit with existing understandings. Additionally, by drawing on extant literature as additional data, this discussion chapter seeks to further enhance understanding of the findings themselves (Breckenridge, 2010).

As discussed in chapters five, six and seven, my grounded theory of dream fulfilment is that dream experiences were conceptualised as alternative milestones. Additionally, the dream fulfilment process from application to the dream itself, reshaped illness by providing moments where illness did not underscore family life, and thus positive shifts in individual and familial perceptions of self occurred.

Findings presented in this thesis are novel. Findings are novel in the first instance because the generated theory presented in this thesis encompasses the views of dream recipients, siblings, parents, and extended family members' experiences of dream or wish fulfilment. Previous researchers examining wish fulfilment (Darlington et al, 2013; Schilling and Sarigiani, 2015; Ewing, 2007) did not interview children and young people, nor did they examine dream or wish fulfilment from a wider family perspective. My findings additionally present an understanding of the impact of dream fulfilment on children and young people with long-term, in addition to life-threatening conditions. My research is thus based on a heterogeneous sample, which could enhance its transferability to wider populations of sick children.

However, more than methodologically, my findings are novel as they show how dream or wish fulfilment as an alternative milestone can facilitate a shift in the perception of illness and self, in serious ill children and their family members.

Although the generated theory, and the methodology used in this study were novel, aspects of the categories informing the generated theory reflects previous research in the field, and in the wider spheres of illness and disability research. The remainder of this discussion examines such literature. I also look at the literature for conceptualisations of experiences that have been found to be similar to the dream experience such, as summer camps for children with cancer.

I structure this chapter by first discussing the first part of my theory, dream fulfilment as an alternative milestone. I then discuss the second aspect of the theory, reshaping illness. After discussing my theory I move on to look more specifically at the generated categories that represent and contribute to the wider process of dream fulfilment. I look to the literature here for existing understandings of how concepts such as agency and validation have been found to impact upon the self and identity in illness. As there is little published research in the field of dream and wish fulfilment I draw on a range of literatures in discussing my findings.

This discussion chapter is long, as in the absence of a literature review, this chapter orients the reader to the literature surrounding dream fulfilment.

9.2 Dream fulfilment as an alternative milestone

My conceptualisation of dream fulfilment as an alternative milestone is conceptually similar to what Charmaz (1997) calls timemarkers. Charmaz is a sociologist, writing extensively on illness, aging and death, as well as on grounded theory methodology. Charmaz (1997) writes that a timemarker places an event in a chronology, a chronology in this sense being what McAdams (2006) presents as a narrative story, one that creates continuity and purpose from the raw material of life experiences (Blagov and Singer, 2004). Timemarkers, as the name suggests, mark time and space, and work as anchor points for measuring illness, health and self. In illness, these markers could be diagnoses, surgeries or treatments, in effect, points in time that mark a shift in direction, and a resulting shift in self (Charmaz, 1997). Charmaz's (1997) concept of timemarkers can be positive or negative. Dream experiences as alternative milestones are likened to timemarkers as they added to individual and family narratives in the same way that Charmaz (1997) asserts that surgeries or treatments in illness do.

Milestones are considered important as they mark periods of time, and achievements (Flensborg-Madsen and Mortesen, 2015; Crylunik et al, 2015). In children and young people, milestones such as finishing school are part of marking the transition into adulthood and identity development (Pinquart, 2014). However as highlighted in my data, pain, limitation in functional ability, worry and embarrassment, and absenteeism from school negatively affect the achievement of these milestones in children with life-threatening or long-term conditions (Schwartz & Drotar, 2009; Last and Grootenhuis, 1998; Pinquart, 2014). Dream experiences, in being validating, normalising and creating

memories became alternatives to traditional milestone events, such as finishing school, in the lives of families with ill children. These alternative milestones became part of family narratives, and helped children and family members extend their perceptions and definitions of themselves away from illness.

My theory of dream fulfilment as an alternative milestone adds to Charmaz's (1997) conceptualisation of timemarkers. Charmaz's concept of timemarkers shows that timemarkers are personal points of reference in a person's life that shape new directions. My theory adds to the concept by suggesting that there are certain milestones considered normative in defining trajectories of childhood. If such perceived milestones are missed, then it is helpful for children and families to replace that missed milestone with an alternative experience or event, the alternative milestone being in the case of this thesis a wished for, or aspired to, experience or event. My theory thus adds to Charmaz's (1997) concept of timemarkers by showing how children and families can create their own positive timemarkers through dream or wish fulfilment, in response to missing out on perceived imposed or normative timemarkers or milestones.

9.3 Reshaping illness

In addition to the dream being an alternative milestone, findings suggest that dream fulfilment facilitated a shift in perceptions of illness. The data show that many families' lives were underpinned by feelings of worry and sadness. Children and family members felt defined by factors relating to illness. These factors being illness routines, illness behaviours, and illness environments. Dream experiences helped to counter such negative perceptions of illness, by facilitating feelings of validation, agency and inclusion. The dream experience worked to change the way that illness impacted upon families with ill children, even if this shift in impact was temporary. Reshaping illness therefore explains the way that a positive experience, like dream fulfilment can shift the impact that illness has on family life.

As the reshaping illness theory is in part, about identity it is useful to look to the literature on illness narratives to understand more about what reshaping illness might mean. Matheison and Stam (1999), writing on cancer and identity explain that a patient who lives with cancer "finds herself in a nexus of dynamic psychosocial events. These events often result in reports of loss of productive functioning, financial strain, family stress, personal

distress, stigma, and threats to former self images. Taken together, these events signal that one's identity will forcibly undergo transformation" (Mathieson and Stam, 1999, 287).

Though each of the constructs identified by Matheison and Stam (1999) might not be relevant to all of the children or families in this study, the quote does appear to reflect the way in which life-threatening and long-term conditions affected families' identities in my sample. The impact of being seriously ill, or having a seriously ill child or sibling affected family members' individual and familial narratives. Narratives are defined as the "internalized, evolving story of the self" (Adler, 2012, 367). They are a kind of self image (Hyden, 1997), and are concerned with the creation of identity through the construction of stories (Ricoeur, 1985). A narrative identity,

> *"Reconstructs the autobiographical past and*
> *imagines the future in such a way as to provide a*
> *person's life with some degree of unity, purpose,*
> *and meaning. Thus, a person's life story synthesizes*
> *episodic memories with envisioned goals, creating a*
> *coherent account of identity in time. Through*
> *narrative identity, people convey to themselves and*
> *to others who they are now, how they came to be,*
> *and where they think their lives may be going in the*
> *future"* (McAdams and McClean, 2013).

It is helpful to look at the concept of narrative identity here because the idea that events within an individual's life help construct that individual's identity (McCadams and McClean, 2013), helps show how my theory of reshaping illness works. As discussed, family stories of illness and the impact of illness were mostly chaotic, sad, and difficult. Families felt defined by illness because of the impact of their, or their child or sibling's condition, on wider family life. Such perceptions stemmed from events like treatment processes, long periods in illness environments, and from daily routines dictated by illness. Due to illness' defining impact on family life, individual and familial narrative identities were also based on illness. Self and familial narratives were thus anxious, uncertain, sad, and based around illness.

McAdams and McClean (2013) write that a person's life story synthesizes memories that create an account of identity. As a reflection of this, a dream fulfilment experience added

to individual and familial narratives, by adding positive experiences to stories that were otherwise mostly defined by illness. Therefore the validating, agentic, and normalising aspects of the dream helped create a different narrative - encompassing feelings of inclusion, agency, validation and fun - and a different identity.

A number of sociologists have given names to moments such as that of dream fulfilment that shift, even temporarily, perceptions within people's narratives or life stories. Thompson et al (2002) for example call such events critical moments. Critical moments are events that have important consequences for individuals' lives and identities (Thompson et al, 2002). While Thompson et al (2002) were writing on youth and transitional experiences, their conceptualisation of the critical moment reflects the way in which dream fulfilment shifted perceptions of illness and identity.

Additionally, Denzin's (1989) concept of epiphanies is reflective of my reshaping illness theory. Epiphanies are described as moments and experiences that leave marks on people's lives by altering their meaning structures (Denzin, 1989). Dream fulfilment experiences could be understood as epiphanies in that the agentic, validating, and normalising aspects of dream fulfilment facilitated a shift in the perception of the impact of illness. While dream fulfilment may not have altered the meaning of illness to families, the positive nature of dream fulfilment resembles Denzin's (1989) concept of epiphany as the dream because of the mark left on family life. This mark being a shift in perception of illness that thus allowed family members time and space to focus on other relationships or interests. As such, Denzin's (1989) conceptualisation of epiphanies theory helps explain my theory of reshaping illness. Thompson et al (2002) and Denzin's (1989) conceptualisations of landmark moments illustrate how experiences or events can have consequences on individuals' identities (Thompson et al, 2002) and leave marks on their lives (Denzin, 1989). My theory of reshaping illness is underpinned by such ideas.

