

DOCTORAL THESIS

**Qualified clinical psychologists' experiences of working with children
with life-limiting conditions. A qualitative study.**

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1. Abstract

Background: Despite the increased presence of clinical psychologists in paediatric services, including palliative care teams, there has been little research into their experience of working with children with life-limiting conditions. Existing studies have tended to focus mainly on the experience of medical professionals working in this area. Such studies have found that working with life-limiting conditions and child death has a significant impact on medical professionals, causing stress, burnout and feelings of professional failure. As clinical psychologists have a role in supporting the emotional needs of children, families and staff teams, it is important to explore their experiences, the impact that such work has on them, and any potential personal and professional implications.

Aims: After identifying the above gap in the research, this study aimed to explore clinical psychologists' experiences of working with children with life-limiting conditions.

Method: Semi-structured interviews were conducted with seven qualified clinical psychologists who were working in hospital settings with children with life-limiting conditions. The transcripts of the interviews were then analysed using Interpretative Phenomenological Analysis (IPA).

Results: Three superordinate themes emerged from the analysis: *'The meeting of two worlds: When psychology and medicine converge'*, *'Nobody is immune: Facing the challenges of working of life-limiting conditions'* and *'Balancing the rough with the smooth: Finding a way to manage'*.

Implications & conclusion: Participants experienced challenges in having to adapt to a medical world and in facing emotional impacts however, they also reported positive experiences from their work. The study raised many implications for clinical practice including the need to potentially help psychologists to prepare for the possible changes required when practicing in a hospital setting. This could perhaps be incorporated more into clinical training or be provided as in-house training when starting in the post.

2. Introduction

The opening chapter aims to share with the reader my relationship with this qualitative study, which explored qualified clinical psychologists' experiences of working with children with life-limiting conditions. I will state my theoretical stance in relation to the study; discuss how my interest in the subject was generated and how this developed over the course of the project. Following these personal introductions, I will define the terms 'life-limiting conditions', 'paediatric palliative care' and 'end of life care' to orientate the reader to how each term has been used in this study. A brief history of children's palliative care services will be presented along with the current prevalence rates of children diagnosed with life-limiting conditions.

The chapter will continue with an overview of the existing literature, focusing on the main themes presented with different healthcare professionals, mainly doctors and nurses. The overview will include a critical review of previous research and will highlight the need for more research in this area, particularly with clinical psychologists. The chapter will close with the proposed aims for this study.

2.1. Positions & standpoints

In conducting research, it is important to acknowledge our own positions as researchers (Elliott, Fischer & Rennie, 1999) and to contemplate our relationship in how we came to approach the study. I will explain my theoretical position as a researcher, my personal position and how I came to approach this subject.

2.1.1. Owing one's perspective - theoretical position

The course that I chose for completing my clinical doctorate best represents my theoretical position towards my clinical work and towards this research, that of constructivism. Constructivist theory investigates the ways in which both individuals and societies generate their own constructions of reality in a community consensus (Guba & Lincoln, 1989; Raskin, 2002) rather than the

more traditional perspectives of empiricism and positivism, which focus on absolute truths (James; 1907; Pierce, 1868). I feel strongly that all points of view are equally valid and that no definite truth or validity exists therefore my ontological position is relativist. I believe that realities are co-created and that there are many constructions of reality. It is with these ideas and this approach that I have undertaken this research. From the development of the Constructivist paradigm, phenomenology (Husserl, 1927) and hermenutics (Gadamar, 1990/1960; Heidegger, 1962/1927) are essential to this method of study, where the researcher acknowledges their experiences resulting in co-constructed meanings. Constructivist approaches are concerned with exploring the understanding and meaning of an experience for an individual.

2.1.2. Owing one's perspective - personal position

I remember as a child that my mum would cry when we went carol singing at Christmas in church and it seemed odd to me to cry at Christmas. All I could think about were my presents and that was something to be excited about. My mum told me that churches made her think of her mum, who had died long before I was born and that she was sad because she was thinking of her. Growing up I have always wondered how she managed losing her mum so young. But my mum had been an adult when her mum died. It made be wonder how people managed when they lost people even younger, like a child. I think this experience sparked my intrigue in how other people manage hardships and difficult emotional situations.