Reshaping illness as a theory is important as it highlights just how much perceptions of the self in illness are shaped by the actions of others, and through interaction with third sector and statutory organizations. Interactions with health professionals, peers and charities that make ill children and their family members feel problematic, or less important, shape both children and adults' sense of who they are. In the same way, positive interactions with charities or other health professionals that provide validation, agency and a sense of normalcy also shape perceptions of self. My theory thus shows how potentially sensitive family members can be to the actions and behaviours of others,

and how these behaviours come to impact upon how families with ill children perceive themselves.

The remainder of this chapter will now focus on examining my findings further, looking for comparisons within existing understandings of dream fulfillment and other positive experiences, and highlighting where my findings are novel. I begin by discussing the way in which dream fulfillment facilitated a positive sense of self and family.

9.4 A positive sense of self

Findings presented in this thesis suggest that the dream fulfilment experience facilitated feelings of agency, validation and positive future focus. Each of these concepts worked to shift the perceived impact of illness on families. This shift in the impact of illness facilitated an additional shift in perception of self and family. It is these small shifts in perceptions of illness and self that will be discussed in this section. This section also examines the concept of illness hierarchies, and how perceptions of these hierarchies impacted upon my participants' experiences of validation.

9.4.1 Validation

Validation was a category relevant to the beginning of the dream fulfilment process. It explains how family members of children with long-term and disabling conditions found eligibility for dream fulfilment to be socially validating of their children's conditions.

In this section I show that parents' perception of long-term conditions being minimized in importance, compared to life-threatening conditions (especially cancer) was not unfounded. Research primarily conducted in Norway, contextualises concern around disease hierarchies and consequential societal and financial attention. Album (1991) and Album and Westin (2008) asked health professionals to rank diseases by prestige (prestige being a measure of regard or esteem). In both studies, leukaemia and brain tumours were amongst the highest of ranked conditions, with conditions such as cerebral palsy and multiple sclerosis positioned at the lower end of the scales.
Similar patterns were noticed in Vanderelst and Speybroeck's (2013), and Mayor's (2006) research into funding priorities in medical research policy. Analysis found cancers to attract more funding than would be expected based on both their morbidity and mortality.

Although cancer has been conceptualised as a long-term condition, due to its long-term, or ongoing impact on people's lives, the narrative emerging from the academic literature is thus that cancer appears to be positioned higher within overall condition hierarchies than disabling or (other) long-term conditions.

While the academic literature describes the medical sphere, participants in this study additionally reported third sector and statutory experiences which reflect the apparent biases occurring at funding and policy levels, described by the literature. Illness hierarchies, perceived by family members and reflected by the literature were for example, evident in third sector wish fulfilment charity 'Rays of Sunshine's' eligibility criteria. This charity ranks conditions by seriousness of condition. Children with conditions in ACT / RCPCH category one (characterised by life-threatening conditions such as cancer) are able to access all wish types that the charity has available. Children with conditions in category two (conditions characterised by potentially life-threatening conditions such as Rett Syndrome) are able to access wishes excluding overseas travel. Children with conditions in the final category (characterised by deterioration or a reduced quality of life) are able to access wishes excluding overseas travel or UK holidays, but inclusive of special days out. While difficult to argue with a charity's stance of prioritising life-threatening conditions, the explicit ranking of such conditions worked to reinforce family member perceptions that society views long-term illness as less important than immediately life-threatening conditions and cancer.

So as to further understand why such hierarchies of conditions exist, I briefly look at explanations from the literature. Fear of death potentially explains the perceived bias of financial support and attention given to families with children. The hypothesis of fear as an instigator of research funding is proposed by Vanderlelst and Speybroeck's (2013) research into research funding priorities, which found that funding levels seem to follow mortality more closely than disability.

Another consideration in the discussion around the development of condition importance is rooted in the philosophy of biology. Canguilheim (1966) writing on the ontological representation of illness believed "that a vulgar hierarchy of diseases exists based on the extent to which symptoms can - or cannot - be readily localized" (Canguilheim, 1966, 39). The application of Canguilgeim's (1966) logic means that cancer, as a condition more likely to be localised, would be nearer the top of an illness hierarchy than cerebral palsy. This explanation reflects Album and Westin's (2008) study on prestige that also suggests

that conditions without objective diagnostic signs are more likely to be accorded low prestige. This argument also supports Sontag's (1978) disease as metaphor theory, which explains that conditions whose causality is murky and for which treatment is ineffectual, tend to be viewed as less significant.

Conrad and Barker (2010) argue that this granting of prestige to conditions that are most clearly defined in medical terms suggests the enduring power of medicalization in illness and disability. Charmaz (1983) supports this theory of worth also, writing that our society is one with a narrow, medicalized view of suffering, defined solely as physical discomfort. This conceptualisation of suffering ignores and minimizes the significance of the suffering experienced by people with chronic illness.

Although Sontag (1978) and Canguilheim's (1966) theories of illness are perhaps outdated, their explanations help contextualize why cancer is prioritized by research funding (Vanderelst and Speybroeck's, 2013; Mayor, 2006), and by status or prestige (Album, 1991; Album and Westin, 2008).

For families with children with conditions such as cystic fibrosis, being eligible for a dream began the process of shifting the way that family members viewed their and their child's conditions. Being eligible for a dream helped families with low prestige conditions (Album, 1991; Album and Westin, 2008) change the way they thought about their condition, and consequentially began to shift the way that family members perceived of themselves and their families.

Validation through dream fulfilment is a novel finding. It has not been addressed in the small literature on wish fulfilment conducted previously (Darlington et al, 2013; Ewing, 2007, 2009; Schilling and Sarigiani, 2014). The novelty of validation as a finding is perhaps because my study is the first to examine the impact of dream or wish fulfilment on children with a range of conditions (i.e. long-term and life-threatening). Previous research examining the impact of wish fulfilment has only looked at wishes fulfilled through the Make a Wish foundation, Make a Wish fulfil wishes only to children with life-threatening conditions. DCT work with children with both life-threatening and long-term conditions. Thus my sample consisted of children with a range of conditions, which subsequently allowed categories to be generated from a more heterogeneous sample. This wide-ranging sample increases the utility of my research.

Due to the unique nature of my research there are not any obvious fields on which to base a discussion of validation. There are however well established understandings of stigma and self-concept in illness that are relevant to my finding of validation. I look to the literature on stigma because validation as a concept arose due to perceptions of exclusion and invalidity. Such perceptions parallel definitions of stigma as undesired differentness (Goffman, 1963).

Dream fulfilment as an intervention shifted participants' perceptions of different, or as undesired (Goffman, 1963), and in this discussion I look to other concepts that have also been found to alter perceptions of self and self concept.

9.4.2 Social support and self esteem as moderators of stigma

Studies have shown that social support predicts lower levels of perceived stigma in illness (Wu et al, 2015; Vyavaharkaret al, 2010). Stigma works to make individuals feel discredited and invalid (Grytten and Maseide, 2006) and has been found to make individuals feel less valuable in society (Raty et al, 2004). The stories of families with ill children, and especially those with children with impairments, reflect such descriptions of stigma.

Social support as a moderator of stigma perhaps then reflects, in part, my finding of validation and my wider theory of reshaping illness. Dream fulfilment supported families by providing them with a positive experience. As a consequence, family members felt validated. Social support through dream fulfilment may have moderated stigma in a similar way to participants in Wu et al (2015) and Vyavaharkaret al's (2010) studies.

The idea that social support moderates perceptions of stigma might additionally help explain why families, post-dream felt a sense of loss after the dream experience was over. Although perhaps related to the ending of a positive experience, this perception of loss may also have been about the ending of social support. This idea is returned to, when I discuss in more detail the post-dream aspect of the dream fulfilment process.

In addition to social support, self-esteem has been found to moderate the internalization of stigma in individuals with impairments. Self esteem being defined as worthiness, adequacy and self respect (Rosenberg et al, 1995). The relationship between self esteem and stigma has been found in disabled Chinese populations (Zhang et al, 2014), in

women with disabilities (Nosek et al, 2003) and linked to better psychological health among caregivers of individuals with disabilities (Riana et al, 2005).

While self esteem is not the same as validation, Rosenberg et al's (1995) definition concerning worthiness and adequacy reflects the way that some family members felt during the dream fulfilment process. Social support and self esteem therefore add context to my finding of validation in dream fulfilment. The next part of the dream fulfillment process that facilitated a positive shift in individual and familial perceptions of self was agency. Agency as a category was most relevant to children and young people in my sample.

9.4.3 Agency

Agency was about the sense of choice and power attributed to the ill child or young person, in choosing a dream fulfilment experience. Agency was important to the young people in my study, perhaps because, as Seeman and Seeman (1983) write, a sense of control is a necessary element to good mental health. Thus, losing a perception of control challenges an individual's ability to cope with life's circumstances (Nannis et al, 1982). Children and young people in my study talked about the loss of control, identified by Nannis et al (1982). They talked about having decisions made for them, and having illness and treatments for illness dominate their lives. Conditions like cancer meant that children and young people needed to spend prolonged periods of time in hospital. Complex care needs, such as ventilator support also meant that young people needed to stay near to their parents or carers in case of ill health. Thus the intrusion, or impact of illness on these young people's lives was formidable.

A general lack of control is a common theme in the literature in illness (Charmaz, 1983; Charmaz, 1997; Bury, 1982; Lowton and Gabe, 2003; Kidd et al, 2009), with findings suggesting that powerlessness in illness is associated with a loss of self. Agency as part of the dream fulfillment process was therefore about having a sense of power and control. Even if this power was momentary, agency, like validation, facilitated a change in the young people in my study's sense of self.

My finding of agency is not evident in Darlington et al's (2013) or Schilling and Sarigiani's (2014) research into wish fulfillment. However my category of agency does parallel a theme from Ewing's (2007) hermeneutic study of wish fulfillment. Ewing (2007) describes

a theme called "I am trying to balance things" (Ewing, 2007, 203) that suggests that seriously ill children might use wishes to balance out the loss of physical control in their day-to-day lives. Ewing's (2007) interpretation of her data is that wishes might help children maintain a balance of power in their lives. Although Ewing's (2007) finding of balance is not the same as my finding of agency, there are parallels in the findings which reflect the way in which dream or wish fulfillment countered feelings of powerlessness in illness.

The next section looks to the way in which participants experienced the waiting list, and how they conceptualized a positive future during this time.

9.5 Conceptualising a positive future

Agency and validation gave way to a positive future focus. A positive future focus was about anticipation and hope, and the reimagining of a different or a better kind of, albeit short term, future. Hope for the dream experience focused thoughts on the future, distracting children, young people and family members from painful treatments or distressing illness environments. As such, I discuss the conceptualisation of a positive future, with a focus on how hope has been used to cope in situations such as illness.

Hope, according to Snyder et al's (1991) seminal psychological theory, involves having personally valued goals, the perceived ability to generate strategies to achieve those goals, and the motivation to apply those pathways in the goal-pursuit process. Snyder's (1991) hope theory has informed research on hope as a moderator of stressful life events such as illness (Klyma, 2005; Elliott and Olver, 2002). Lewis and Kliewer (1996) for example report that higher levels of self-reported hope predicted the increased use of active coping strategies in illness. Parents of children with Down's syndrome expressed how hope provided them with a new positive direction and way of living life (Truitt et al, 2012). In traumatically acquired disability, hope was used to cope with loss (Elliot, Witty, Herrick and Hoffman, 1991) and, in Drach-Zahavy and Somech's (2002) research on students, these researchers found that hope was useful in coping with health problems.

Although Snyder's (1991) theory of hope is helpful in contextualising my findings, it is apparent that there are many definitions and understandings of hope. Thus, I take a look at the palliative care literature for alternative explanations of hope in illness. Although not every child's condition in this cohort was life-threatening, the importance of hope in illness

has been widely discussed within this literature (Herth, 1990; Benzein and Berg, 2005) and so is useful to explore.

Scanlon (1989) suggests that hope in a palliative care context is about the belief that better days can come, with hope being recognized as an important component of patients' existential needs (Olsson et al, 2010). In caregivers, hope has been defined as a dynamic inner power that enables transcendence of the present situation and fosters a positive new awareness of being (Herth, 1993). These definitions are similar to wider, dominant conceptualisations of hope discussed earlier, in that they view hope as an internal trait. However, they differ in that they also consider philosophical concepts such as the meaning of existence, a common theme in end of life discussions (Kaasa and Loge, 2003).

Research on the role of hope has found that ill adults with limited life expectancies fostered hope through practical and emotional support, as well as the exploration of realistic goals (Clayton et al, 2005). The idea that goals may be helpful in fostering hope is reflective of my data. The hope aspect of my findings suggest that the existence of a hoped for short-term future was helpful in child and family member coping.

Although dreams were not conceptualised as goals, as in Clayton et al's (2005) findings, having a hoped for future or goal appears to be helpful. Duggleby and Wright's (2005) work supports this, finding that both striving for meaning and acceptance of a situation are ways of retaining hope in severely ill patients. Borneman et al's (2002) study of hope in caregivers, found that hope was about the strong connection between hope and faith, and inter-relatedness with others. Other themes from Borneman et al's (2002) study included being realistically hopeful and taking things one day at a time. Both Duggleby and Wright (2005) and Borneman et al (2002) support the finding that hope in serious illness is about having realistic future objectives. Dreams perhaps characterize these objectives / goals, in that they present positive experiences, to be looked forward to and hoped for in the short-term future.

The positive future focus finding discussed here is reflective of Ewing (2007), Schilling and Sarigiani, and Darlington et al's (2013) research into wish fulfilment. These researchers found that, like my participants, wishes were experiences to be hoped for or anticipated. Ewing (2007) writing on hope, explains that fantasy can help children adapt to tensions, anxieties and fears. Fantasy being, "a way to negotiate tormenting emotions and

deal with conflicts. It is a way to alter the situation to make the child feel safe and better"
(Ewing, 2007, 198). My data reflect Ewing's (2007) statement, in that participants'
conceptualisation of a positive future helped them feel more positive as part of their
current situations.

Distraction was another important part of anticipating a positive future experience.
Anticipating and hoping for a dream fulfilment experience helped families in difficult or
painful situations. In the next discussion section on illness decentralisation, distraction
was also used, this time during the actual dream experience.

9.6 Illness decentralisation

In discussing illness decentralisation, I look first at distraction. There is a wide-ranging
literature on the use of distraction in illness, particularly informed by research in the field
of paediatric nursing (Koller and Goldman, 2012; Gershon et al, 2004; Yun et al, 2015).
This work is primarily around distraction's role in physical pain. Koller and Goldman
(2012) write that distraction operates on the assumption that by shifting a child's focus to
something engaging and attractive, his or her capacity to attend to painful stimuli is
hindered, thereby reducing distress, and anxiety. Such distraction techniques range from
clown nurse interventions (Yun et al, 2015) to parents as distraction coaches (Klieber et
al, 2006) to virtual reality distraction techniques (Hua et al, 2015). Findings from such
studies in part reflect dream fulfilment as distraction in my data. Where clown-nurses
provided positive distraction from painful medical procedures, dream fulfilment
experiences such as meeting a favourite Disney character, provided distraction from
difficult or chaotic illness environments and routines. Dream experiences worked to shift
children and family member focus away from illness, in line with Koller and Goldman's
(2012) definition.

However, the distraction provided in response to a painful medical procedure differs
slightly from the distraction experienced during dream experiences. In my data, dream
fulfilment experiences provided longer-term distraction from illness. This distraction was
important as family members in my study felt controlled by their conditions and restricted
by apparatus or equipment, with rare opportunities for relaxation. Dream experiences
provided opportunities to relax and shift focus away from illness, this being the crux of my
finding illness decentralisation, and an important aspect of the alternative milestone
theory.

Distraction is a theme that occurs in each of the papers examining dream fulfilment (Darlington et al, 2013) and Schilling and Sarigiani's (2014) research papers. Schilling and Sarigiani (2014) report that parents felt that wish fulfilment helped wish recipients think less about illness. Darlington et al (2013) also report distraction. My findings therefore in part, reflect existing understandings of wish fulfilment.

9.6.1 Group holidays as normalising

In addition to distraction, group holidays helped facilitate illness decentralisation – the shift in focus away from illness. My data suggest that the collective and consequentially normalising nature of group trips helped shift the focus of illness away from feeling stigmatising, constraining (Larmbert and Keogh, 2015) and lonely (Elliott et al, 2005).

Dream fulfilment as normalising is a novel finding. Although Schilling and Sarigiani (2014) found that wish fulfilment experiences facilitated a sense of normalcy through distraction from illness, normalisation was different. My finding is different as it is concerned with normalisation (i.e. a feeling that illness was accepted or common) *of illness* through collective dream fulfilment experiences. Schilling and Sarigiani's (2014) finding of normalcy was concerned with *thinking less* about illness.

My finding is also novel in context, as prior to this study, collective dream or wish experiences to Disneyland had not been explored through research. Normalisation of illness as part of a collective dream experience is therefore novel and adds to the growing literature on dream and wish fulfilment.

However, previous studies that have evaluated non - dream or wish group holidays for ill children reflect my theory of dream fulfilment as an alternative milestone, which reshapes illness. Torok et al (2006) for example found that group holidays catering to ill children increased self-esteem and self-efficacy. Gillard and Watts (2013) found that collective holiday experiences produced positive developmental experiences. Group holidays for children with cancer have also been found to be useful in increasing knowledge on cancer and its treatment (Bluebond-Langner et al, 1990). Previous research has also, albeit rarely, examined the experience of holiday camps for siblings of children with cancer. Like the holidays for ill children these studies show that the group holidays worked to improve social competence (Sidhu, Passmore and Baker, 2005) and self esteem (Packman et al,

2010) in siblings. Recurring themes in the literature on camps and holidays for ill children and siblings of ill children are those of sociability and inclusion (Gillard and Watts, 2006; Cushner-Weinstein et al, 2007), acceptance (Misuraca et al, 2006) and improved attitudes to illness (Briery and Rabain, 1999).