The people who really amaze me are those who work in roles surrounded by death and grief. I have always been in awe of such individuals and wondered if there is something about them that makes them different in their ability to manage the physical and emotional demands of their work. As I contemplated my career choices following clinical training, I realised that I too wanted to work in a role that might involve death and grief, the role of the clinical psychologist working in paediatric palliative care.

2.2. How I arrived here

During my clinical psychology training, I completed a six-month placement in a Child and Adolescent Mental Health Service (CAMHS) and a Paediatric Psychology Service where a number of children on my caseload had complex physical health conditions. The psychologist working in paediatrics often seemed isolated from other psychologists because she was based in a hospital setting. She also seemed to be trying to 'hold her own' in a world surrounded by medics. At times she appeared to enjoy the challenge of the medical world but at others, it felt like hard work she could do without.

I noticed the differences between the two teams. The CAMHS team had a number of psychologists in the team however the paediatric services often had one psychologist per team of medics, despite the demand for greater input. I began to contemplate what clinical psychologists working in physical health settings with children with serious health conditions might experience in their day-to-day work. What was their experience of working in a medical setting? Were they given additional training or guidance in how to manage their experiences? Were there support groups that they could access to discuss their experiences? And did their experiences change them as people?

I was intrigued by the medical world that the clinical psychologists were involved in. I was interested in how their work with children who were seriously ill might be different to traditional mental health work, the main focus of psychologists' training. I was also curious how psychologists managed working with children and young people who would experience an early death and the impact this might have on the therapeutic relationship. I thought about how working in end-of-life care settings forces professionals to face the possibility that their patient will die in the near future. However, in working with life-limiting conditions this potentially raises more uncertainty for the professional. Periods of wellness or times when the condition is managed

may extend the child's life for many years to come and I wondered how, as a psychologist, you would manage these experiences.

During the literature search of the published research, I discovered a number of studies from the perspectives of medical professionals but very little from the discipline of psychology. I also discovered a much greater number of studies that explored the experience of health care professionals working with the dying and the bereaved but very few on working with life-limiting conditions where death was not imminent. These gaps in knowledge encouraged the development of this study.

2.3. Literature review scope

2.3.1. Literature search strategy

I carried out a review of existing literature in journals, books and searching online. The key search terms I included when searching online databases were 'children life-limiting conditions', 'professionals coping life-limiting conditions', 'working end-of-life care children', 'medics dying children', 'psychologists dying children', 'healthcare professionals dying children', 'impact', 'burnout' and 'reward'. The search incorporated a number of large databases including PsycINFO, Web of Science, PubMed, Medline and search engines such as Google/Google Scholar.

The review of the literature presented below explores a range of healthcare professionals' experiences including doctors, nurses, social workers, hospice workers and psychologists. While reviewing the literature it became apparent that the term 'life-limiting conditions' was rarely used however, specific conditions such as cancer, which would be classified in this group, were often referred to in the literature.

As the study explored experiences of psychologists working with life-limiting conditions and not just their experiences of working with a child who has died, it was important to search within general paediatric and paediatric palliative care work not just research from those working in end-of-life services. This

was important as experiences of working with children facing imminent death may have been different to working with children not expected to live into adulthood. From the literature search, there was more literature available around healthcare professionals' experiences of working with children who were imminently about to die from their condition or whose life had already been taken due to their condition rather than with children whose condition meant they would not survive into adulthood. Including this literature was relevant to the study as professionals working with life-limiting conditions may be caring for children in the final stages of their illness and thus may experience a child's death. Literature was also sought around working with children whose death might not have been imminent, which proved more difficult.

2.3.2. Terminology

The Association for Children's Palliative Care (ACT) define life-limiting conditions as "*those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers*" (ACT, 2008). Life-limiting conditions are divided into four categories (ACT/Royal College of Paediatrics and Child Health [RCPCH], 2003):

Category 1 – conditions which may be cured by treatment however, this may be unsuccessful. Examples may include cancer and irreversible organ failures.

Category 2 – conditions where early death is inevitable, possibility of long duration of intensive treatment aimed at extending the child's life. Example would include Cystic Fibrosis and muscular dystrophy.

Category 3 – progressive conditions with no cure available, treatment is solely palliative and often lasts for many years. Examples would include Batten's disease and mucopolysaccharoidosis.