The literature cited above therefore reflects my theory that dream fulfilment experiences facilitate a shift in perceptions of self in illness.

Although the literature on camps for ill children is reflective of my finding, there is little literature on the impact of holidays for whole families of ill children. Martiniuk (2003), writing on family camps for children with cancer, explains that although camps for families are popular, little documentation exists on their existence or impact. My finding, that group holidays for ill children and their families, support whole families in feeling normal and supported in their experience of illness, thus adds to the limited understanding of the phenomenon of whole family, group holidays.

9.6.2 Group trips and milestones

In addition to the illness decentralising aspect of group holidays, and the consequent shifts in self that illness decentralisation facilitates, Gillard and Watts (2013) write that holidays for ill children provide opportunities for milestones to be achieved. Examples of such milestones are, autonomy development, social development and psychosexual development (Stam et al, 2006). In developing their argument on the benefits of group holidays on developmental milestones Gillard and Watts (2013) cite research by Henderson, Bialeschski and James (2007) which suggests that participation in collective holiday programs supports developmental processes such as emotional regulation, peer relationship building, exploring emerging identities and interests, and character building. My data reflect this, with children and family members on group holidays making new friends, travelling together and having new experiences in a different environment.

Collective experiences that develop psychosocial development are important as both my data, and the literature, suggest that many ill children do not have the support or opportunities to achieve such milestones in the same way as well children (Gillard and Watts, 2013). Last and Grootenhuis (1998) write that children with cancer are frequently unable to attend school, participate in sports, and / or play with friends. The outcomes of illness-related restrictions on play and education are quantified by Stam et al's (2006) and

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Montiero et al's (2013) work on illness and psychosocial development. Both Stam et al (2006) and Montiero et al (2013) found that children who had grown up with a life-threatening or long-term condition reported achieving fewer milestones in the developmental domains of autonomy, psychosexual (Stam et al, 2006) and social development and personal growth (Montiero et al, 2013) than control groups.

Group trips therefore provide opportunities to develop, play and feel normal. The developmental milestones discussed by Stam et al (2006) and Montiero et al (2013) are dissimilar to the dream fulfilment as alternative milestone theory. However, the psychosocial development aspects of holiday experiences contributed to the overall sense that the dream was conceptualised as a form of milestone. Grant et al (2006) suggest that opportunities for psychosocial development such as group trips might be more important than ever, as we see increasing survival rates for conditions like cancer (Grant et al, 2006).

9.6.3 Integration

The final aspect of illness decentralisation is integration, through the use of specialist equipment. As discussed, equipment dreams were conceptualised as pragmatic for some dream recipients, due to financial restrictions and difficulties travelling. They were utilitarian in nature for the participants in my sample, rather than being for example, aspirational.

The finding that equipment dreams were conceptualised by some families as pragmatic or utilitarian is novel. The finding does not appear in previous analyses of wish fulfilment, perhaps because previous studies utilising surveys (Darlington et al, 2013; Schilling and Sarigiani, 2014) and creative methods (Ewing, 2007) were not able to capture nuanced aspects of the wish fulfilment interventions such as the finding concerning equipment as a utilitarian dream. The generation of this novel finding concerning equipment dreams highlights the relevance of grounded theory methods for this study into dream fulfilment and impact. That equipment dreams are conceptualised as pragmatic or utilitarian by some families thus adds to existing understandings of dream and wish fulfilment.

However, although equipment dreams were perceived as utilitarian by some families, equipment dreams, like group trips and holiday experiences, decentralised illness by supporting integration into peer group and families. Mobile phones with large screens

helped young people join online communities and feel independent and adapted computers facilitated sibling play. Like distracting experiences and normalising group trips, equipment dreams allowed disabled children to in part, transcend illness and facilitate illness decentralisation. In decentralising impairments associated with illness, children and family members were able to feel normal and be a part of their families and peer groups in a different way. Again, this finding supports my wider theory that shows how dream fulfilment experiences shift perceptions of what illness means, and how illness impacts on family members' lives.

Existing understandings of specialist equipment's role on the lives of children with disability are in line with my findings. Like my data, findings drawn primarily from the learning disability literature suggest that specialist equipment facilitates integration into peer groups and social participation (Lupton and Seymour, 2000; Cook and Polgar, 2015; Heiman and Shemesh, 2012; Byrant and Byrant, 1998).

Normalisation on group trips, distraction in new environments and integration through dreams of equipment all facilitated the wider category of illness decentralisation. Illness decentralisation, through normalisation, distraction and integration was important because it shifted illness away from the centre of the family. In doing so, it provided an often-rare opportunity for families to play, travel and be together as a family. In normalising, distracting from, and integrating children into families and peer groups, dream fulfilment helped family members re-define their perceptions of illness. Illness became decentralised, and as such did not dominate dream experiences or family life for the duration of the trip. It is unclear how long the impact of the dream lasted, but momentarily at least, families were able to define themselves by things other than illness.

In the next sections of this chapter I discuss the conscious curation of memories and continuing bond categories. These categories are connected across phases three and four, with the conscious curation of memories occurring in the dream phase, and continuing bonds, post dream. Both categories were relevant to families in this sample with a child who had a short prognosis at the time of the dream. Continuing bonds was only relevant to bereaved families. The categories outlined in the findings section inform this discussion and subsequent review of the literature in the field. Later in the chapter I also discuss the sense of loss that family members experienced when returning from holiday or travel dreams.

9.7 The curation and use of memories

This section looks to the literature for a discussion on the way in which family members consciously curated and then used memories after a child or sibling had died. My finding here is unique to the small literature in this field and as such there is not a dedicated literature relevant to the finding of memory curation during dream or wish experiences. Although conscious memory curation might appear similar to the findings reported by Ewing (2008), Darlington, et al (2013) and Schilling and Sarigiani (2014) that suggest wish fulfilment creates positive memories, there are marked differences between my finding of conscious memory curation and previous understandings around positive memory creation. Where the *creation* of positive memories (Ewing, 2008; Darlington et al, 2013) is about remembering a wish in bereavement, the *conscious curation* of memories is about the conscious collecting of positive moments during a dream experience. In this sense, positive experiences are consciously curated with bereavement in mind. In the absence of a literature on this subject, I look to existing understandings and discussions on legacy building, anticipatory grief and the wider adult palliative care literature to add context to and extend understanding of memory curation as a concept.

9.7.1 Legacy building

In my study the conscious collecting of experiences by family members, in preparation for bereavement happened organically during dream experiences. However, similar practices also happen more formally, within paediatric palliative care contexts. Foster et al (2012) call the preservation of a child's personality or experience 'legacy building'. Legacy building can be defined as doing or saying something that is remembered, including both intentional and serendipitous legacies (Foster et al, 2009; 2012). Examples of legacy building include memory books, hand moulds, song writing, artwork, jewellery making, photographs, and videos.

Studies looking at formal legacy building have found that legacy building interventions increased positive emotional experiences (Allen, 2009) and family communication (Allen et al, 2008). Legacy building activities have also been found to lower anxiety in individuals and family members (Walsh, Martin and Schmidt, 2004) and decrease suffering in dying children and their families (Foster et al, 2012).

The studies outlined above suggest that legacy building can help ill children prepare for their own deaths. Additionally, research shows that family members might also benefit (Akard et al, 2015; Foster et al, 2012; Sisk et al, 2012). Foster et al's (2012) study reports that legacy making helped bereaved families, by providing a tangible way to remember a deceased child. It is this family support aspect of legacy building that reflects my own finding of memory curation.

While memory curation is reflective of aspects of legacy building in paediatric palliative care, such as the tangible photographs that result from the collection aspect of memory curation, there are nuanced differences. Legacy building is a formal, structured activity, supported by health professionals (Sisk et al, 2012; Allen et al, 2008) and memory curation is family-led and informal. Regardless of the difference, my findings acknowledge the importance of memory collecting and curation in anticipating bereavement and bereavement, and thus suggest that memory curation and continuing bonds (as part of bereavement) are connected. Foster et al (2012) support this connection, writing that the concept of legacy making may be associated with the continuing bonds theory (Klass, Silverman and Nickman, 1996). The literature surrounding continuing bonds is discussed next.

9.7.2 Continuing bonds

My continuing bonds category takes its name from Klass, Silverman and Nickman's (1996) theory of the same name. The palliative care literature defines continuing bonds as the presence of an ongoing relationship between a bereaved individual and a deceased person (Stroebe & Schut, 2005). My findings parallel this existing definition in that family members used positive memories, photographs and objects from the dream experience after their child or sibling had died.

These memories and mementos were used to continue bonds and relationships, such as those described by Klass, Silverman and Nick (1996), after dream recipients had died. Some family members also created artwork of the dream experience post death. Narratives from the continuing bonds literature reflect this, citing keeping possessions that once belonged to the deceased (Harper et al, 2011), music (O'Callaghan et al, 2013), visual representations and personal belongings (Foster et al, 2011) as ways in which bereaved family members maintained bonds with their deceased family members. The literature shows how anticipatory grief behaviours support continuing bonds.