Category 4 – conditions that are irreversible but not progressive in nature, cause severe disability which often lead to health difficulties and the possibility of early death. Examples may include severe cerebral palsy and severe brain or spinal injury.

It is likely that the care needs of a child diagnosed with a life-limiting condition will change depending on the condition at a specific time. Children may not therefore require constant access to care resulting in the child often dipping in and out of services over their life span (Craft & Killen, 2007) or being cared for over long periods of time (Liben, Papadatou & Wolfe, 2008). When children do require specialist support services, children's palliative care teams treat children with life-limiting conditions described above. Palliative care differs from conventional medical care where the aim is to cure the patient and instead offers care and support when treatment has either failed or is not possible. Palliative care for children is defined as "*the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease*" (World Health Organisation [WHO], 1998). The definition states that health providers must consider the child's physical, psychological, and social distress and should take a multidisciplinary approach to the child's care.

End of life (EOL) care refers to the help that is offered to children with advanced, progressive and incurable illness to live as comfortably as possible until they die. EOL care services include the management of pain and other symptoms, spiritual, social, practical and psychological support (International Children's Palliative Care Network [ICPCN], 2008)

The terms life-limiting conditions, palliative and EOL care for children as described above will be used throughout this study.

2.4. Development of children's services

2.4.1. Children's palliative care services

The recognition of a need for specialist palliative care services for children was developed some 20 years after services were provided for adults and led to the development of outreach teams and specialist palliative care units. Helen House in Oxford was built in 1981 as the world's first children's hospice (Stein, Forrest, Woolley & Baum, 1989) and Great Ormond Street Hospital (GOSH) has offered specialist care in this field since 1986 (GOSH, n.d.). Children's palliative care focuses on both maintaining and improving the child's quality of life for the time period before death, whatever the time period may be (Craft & Killen, 2007). There are similarities between adult and children's palliative care services however, it is also important to recognise the differences between the principles of care for children. Children's palliative care focuses on support for both the child and the family from the point of recognition to death and beyond (ACT, 2009)

2.4.2. Development of clinical psychology in paediatric care services

Clinical psychologists often make up part of the healthcare team that work to support children with life-limiting conditions and their families. Clinical psychologists are not medically trained professionals and are often found in mental health services however, they are developing roles within physical health settings. In order to meet the holistic care model, clinical psychologists working in paediatrics provide a different perspective to those of the medically trained staff on the team. This role often focuses more on reducing distress, improving psychological well-being and promoting development (Paediatric Psychology Network United Kingdom [PPN-UK], 2008) compared to the medical role, which focuses on pain management or symptom control.

There are currently 488 members of the PPN-UK. This is a forum for clinical psychologists working in paediatrics or those with a specific research interest the area (e.g. assistant & trainee psychologists). Clinical psychologists are often part of a dedicated paediatric clinical psychology service within a

specialist children's hospital with psychology sessions integrated into the health teams (PPN-UK, 2008). Research has indicated that input from psychology can be both clinically and cost effective with a range of different medical conditions in paediatric settings (Channon et al, 2007; Edwards & Titman, 2011; Holmes-Walker, Llewellyn & Farrell; 2007; Roberts & Steele, 2010).

2.5. Literature review

Given the limited amount of literature available on healthcare professionals' experiences when working with life-limited conditions, the review presented below will include both qualitative and quantitative research as well as theoretical and anecdotal literature. To just include empirical research would discount a number of interesting and important contributions to the area. I have attempted to clearly distinguish between the different types of information and have stated when the information relates to a research study e.g. Papadatou et al (2002) studied the experiences of doctors and nurses who were caring for children dying of cancer. When the information is an author's comment, it has been presented as such, e.g. Papadatou (2009) suggests that there are a number of social expectations that exist for professionals working with dying patients. The anecdotal evidence within the review is from respected researchers and clinicians who have either conducted extensive research or have worked clinically for many years in the area.