The literature on bereavement in paediatric palliative care adds to, and reflects, continuing bonds as a category in my study. However, Foster et al (2012) write that there is little existing understanding of possible associations between legacy-making (especially prior to death) and continuing bonds post-death. Although the dream experience was not a formal legacy-making activity, my findings suggest that families did collect experiences and memory objects during the dream in a way that might be conceptualised as legacy making. Data show how family members consciously prepared for bereavement during the dream experience by collecting memories while the children and young people were alive. These were then used in bereavement, shown by the category continuing bonds.

My findings therefore contribute to the gap in understanding between legacy making and continuing bonds identified by Foster et al (2012). My findings highlight the importance of having memories to use in bereavement. The importance of memories being that which Klass, Silverman, and Nickman (1996) propose could provide comfort, ease the transition from the past to the future, and facilitate coping for both bereaved adults and children. My finding which connects the categories of memory curation and continuing bonds also provides support to the practice of legacy making, already conducted in paediatric palliative care contexts (Romanoff and Thompson, 2006; Sisk et al, 2012).

9.8 Post-intervention support

This discussion of dream fulfilment has mostly focused on the positive impact that processes experienced during the fulfilment of a dream had on children and family members. The experience of the dream fulfilment process, from nomination to the dream was an affirming one.

Thus, my findings suggest that when families returned from dream experiences, especially those who had travelled overseas for longer periods of time, they felt a sense of absence. On returning from the dream experience families returned to their often difficult or chaotic lives. There was an absence of hope in this return, and a sense that there was nothing to look forward to or plan for. Although this was difficult for family members to adjust to, the literature shows that this is a fairly common response, post support or intervention. As there is little in the literature on dream and wish fulfilment I look to the cancer survivorship literature for a discussion on how individuals feel after a period of treatment or support ends. The term survivorship in cancer refers to, "the period of health

and well-being experienced by survivors after active cancer treatment" (Rowland, Hewitt and Ganz, 2006, 5102).

A common theme within the survivorship literature is that of patients' psychosocial needs not being met, post-cancer treatment (Hewitt et al, 2007; Prasad et al, 2015). Miller Pittman and Strong (2003) for example report that sadness, a loss of control and feelings of nervousness and worry were experienced post-cancer treatment. This is because while undergoing treatment for cancer there are many appointments, enquiries and interventions. When this ends, after treatment, there is a loss of contact and a loss of information (Hodgekinson et al, 2007). Survivors of cancer are therefore left with a void of medical contact. This loss, or sense of absence is similar to how my participants felt, post dream.

Sekse et al (2010) found that some patients felt alone and unsupported after treatment, and Olesen et al (2015) reported that participants found it difficult to manage new circumstances. These studies examined adult experiences post-cancer. In children and young adult studies, bad dreams and anxiety (Greene et al, 2013) have been reported, in addition to a difficulty in finding a new sense of what is normal after cancer treatment (Kinahan et al, 2015). Perhaps because of reasons such as this, parents of childhood cancer survivors express desires to stay in contact with the healthcare providers that had been a part of their lives for so long, for psychosocial support (Leventhal-Belfer et al, 1993). Thus, rather than the experience of the dream ending, it may have been the lack of organisation, phone calls and enquiries related to the planning of the dream that family members missed.

Some of the themes reported in this literature reflect my participants' experience on returning home from their dream. Although the actual dream experience might have only lasted for a short time, the planning, hope and agentic aspects of the experience were part of the experience of the wider process. Families felt supported throughout the dream fulfilment process, and once it was over, felt the absence of support from the charity, and an absence of hope for a future experience. Miller et al's (2003) finding that his participants felt a loss of control post-treatment perhaps explains a part of the feeling of absence experienced by my participants.

The feeling of being alone and unsupported (Sekse et al, 2010) also echoes my findings. As reported in my findings, many families with ill children struggled to find appropriate

support, and felt that DCT were more inclusive than other third sector services they had been turned away from previously. The ending of DCT's support may thus have felt especially difficult in light of knowing how difficult it was to find appropriate support.

9.9 Conclusion

This discussion chapter has used the academic literature to extend understanding to, and contextualise my findings. It has shown where my theory and the categories that informed them are reflective of and connect with the literature in social sciences around illness and loss. It has also shown where my findings are novel. The next and final chapter concludes the thesis, highlighting possible areas for future research and discussing the limitations and challenges of the study.

Chapter 10: Thesis conclusions

This section concludes my thesis. In this chapter, I show how my research questions have been addressed and highlights where there is potential to extend detail to understandings identified in this thesis through future research. In this chapter I also reflect on the research process and discuss the limitations of the study. I firstly return to my research questions and show how I addressed my research aims.

The purpose of this study was to understand the experience of having a dream fulfilled by children and young people with life-threatening and long-term conditions, and their family members. My research questions were, what is the impact of dream fulfilment on children and young people with life-threatening and long-term conditions, and what is the impact of the dream on the ill child's family?

These questions have been addressed through the generation of a theory that suggests that dream fulfilment reshaped perceptions of illness during dream fulfilment experiences. My theory also conceptualises dream fulfilment as an alternative milestone in families with seriously ill children's lives. The impact on dream recipients specifically was that dream fulfilment was agentic, validating, and provided distraction from illness. It reshaped perceptions of illness impact. For the wider family, dream fulfilment validated long-term and disabling conditions. For siblings, dream experiences normalised the experience of living with a seriously ill child. Dream fulfilment experiences decentralised illness in families. For families where dream recipients had died, the dream experience provided positive memories that could be used in bereavement. My thesis therefore provides answers to my research questions through the generation of theory and an accompanying theoretical model (figure 4). Such findings have implications for practice, as discussed in the subsequent section.

10.1 Implications for practice

This section of the thesis looks at how dream and wish fulfilment organisations such as DCT could use the findings presented in this thesis. While this study was about the examination of impact, rather than exploring how dream and wish fulfilment organisations could develop their dream and wish interventions, I suggest a few points from my data that may be useful to DCT, and perhaps to other charities in the field.

My first point is that organisations such as DCT provided a much needed period of support for families with seriously ill children that went beyond the actualization of a dream or a wish. As much as dream fulfilment was meaningful, families also appreciated the charity for providing support more generally, in the form of phone calls and dream fulfilment updates. It is potentially useful for charities like DCT to have an understanding of how important telephone calls, dream fulfilment updates, and emails are to families with ill children who may feel isolated, excluded, and generally unsupported. Categories such as validation reflect the idea that support for family members was important. Additionally, the category 'post-dream support void' reflects the impact of support, by showing how this ending of support impacted upon family members' lives.

As discussed, 'post-dream support void' reflects the impact of the loss of support post dream. This was due to the ending of the dream fulfilment process, including the hopefulness, agency, and the positive impact of the dream fulfilment itself but additionally, and perhaps more importantly, the ending of the day-to-day support that accompanied the dream fulfilment process.

Since presenting the category 'post dream support void' to DCT, the charity has begun developing an online support forum for families who have experienced dream fulfilment, and who are looking to continue their relationship with DCT. In addition to feeling connected to DCT, the forum will provide an opportunity for family members to interact with each other to discuss their dream and illness stories, and perhaps share thoughts and feelings about having an ill child, or sibling. Although post-dream support is perhaps not the responsibility of dream or wish fulfilment organisations, it is hoped that this forum will provide an element of support for families who might feel low post-dream. Thus, as a consequence of my research, DCT are changing their ways of practicing in order to offer the support which it now knows is important and valued by families.

My second point is that families with children with non-life-threatening conditions may not be aware of their eligibility for dream and wish fulfilment. Many of the families with children with non-life-threatening, but serious long-term conditions in my sample had been unaware of their eligibility status for dream fulfilment. Such families made the assumption that dream and wish fulfilment organisations worked only with children at end of life.

As such, many children and families may be missing out on dream and wish fulfilment experiences. It may thus be useful for dream and wish fulfilment organisations who have

wider ranging eligibility criteria to let the public know about who they can provide dreams and wishes to, what conditions provide eligibility, and how these families can apply. Letting the public know that dream and wish fulfilment organisations might provide dreams and wishes to children other than those who are dying is important. This is important as this study suggests that families with children with non-life-threatening conditions feel like their conditions are not recognised, and that their suffering goes unnoticed. A dream was meaningful, not least because it validated the seriousness of long-term conditions, and helped children with long-term conditions, and their family members feel more positive about the conditions they were living with, and their identities in illness.

Overall, findings from this study suggest that dream fulfilment had a positive impact on family life. Thus, charities such as DCT are already providing a useful service. My theories conceptualising dream fulfilment as an alternative milestone, and as an experience or event that reshapes illness perceptions illustrate the impact that dream fulfilment had on some families. However, it would be useful for individuals working with organisations like DCT to understand the impact that support from charities such as DCT has on families with ill children, as well as the kind of impact that dreams have on children and families. Knowing that for example, a family with a child with a non cancer condition might feel excluded from statutory or third sector services is important. Or, that some families sitting on the waiting list are not frustrated, but enjoying hoping for and anticipating their dream fulfilment experiences. Understanding the processes happening at each phase of the dream fulfilment process might support individuals working for such organisations to provide a more informed or sensitive service.