Given the prevalence of children who are diagnosed with life-limiting conditions, now believed to be much greater than 10 years ago (Fraser et al, 2012) there is still only a limited amount of research that explores healthcare professionals' experiences of working with children with life-limiting conditions or dying children (Clarke & Quin, 2007; Clarke-Steffen, 1998; Costello & Trinder-Brook, 2000; Davies et al, 1996; Davies & Eng, 1993; De Graves & Aranda, 2005; Kaplan, 2000; Liben, Papadatou & Wolfe, 2008; McCloskey & Taggart, 2010; Oehler & Davidson, 1992; Olson et al, 1998; Papadatou, 1991;

1997; 2000; 2001a; 2001b; 2006; Papadatou, Bellali, Papazoglou & Petraki, 2002; Papadatou, Martinson & Chung, 2001; Papadatou, Papazoglou, Petraki & Bellali, 1999; Totka, 1996; Woolley, Stein, Forrest & Baum, 1989).

Research with healthcare professionals has focused mainly on medical professionals and their experience of working with children when they die. There are a number of studies, which have explored working with children who are receiving EOL care (Clarke-Steffen, 1998; Costello & Trinder-Brook, 2000; Hilden et al, 2001; McKelvey, 2006; Vachon & Pakes, 1984), again mainly from professionals who are medically trained. A large amount of the EOL literature available explores death and grief for professionals involved in this type of work (Davies et al, 1996; Kaplan, 2000; Papadatou, 1991; 2000; 2001b; Papadatou et al, 2002; Papadatou et al; 2001; Papadatou, 2009). Certain life-limiting conditions have been researched more than others, with cancer being most often reported in the literature (Davies et al, 1996; De Graves & Aranda, 2005; Papadatou et al, 2002).

There have been a number of areas of interest in the existing research with professionals working with children with life-limiting conditions. Themes from the research include impacts to professionals in their work (Davies et al, 1996; De Graves & Aranda, 2005; Papadatou et al, 2002), training and preparation for the role (Hilden et al, 2001; Kaneja & Milrod, 1998), professional grief reactions (Neimeyer, 2001; Papadatou, 2009), benefits and rewards from the work (Clarke- Steffen, 1998; Davies et al, 1996; Maeve, 1998; Olson et al, 1998; Papadatou et al, 2002; Papadatou et al, 2001; Robson & Beattie, 2004; Rushton, 2005; Woolley et al, 1989) and support strategies available (Beringer, Eaton & Jones, 2007; Maeve, 1998; McNeilly, Price & McCloskey, 2006). The following section will review and critique the key research that has been carried out with professionals and the major themes from the literature.

2.5.1. Prevalence of life-limiting conditions

It is estimated that in a health district of 250,000 people, with a child population of 50,000, there will be approximately eight children each year that

will die of a life-limiting illness. Of these eight children, it is believed that three will die from cancer, two from heart disease and three from other life-limiting conditions (Department for Children, Schools & Families [DCSF], n.d.). A recent study found that for 2010, the prevalence of life limiting conditions for children under 19 was 32 in 10,000. This research estimates that there are approximately 40,000 children in England who are currently living with a life-limiting condition, which is double that of previous estimates (Fraser et al, 2012). The study found that the highest prevalence of a life-limiting condition was congenital anomalies (30.7%) followed by cancer (13.7%) and neurological conditions (12%).

2.5.2. Impacts to professionals when working with life-limiting conditions

Healthcare professionals working with life-limiting conditions and in palliative care face complicated challenges in their work with children and their families. Working in this area has been described as one of the most challenging areas in the nursing profession (ACT/RCPCH, 2003). Such work can often result in emotional impacts on the professional including experiences of stress, burnout, anger and feeling unsupported (Costello & Trinder-Brook, 2000; De Graves & Aranda, 2005; Kushnir, Rabin & Azulai, 1997; O'Leary, Flynn MacCallion, Walsh & McQuaillan, 2006; Rushton, 2005). In working in this area, a healthcare professional is also likely to encounter working with a child during the later stages of their illness. Contact with a person who is dying will inevitably evoke personal responses from professionals. People who work with dying children often experience powerful feelings in relation to their work (Vachon, 1987) that Doe & Katz (2006) believe to be important in bonding and empathising children and their families. However, such feelings are often reported in the literature to have potentially negative impacts on the individual team member, the larger staff team and as a result, the children and families under their care.

The emotional responses

The available research highlights a number of common emotional impacts for professionals working in this area. The feelings most commonly described in the literature are those of powerlessness (Davies et al, 1996) and helplessness (Downey, Bengiamin, Heuer & Juhl, 1995; Papadatou et al, 2002; Raeside, 2000; Wells, 1996; Yam, Rossiter & Cheung, 2001). Such emotions were often reported in relation to healthcare professionals feeling unable to reduce suffering for the child they were caring for as they faced death. Other emotional responses included feelings of anger, uncertainty (Quin, Clarke & Murphy-Lawless, 2005), frustration, increased levels of stress and general emotional difficulties related to the work (Papadatou et al, 2002).

Papadatou et al (2002) used qualitative and quantitative methods to explore and compare the experiences of 14 Greek doctors and 16 nurses working with children dying from cancer. The results found the experiences had been highly stressful for both groups of professionals but differences between the disciplines were evident in how they perceived the loss of the child, which will be discussed later in 'Grief experiences of professionals'. The study provided insights into the experiences of working with dying children and reflected the difficult and challenging experiences felt across professions. The authors were able to gain data from both doctors and nurses in their research, which very few other studies were able to achieve and reflected on the differences between the professional groups. From a critical perspective, the study had limitations. The participants were from Greece which the authors acknowledge has a distinct cultural and social way of responding to dying compared with other Western countries. It is possible that the experiences of doctors and nurses in this study would be very different to those of another European country. Participants were also asked to rate a list of 10 stressful conditions related to care of dying patients. The authors do not make clear who devised the list and how the 10 items were chosen. It is possible that the items were perceived by the authors to be potentially stressful but perhaps not items that given the chance, participants would have included.

Davies et al (1996) carried out a qualitative study with 25 nurses to explore their experiences of caring for dying children. They found that nurses experienced and struggled with distress in their roles and were often left feeling torn between showing emotion and acting in a professional manner. The results also suggested coping strategies that were helpful which will be revisited later in the chapter. The study attempted to better understand the nurses' experiences and provided interesting insights into their encounters. On a critical note the study relied on reported experiences from professionals that could have happened up to 19 years previously. This may have impacted on their ability to remember details and emotions related to the incident compared to others who were recalling experiences that had occurred just 3 weeks previously.

Physical impacts

Working with children with life-limiting conditions has shown to also have physical impacts on the healthcare professional. Rushton (2004) suggests that common physical symptoms of caregiver suffering include weight gain/loss, impaired sleep, susceptibility to illness and impaired mental processes.

Physical impacts to professionals have often been reported in connection to working with newborn children with life-limiting conditions. Sick infants are cared for in neo-natal intensive care units (NICU) and Raeside (2000) carried out a quantitative study with 59 NICU nurses to explore their experiences. The study found that they reported experiences of physical stress including irritability, tearfulness and headaches when caring for dying babies in addition to feelings of sadness, intense sorrow and helplessness. This study showed that healthcare professionals experienced impacts to their physical as well as emotional state in relation to their work which was an important finding. A possible limitation to the study was that a member of the NICU staff had carried out the research which could have impacted on what the nurses were

prepared to share in the interview and the sample size was small for a quantitative study.

Downey et al (1995) conducted a similar study with 59 staff nurses caring for dying babies who also reported experiences of helplessness and sorrow. They too reported physical health complaints such as irritability and chronic fatigue indicating that the work had both emotional and physical effects on the staff. The study also highlighted important coping strategies when managing grief. The findings have contributed to developing a better understanding of professionals' experiences and indicated the importance of developing coping strategies in the role. On a critical note, the study was conducted with all White British nurses which may make the findings difficult to apply to other groups of professionals and the response rate was only 35%.

Burnout & stress

“There is a cost to caring for those with chronic illness just as there is a realization that these clients will never fully recover” (Figley 2002, p. 1433)

Caring for children who are dying is agreed to create more stress for professionals than caring for adults who are dying (McKelvey, 2006). Some researchers suggest it to be one of the most stressful areas for a medical professional to work in (Knazik et al 2003; O'Connor & Jeavons, 2003; Pearson; 2010). Nursing has been recognised as an occupation where professionals are likely to experience stress (Health and Safety Executive [HSE], 2005). Those who work in palliative care settings are reported to be prone to sickness, burnout and low morale and are argued to be exposed to additional stresses to those identified by the HSE (McCloskey & Taggart, 2010).