Although my position as researcher is not to recommend changes to practice, I highlight my suggestions here so as to make explicit the real world impact that this study might have, and has already had, on the way that organisations such as DCT work.

10.2 Limitations

This section discusses the limitations of this study on dream fulfillment. The first being related to the wide-ranging research questions. My broad research questions meant that I looked at a range of different groups and experiences. For example, dream experiences ranged from adaptive equipment, to collective holiday experiences. Although there were conceptual similarities across the range of dream choices (holidays, equipment, Disney, and meet a hero), sample sizes were relatively small for each examination of dream

choice. Although categories were saturated, categories were constructed conceptualizing the broader impact of dreams, rather than examining smaller or more detailed aspects of dream fulfillment.

Related to the wide-ranging research question was the range of conditions that children participating in this study had. Participants had life-threatening conditions, long-term conditions, and conditions in remission. I additionally interviewed bereaved families. While illness as an experience connected my population, the differences in conditions were also broad. As my previous example highlights, this meant that sample sizes for each condition group were small. Although again, I interviewed until categories were saturated, there were nuances in data that were specific to conditions that might have been missed due to a concern with capturing the wider impact of dream fulfillment.

My next limitation concerns my choice of method. As discussed in section 2.6, as a researcher I was interested in what children had to say. I felt strongly that the views of children should be included in research, and that children's voices are not excluded from research on the basis of age. However, I found it difficult to capture some of the experiences, thoughts and feelings of ill, young children as part of this research. As discussed, the children and young people I interviewed in this study did not wish to engage with resources such as Talking Mats©, rather, expressing interest in 'doing a normal interview.' As such, I did not gain the level of insight into dream fulfilment and its impact from children that I would have liked. Perhaps rather than Talking Mats© I could have utilised another form of visual or participatory methods. Observation of dream fulfillment experiences, or conducting multiple interviews over time may also have provided me with more insight into children's experiences.

My final limitation is that my entire sample came from a single dream fulfilment charity. Although the purpose of the study was to examine the impact of dreams fulfilled by DCT, this also limits the transferability of my findings to other organisations. Further thoughts and reflections on the research process are discussed in the following section.

10.3 Reflections

This part of my thesis presents a brief overview of the thoughts, frustrations and reflections that were documented in my reflective diary over the course of this doctoral research. A brief analysis of my reflective diary section finds that my thoughts primarily fell into three categories: the personal challenges of doing research with seriously ill children

and with families; conducting research funded by a small third sector organisation; and utilising grounded theory to conduct research that is both emergent and planned (i.e. it answers a specific research question). I discuss each construct, beginning with my thoughts on conducting research with seriously ill children and young people, and their family members.

10.3.1 Conducting research with seriously ill children and their family members

One of the most difficult parts of this research was working with ill children and their family members. Aside from the methodological challenges outlined in the literature and discussed previously as part of this thesis, I report here, some of the personal challenges I experienced in conducting research with this population.

The first aspect of this was that I felt like an outsider to the pain, worry, anxiety and sadness of many of the family members I interviewed. Although having some personal experience of illness and death, I have not experienced the level of sadness, distress and pain that accompanies a life-threatening or long-term condition, or what it might be like to have a seriously ill child or sibling. Neither have I experienced the sadness of having a child or a sibling die. As such, I sometimes felt unable to understand fully what children, parents and siblings were saying when they discussed illness, death and dying.

My perception of being an outsider to family experience was perhaps not one sided. Many parents in my sample asked me if I had children. Although understanding that I was not compelled to answer, I felt that this was part of rapport and trust building on some parents' behalf, and that I should be honest in my response. In finding out that I did not have children, I felt that some participants might have made an assumption about my level of understanding of their experience, which affected the depth of my interviews with these individuals. Although perhaps a relevant assumption, in that I do not have experience of parenthood, I felt that had I been a parent I might have experienced a different, or deeper level of interview. This again felt frustrating as I sensed that at times, I was hearing rehearsed or prepared stories of experiences.

Although frustrating, I recognise that rehearsed or prepared stories might have been protective on the part of family members whom I was interviewing. Interviews were based around the dream experience but many drifted into being about illness, anxieties around illness, and for bereaved family members, memories and grief. Rehearsed stories might

have thus felt easier to discuss with a stranger, than perhaps more reflective accounts of difficult situations.

Another concept I wish to reflect on here comes from involving whole families in research. As discussed, where it was possible, I interviewed family members individually. This was so as to allow each family member equal time to be heard, and not be constrained by family dynamics or individuals with more powerful voices.

However, interviewing individuals presented an uncomfortable situation in one instance. On one visit to a family I was made aware of an interesting and relevant, yet confidential piece of information in an interview with a family member. This information, had it been shared with the remainder of the family, may have affected other family members' conceptualisation of the dream experience. Yet other family members were unaware of the information. The sharing of this confidential piece of data with myself had implications for this study. Firstly, it made my subsequent interviews with the remainder of the family feel uncomfortable. I felt as if I had become part of the family's complex dynamic.

Additionally, the confidential nature of the data meant that I did not feel as if I could use it, as part of my findings. Although the possibility of the family reading my thesis is perhaps unlikely, I did not wish to make publicly available something that could upset a family of participants. However, I felt as if I had missed out on sharing discussing a relevant and interesting issue in the family experience of life-threatening illness. My experience interviewing multiple family members reflects some of the challenges of conducting dyadic interviews, such as undesired disclosure, described in the literature (Reczec, 2014).

10.3.2 Doing collaborative research with a funding organisation

As discussed in section 1.4, there were a number of issues around doing research for a small organisation. These issues were around the perception of pressure to produce positive findings, and the feeling that participants may not have seen me as an objective researcher due to my relationship with DCT.

While working with DCT, I felt that the charity were not always open to findings that did not positively reflect the work of DCT. However, on reflection this may have been partly due to miscommunication on my part. For example, research terms such as 'negative cases' were negatively construed by DCT, rather than being understood in a research

context. Additionally, my finding that family members felt a loss of support post dream was initially perceived by DCT as a criticism of the charity. However, when contextualised alongside other research that suggested that a sense of loss after the removal of psychosocial support is common, the charity appeared more accepting of the finding. I therefore learnt to be cautious about the way in which I presented research findings.

When collecting data, I additionally felt that some participants were perhaps not as honest or open with me due to thinking that I worked for DCT, rather than being an objective researcher. As such, I felt that some families might have been uncritical in their account of the dream fulfilment experience. Although this was not the case in all families, it did at time feel frustrating.

10.3.3 Grounded theory: doing planned yet emergent research

My final reflection is related to the grounded theory methodology. As discussed, grounded theory methodology supports researchers in studying uncharted, contingent, or dynamic phenomena (Charmaz, 2008). Research processes are thus inductive. However, while being open and indeterminate, I also needed to stay close to my initial question concerning impact, so as to answer my research question.

Using grounded theory methods therefore meant that I needed to engage in a research process that was both planned and emergent, planned in that I needed to answer my research questions as appropriately and fully as possible, and emergent, in that I also needed to allow participants to answer questions openly and without a highly imposed structure, so as to develop new insights into the experience of dream fulfilment. My reflections on conducting grounded theory are about the conflict I felt between staying close to my research question, while also allowing myself to feel uncertain in my analysis, and be open to new thoughts and ideas throughout the process.

Staying close to my research question was difficult as I was told many stories at interview that were not immediately relevant to my research question. But, such stories were interesting and pertinent to the field of paediatric palliative care and disability. These were stories and reflections around grief, of rituals in illness and death, of treatment by peers and by other services, of exclusion and of ethics. As well as being relevant to the field more generally, these stories appealed to my personal research interest in children's experiences of death and dying, and the processing of grief. While these aspects of

interviews were interesting and important, I was conscious of straying too far from my research question.

However, in being conscious of shifting my focus away from my research question, I was additionally aware of grounded theory's focus on remaining open to various explanations. I wanted to ensure that I captured families' background stories and context, so as to help me understand their understandings and experiences of dream fulfilment. I also felt that I wanted participants to feel heard and to be able to tell their stories as part of my interviews. But, again, I felt an uncertainty about how much I could shift my focus away from my initial line of questioning, that being about dream fulfilment and impact.

I felt this conflict much of the way through the first half of my data collection and analysis. I was unsure what was relevant, and felt uncertain about my findings, feeling that they were not useful, or vague. However, as I developed categories, and refined my findings, I felt that I was able to make my research process both planned and emergent. However, I consider being open and inductive, yet focused and planned to be the most difficult part of using the grounded theory method.

This overview of my reflections documents the aspects of this study that I found to be most challenging. These included feeling frustrated at not being able to discuss some of what was shared with me in confidence, feeling unable to fully understand or relate to family experiences, not being seen as an objective researcher, and an uncertainty about using grounded theory methodology. I have found it useful to reflect on these parts of the research process, and hope that in being explicit about my role as a researcher within this study, I bring a sense of transparency to my findings and thesis as a whole.

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10.4 Future work

My first suggestion for future work is around legacy building and anticipatory grief. My findings suggest that consciously creating positive memories while children with short prognoses were alive was helpful for family members. Findings in this thesis also suggest that the positive memories created by dream fulfilment were helpful in bereavement, facilitating continuing bonds. However, there is little existing research that connects the concept of legacy with the theory of continuing bonds (Foster et al, 2012). Further research might help establish memory curation, or memory gathering (Duke, 1998) as part of the continuing bonds theory. It would also be helpful to develop understandings of why collecting experiences or mementos is useful, and how children's hospices for example could support family members in engaging with memory curation as part of informing their legacy building work.

Another aspect of my study that would be useful to examine further is the impact of collective experiences for families with ill children. Although the literature on camps for ill *children* is reflective of my finding on holidays for *families* with ill children, there is little published literature on the impact of holidays for families with ill children (Martiniuk, 2003). My finding begins to contribute to this gap in understanding but due to small sample sizes, a larger study would be useful in conceptualising the impact of collective holiday experiences on families with ill children further.

Each of these points, as well as the wider study on the impact of dream fulfilment would benefit from being explored by different dream or wish fulfilment organisations, and in different countries. Such studies would add depth and further understanding to my findings presented here. A future trial to explore the wider generalisability of my theories would also be of benefit in examining the findings presented in this thesis further.

My final point on future work concerns the large number of families requesting equipment as a dream from DCT. The data I presented at the beginning of this thesis shows that 29% of dream requests were for equipment. Although the impacts of such equipment on

children and young people with impairments were great, I query why families, or other family advocates were requesting such equipment from a dream fulfilment organisation. If children and young people with disabilities have the right to play and to interact in the same way as children without disabilities (UN Convention on the Rights of Persons with Disabilities), why are their needs for equipment not being met by statutory services? Additionally, are children with disabilities and long-term conditions now looking to the third sector instead of statutory services for support to buy equipment? Answers to such questions would help contextualise my finding around equipment provision and disabled children and young people.

10.5 Final conclusions

This thesis has presented, for the first time, a grounded theory of dream fulfilment's impact on seriously ill children and their family members. The findings generated through the rigorous application of grounded theory research strategies are, that dream fulfilment was conceptualised firstly as an alternative milestone, and secondly, that the process of dream fulfilment reshaped perceptions of illness.

My theory parallels previous work on the self in illness, such as: Charmaz's (1997) theory of timemarkers; Matheison and Stam's (1999) work on identity renegotiation in illness; McCadams and McClean's (2013) life story theory; and the literature around hope and coping in illness (Kaylma, 2005; Elliott and Olver, 2002). My findings also reflect aspects of previous research into dream and wish fulfilment (Ewing, 2007; Darlington et al, 2013; Schilling and Sarigiani, 2014), and additionally extend and add to existing understandings.

My findings are important as an examination of the literature shows how children, and family members, particularly with long-term conditions or impairment can feel stigmatised, that they miss out on social milestones, and that they lack power or agency. Dream fulfilment as an intervention provided an alternative milestone, and opportunities for agency. Dream or wish fulfilment, as a family experience at end of life and in long-term illness can therefore be understood as a helpful process.

It is hoped that the findings presented in this thesis will be useful to DCT and to the children, young people and families who use their service, as well as to other dream and wish fulfilment third sector organisations. The theory, and wider findings produced by the thesis add to the growing literature, and interest in dream and wish fulfilment.

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Dear Family

The Power of Dreams: an exploration of the impact of dream fulfilment on children with life limiting and long-term conditions, and on their families

I hope that this letter finds you all well. It has been a while since we were in touch, and I realise that things might have changed with you and your family. Whatever is going on in your lives at the moment, I'd like to thank you for taking the time to look at this letter.

I am writing to invite you to take part in an important new project that will help Dreams Come True gain a better understanding of the value of the work we do. We are working with a team of researchers at the University of Stirling to look at the impact of making a dream come true on children and their families. The project will involve a careful process of confidential interviews with families, like yourselves, whose child has had a dream fulfilled and who are willing to help us by taking part.

The results of the project will help Dreams Come True better understand the children and families we work with and strengthen our services for other families in the future. A better understanding of the value of the work will also help encourage people to support our cause, and, just as importantly, inspire other families to refer their child for a dream.

The project will involve interviews with families like you, whose child had a dream fulfilled by Dreams Come True. I have attached some information sheets to give you more information on the project, one for adults, and one for children and young people. Your details have not, and will not, be passed on to anyone from outside the charity.

It is completely up to you whether you would like to take part or not. Your relationship with us at Dreams Come True is very important, and will not be affected whatever you decide to do. We also appreciate that while you may wish to participate you may not feel it is appropriate for your child or children to take part, and that is also ok.

If your child who received the dream has sadly died since we were last in contact we would still be really interested in how you feel the dream affected their life and yours, if you feel ok to talk to us about it. We would really value your response because one of the

things that we would like to understand is how a dream come true may provide comfort to bereaved families. However, we understand that this may not be a good time for you or your family, and that you may not want to take part.

If the timing isn't good now, but you think you might be interested at a later point please call Jayne on the number at the top of the page when you feel ready. Jayne will be interviewing until around spring 2014.

If, after you have read the information sheets you decide you would like to take part, please complete the 'Yes please' form included and send it back to the researcher Jayne Galinsky at the University of Stirling in the reply-paid envelope. She will then contact you directly if she needs to arrange an interview.

If you don't want to take part in this project please fill in the 'No thank you reply form' and return it to Jayne at the University. Dreams Come True will not know if you decide you would like to take part in the project or not.

There is more detail on the information sheets but please feel free to give the research team a call if you have any questions at all. You will find their contact details on the sheets.

Thank you again for taking time out to read and think about this. If you decide not to take part we won't contact you again about the research, although we will remain in touch with all our charity news as usual.

With best wishes to you and your family.

Yours sincerely,

Martin Plowman
Head of Dreams

Appendix B: Information sheet for adult family members

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Information Sheet for adult family members

Project Title: The Power of Dreams: a grounded theory study into the impact of dream fulfilment on children with life-limiting and long-term conditions and their families

You are being invited to take part in a research project. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your family. Please ask if there is anything that is not clear or you would like more information.

Why have I been invited to take part?
You are being invited to take part in this project because your family includes a child or young person who received a dream from the charity 'Dreams Come True'. They have written out to 50 families who have had a dream fulfilled to invite them to consider taking part.

What is the purpose of the project?
The purpose of the project is to understand what having a dream fulfilled means to children, young people and their families. We want to know if the dream experience affects families, and in what way. This information will benefit Dreams Come True as it will help them to better understand the children and families they work with and strengthen their services for other families in the future.

Who do we need to speak to you?
We would like to speak to up to three members of your family. We would like to speak to the family members who shared most in the dream experience and live in the same house as the child who received the dream - so perhaps yourself, other parents or guardians, brothers, sisters or aunties or uncles. We would also be interested in speaking with the child or young person who received the dream, if possible. If your child has sadly died since they had their dream, we would still be really interested to speak with you, it this is not too difficult for you to do. This is because we'd like to know more about how these dreams can be a comfort to families who have been bereaved. We would like to talk to

you about their dream and your views of the experience, if this is okay. Your thoughts and opinions are important to us and valuable for the project.

We would like to leave it up to you to think about whom in the family would be best for us to speak to, and let us know if they would like to be involved.

We are interested in anyone you think is important, but appreciate that you may not wish for younger children to be involved. Again, we would like to leave this decision with you.

Do I have to take part?
No. It is up to you to decide whether to take part. If you would prefer not to be involved please fill in the 'No thank you reply form' and send it back to Jayne in the stamped addressed envelope. If you say no, then please be reassured that the support you receive from Dreams Come True will not be affected in any way.

What will the project involve?
If you are interested in being involved in the project, you and the relatives you nominate might be asked to take part in a one-off interview. We won't be doing anything else other than talking with you and your family; we're just interested in your thoughts, feelings and experiences of dream fulfilment.

You can choose where you would like to be interviewed. There will be no cost to you, and you will not have to travel anywhere to take part. Interviews would probably last for about an hour.

Interviews will be conducted by Jayne Galinsky. Jayne is an experienced researcher who has previously worked at Richard House Children's Hospice, and on various research projects within the NHS.

She will be supervised by Dr Liz Forbat and Dr Emma France. Liz works in the Cancer Care Research Centre within the University of Stirling and Emma works within the Nursing, Midwifery and Allied Health Professions Research Unit, also within the University.

We will conduct a number of rounds of interviews between now and the spring of 2014. We will be selecting families to interview as the study progresses and as we learn more about what it is like to have a dream fulfilled.