Experiences of stress and burnout may be mediated by a number of different factors including age and social background (Brown, 2007) with younger members of staff, who perhaps have little experience of death, being more likely to experience burnout (Ramirez, Graham & Richards, 1998). Brown

(2007) suggests that an individual's motivation to work with children with life-limiting conditions can also be a source of stress, giving the example of being drawn to the career in order to resolve their own experiences of loss or guilt.

Burnout is defined as a condition of physical, emotional and mental exhaustion, triggered by long term involvement in emotionally demanding situations (Pines & Aronson, 1988). Burnout develops over time when individuals are exposed to a highly stressful workload, when required to suppress emotions or when professionals feel powerless in their role. Burnout can result in feelings of incompetence, detachment from the role and depersonalisation with patients (Maslach, 2003), all of which have negative consequences for the professional but also for the child and family receiving care. Liben & Papadatou (2011) believe that 'caring burnout' can be the result of prolonged caring for others. More serious experiences such as compassion fatigue occur when professionals encounter symptoms like post-traumatic stress disorder. At such times, individuals report experiences of intrusive thoughts, flashbacks and nightmares (Figley, 2002).

McCloskey & Taggart (2010) used semi-structured interviews to explore the occupational stress experienced by 75 children's palliative care nurses working in Northern Ireland. Nurses commented on the negative impact that stress was placing on their personal and professional lives. They experienced grief when the child died that supported previous research (Papadatou et al, 2002; Liben et al, 2008) and the study highlighted important issues about nurses feeling they had to present in a certain way when managing grief. On a critical note, the study had a limited response rate of 24% which the authors raised as a concern for transferring the findings to the wider area of children's palliative care. The authors defended this by commenting on the robustness of the design and the 'fit' with previous studies.

There is however, contradictory evidence relating to experiences of stress and burnout when working with people who are dying. Research suggests that being exposed to multiple deaths is a stressor (Papadatou et al, 1999) but

burnout and stress levels are not believed to be different to professionals working in other areas (Foxall, Zimmerman, Standley & Bené, 1990; Jenkins & Ostchega, 1986). Some research even suggests that stress is less in palliative care because of the extra access to support and the acknowledgement that caring for such individuals is likely to cause stress (Vachon, 1997).

Lack of support

The lack of support available to healthcare professionals was another theme evident in the literature with some research suggesting this was most correlated with dissatisfaction and staff leaving their roles (Oehler & Davidson, 1992). Clarke & Quin (2007) conducted a quantitative study with 15 professional carers to explore their experiences of providing paediatric palliative care in Ireland. One subtheme '*struggling in the absence of resources*' found that some professionals did not always feel supported in their roles especially those working in the voluntary sector who felt they had to "*take up the slack*" (p. 1228) from the statutory services. The participants made suggestions about having increased support following the death of a child by introducing education, training and the opportunity to debrief. The authors concluded in seconding this request, highlighting the need for investment in training and education for professionals. The study provided useful information from a number of different professional groups on their experiences. On a critical note however, the focus group design may have made it difficult for individuals speak openly in front of other colleagues. This could have impacted on what they felt able to share in front of colleagues and other disciplines. The researchers also attempted to explore the experiences of many disciplines and despite managing to include over 10 different professional groups including doctors, nurses, social workers, care workers and teachers in their focus groups, they did not invite psychologists to take part. This would have been a useful addition and could have contributed different experiences to their findings.

McKelvey (2006) interviewed a number of paediatric physicians and nurse colleagues over a three year period to hear their stories. He found that both doctors and nurses spoke about professional isolation and suggests that the *“lack of support provided to them by their supervisors, programs, and institutions make them even more vulnerable because they are often left to deal with feelings alone”* (p.7). Contro, Larson, Scofield, Sourkes & Cohen (2004) conducted a survey of 446 staff members (hospital staff & community doctors) and 68 family members of deceased children to gather information on perspectives of quality of paediatric care. They found that staff perceptions of emotional, psychological or social support were either lacking or non-existent and when asked “does the hospital provide adequate support for staff working with dying patients?” 54% of the respondents answered “no”. On a critical note, the authors acknowledged that some staff members may have been more motivated to reply to the survey if they believed improvements needed to be made or may have been more interested in palliative care, which may have created a selection bias. The study also relied on self-report measures however the authors were able to highlight the perceptions by staff around a lack of support which indicated areas for improvement in paediatric palliative care.