We might not interview everyone who tells us they are interested in being involved. It might take us some time before we get in touch, so it could be in the spring of 2014. Don't worry though – if you say yes now but change your mind later that is okay.

Jayne will ask to audio-record the interview. This is so that we listen to it again, and make sure we heard everything you said. We'll also copy down what we hear on tape, so we have a paper copy. Nobody else outside of the research team will hear the recording, and we will destroy it once it has been transcribed.

If after the interview, you feel upset and would like to talk over any issues that came up during the interview you can speak to Jayne on the day after the interview. If you feel you need it, we will also pay for you to have one telephone counselling session with an experienced family counsellor, which can be used by any member of your family. You can access this for up to one week after your interview. This counsellor can also recommend other services or local counsellors if you need more support.

Will my taking part be kept confidential?
Yes. All members of the research team have had training in confidentiality. You and your family's personal details will be kept confidential and separate from their interview recordings and transcripts

What will happen to the results of the research project?
A summary report from this project will be written and sent to you. Quotes from the interviews may be used in this report and other publications, but we will remove any details that could identify you or your family, for example your name or where you live. The final report will be available in October 2015, at the end of the project. DCT will get a copy of the report. I will also present the project results at conferences, publish them in academic journals, and in my PhD thesis.

Who is supervising the research?
Dr Liz Forbat and Dr Emma France (University of Stirling).

Who is funding the project?
Dreams Come True and the University of Stirling.

What happens next?

If you do decide to take part please let the research team know by filling in the attached 'Yes please - reply form', and sending it back to Jayne Galinsky at the University of Stirling in the envelope provided. Jayne **(Jayne.galinsky@stir.ac.uk, 01786 466105)** would also be happy to answer any questions you might have before replying. You will be asked to sign a consent form to confirm that you are willing to be involved in the project. If you decide to take part, you can still withdraw at any time without giving a reason.

If you would prefer not to be involved please fill in the 'No thank you reply form' and return it to me.

Who do I contact for further information?
Please contact Jayne Galinsky, whose contact details are below. She will be happy to answer any questions you might have about the project.

This project has been considered by the University of Stirling research ethics committee to ensure that it adheres to the highest ethical standards. The committee reviewed all project paperwork and is happy for the project to proceed, having raised no concerns

Thank you for taking the time to read this and for considering whether to take part in the project.

Jayne Galinsky
Researcher
Cancer Care Research Centre
School of Nursing, Midwifery and Health
University of Stirling,
STIRLING, FK9 4LA
Tel: + 44 (0)1786 466105
Email: Jayne.galinsky@stir.ac.uk
Web: www.cancercare.stir.ac.uk

Independent contact
If you wish to raise a concern or complain about the study to someone who is not a member of the research team please contact:
Professor Billy Lauder
School of Nursing, Midwifery and health
University of Stirling
Stirling, FK9 4LA
Tel: 01786 46 6345
Email: William.lauder@stir.ac.uk

Appendix C: Information sheet for children and young people

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Information for children and young people

Project Title – **The Power of Dreams: a grounded theory study into the impact of dream fulfilment on children with life-limiting and long-term conditions and their families**

Hello! My name is Jayne and I would like to invite you to take part in a project. Before you decide if you want to take part, you need to know why it is being done and what will happen.

Why have you asked my family?
A little while ago you or someone from your family asked an organisation called Dreams Come True to help out with something you or your brother or sister really wanted to do. We call something that a person really wants to do a dream. I want to know more about that, and how people in the family felt afterwards. I would like to hear what you think about this.

Why are you doing a project?
I want to know what it was like when you got to do the thing you'd always wanted to do, or went on the exciting holiday, or whatever it was that you chose for your dream. I would like to know if you felt any different afterwards, and how long those feelings lasted. I want to know because I think these feelings are really important, but don't really understand them very well. I also want to be able to help the charity Dreams Come True do an even better job for families in the future.

Do I have to take part?
No. It is up to you to decide whether to take part.

What does the project involve?
The project will involve me talking to families trying to find out as much as I can about having a dream come true. If you want to take part, then I would come and visit you (probably at your home, but you and your mum, dad or person who looks after you can

help us decide that). I would ask you all about the dream, and if it was your brother or sister's dream what you think about it.

I am asking 50 families if they want to talk to me between now and next spring. Once I have talked to the first few families, I'll have a better idea of what it is like to have a dream come true. I might then decide that I will just talk to families where the dream involved a trip or meeting someone famous, or I might want to speak to families where the person who had the dream was young. What this means is that I'll need to decide as I go along who I speak to.

I will not be able to speak to everybody. Even if you tell me that you'd like to take part in this project, I might not need to speak to you.

This does not mean that I am not interested in what you have to say; it just means that I might be interested in somebody who is a different age for example.

Who will know that I am helping in the project?
Your mum, dad or person who looks after you will know. People I work with at the University of Stirling will also know – you can have a look at our pictures at the bottom of this sheet! But I won't tell anyone else that you took part, so anyone reading about the project when it is finished will not know it was you that I talked to.

What will you do with what I tell you?
I will write a report and show it to Dreams Come True, and some other people who might be interested. I can send you a copy too. Your name will not be in the report. No-one else will know it was your family that was involved.

Who has given you money to do this?
Some money is from Dreams Come True and some from the University of Stirling.

What happens next?
If you want to take part – please tell your mum, dad or person who looks after you. They can phone me on: 01786 466105. You can also phone Liz or Emma who are in charge of the project on 01786 466421.

If do not want to take part that is okay. Dreams Come True will still treat you and your family in exactly the same way as before if you want to take part or not.

Thank you for reading this!

Appendix D: Word search for children and young people

All of the words written below in **bold** are hidden in the grid. Can you find them?

R	S	Z	P	I	C	T	U	R	E	S	D
P	L	K	M	N	J	Q	S	B	C	V	R
A	T	F	A	M	I	L	Y	E	S	C	E
R	L	U	S	O	U	T	I	T	A	X	A
T	U	Q	M	C	L	A	N	T	D	A	M
I	C	D	O	B	E	L	G	E	O	G	S
C	I	M	T	S	I	K	L	R	P	Q	E
I	F	C	P	A	A	S	B	V	E	C	P
P	F	O	M	X	Z	Y	I	T	C	E	A
A	I	M	Y	C	N	Y	N	J	K	X	T
T	D	G	S	T	U	D	Y	O	L	O	I
E	B	E	S	N	O	I	T	S	E	U	Q

We are doing a **STUDY** about **DREAMS** to try and help the charity Dreams Come True to get **BETTER** at helping other children and their families. We would like you to **PARTICIPATE**. If you **AGREE**, we will ask you to **TALK** a bit about the dream and what

happened next. We will also ask you **QUESTIONS** and we will **TAPE RECORD** your answer. It won't be **DIFFICULT**, but you can **SAY NO**.

Appendix E: Opt In Reply Form

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Yes please - reply form

About me and my family

Thank you for reading the information sheets. By completing this form, you have kindly agreed to help Dreams Come True and their Power of Dreams project.

Please answer the questions below and send it back to Jayne Galinsky in the stamped addressed envelope provided. Jayne will be in touch if she needs to speak with you. This may not be until spring 2014.

Any details you give us will be kept completely confidential.

Your name: ………………………………….

Your relationship to the child who received the dream, e.g. mother / father / guardian / carer:

……………………………………………………………………………………………..

Your address: ……………………………………………………………………………

....
....

Best number to contact you on (to arrange an interview):
…………………………………………

Is there a best time to contact you? ……………………………………………………..

Please tell us who lives at your address and how old they are- you don't need to give us names just how they are related to you e.g. daughter, son, brother, wife, husband, partner (this is because we are interested in how dream fulfilment affects the people around the child / young person who received the dream):

………………………………………………………………………………………………..

……………………………………………………………………….......................................

………………………………………………………………………………………………..

………………………………………………………………………………………………..

<u>Child / young person who received the dream</u>

What is the name of the child who received the dream?...

How old was your child when their received their dream (in years)? ……………………..

What is the month and year they received the dream? ………………………………………………

Is your child still living, or deceased? ....…………………

What was the dream your child received?

Met a celebrity ☐

Went to Disneyland / Disney world ☐

Had a dream experience ☐

Went on a dream holiday ☐

Had some help getting equipment ☐

Something else ☐

What health condition did your child have at the time he / she received their dream?

…………………………………………………………………………………

Any other information you think might be relevant:

…………………………………………………………………………………………………… 215

……………………………………………………………………………………………………

Thank you for taking the time to fill out, and post this form. Please use the stamped addressed envelope and return it to Jayne Galinsky. If you lose the envelope the address to return this form to is at the top of this page.

Appendix F: Opt Out Form

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<u>No thank you reply form</u>

I am not interested in being part of this project. I understand that this will not affect my relationship with Dreams Come True, now or in the future.

Name ………………………………………………………………………………….

Address ………………………………………………………………………………….

Please return this form to Jayne Galinsky in the stamped addressed envelope attached. If you lose the envelope the address to return this form to is at the top of this page.

Thank you.