Vachon (1997) however, contradicts the idea that healthcare professionals do not have support in their roles and suggests that professionals working with death have access to additional support from palliative care teams and hospices.

These studies showed very different levels of support available when working with children with life-limiting conditions and some of the potential impacts when staff did not feel supported. If professionals do not feel supported in their role this generates concerns for their well-being, especially given the possible emotional and physical impacts on healthcare professionals already discussed above.

2.5.3. Professional dilemmas

Stevens (1995) states that medical training is to cure patients and from diagnosis, cure is the focal point, achieved through treatment. When working in children's palliative care, the role of the medical professional, in the WHO definition (1998), is to offer care to the child's body, which is most often providing pain relief and symptom management rather than a cure. Working with life-limiting conditions and in palliative care settings therefore does not follow the traditional curative model taught in medical training.

Expectations of the professional

Papadatou (2009) suggests that there are a number of social expectations that exist for professionals working with dying patients. These expectations may include ideas about protecting the self by being strong, being detached from dying people and preventing suffering in not addressing death related issues. Papadatou notes that these expectations are often reinforced in professional training. Haidet & Stein (2006) also support Papadatou's (2009) idea of professional expectations and proposed that the medical culture has a hidden curriculum that is built on certain values including assumptions that doctors should be perfect, uncertainty should be avoided and hierarchy triumphs. If such expectations do exist, it poses questions about how the healthcare professional is left feeling if they cannot achieve these ideals set by their profession.

Research has shown that nurses caring for dying children struggled between expressing the sad feelings they were experiencing and the expectations of their professional behaviour. Such expectations included not crying while on duty and being strong for their colleagues and the patient (Davies et al, 1996). McCloskey & Taggart (2010) reported that the opportunities to show grief following the death of a child may have been limited because nurses needed to "*get on with the job*" (p. 239). Vachon & Parkes (1998) also suggest that it can be difficult for nurses to experience grief because of the expectation, from their profession, to move on from the loss.

Liben et al (2008) proposes that it may be inappropriate for professionals to express emotions in public and therefore they are left with such feelings until a time when they can share them, if this provision is available from colleagues, family or friends. They put forward that professionals hold mistaken beliefs such as effective care is provided through rational thinking, emotions lead to biases and staff must take a position of detached concern to protect the self from burnout and compassion fatigue. It seems that in maintaining and adhering to expectations determined by their professional position, healthcare professionals may face additional struggles in their work.

Lack of death education

There are inconsistencies in how much death education and preparation is available to medical professionals working in palliative care settings (Bagatell, Meyer, Herron, Berger & Villar, 2002; Charlton, 1996; Copp, 1994; Dickenson & Field, 2002; Hilden et al, 2001; Lindop, Beach & Read, 1997; Lockard, 1989; Papadatou, 1997; Roberts & Boyle, 2005; Totka, 1996; Sahler, Frager, Levertown, Cohn & Lipson, 2000).

Seale (1998) believes that death education is especially important when working with dying children in Western cultures, where death is more commonly experienced in old age. In times when death was more frequent, people were more familiar with the process and thus people learned to cope with death and mortality (Whittle, 2002). However, as death is less common place in the Western world (Papadatou, 1997), it would appear more important that professionals facing death should be sensitively and consistently trained.

The lack of death education for healthcare professionals has led to increased research and more calls to expand the training for those working with dying children (Corr et al, 1992; Davies et al, 1996; Ferguson, Fowler-Kerry & Hain, 2006; Papadatou, 1997; Papadatou et al, 1999). However, Whittle (2002) says that the availability of research into death education has not always resulted in changes to practice and that the difficulties that professionals face in caring for children who are dying, is possibly connected to poor death education.

Engler et al (2004) conducted a survey with neonatal staff and practice nurses to explore their perceptions of EOL care for dying children. They found that those with more experience and education in this area felt more confident when providing care to children and their families. They concluded that education on EOL care could affect how comfortable nurses felt in caring for children who were dying and reiterated the importance of EOL training on nursing curricula. On a critical note, the response rate was 52% and the participants were registered nurses or advanced practice nurses who may have been more comfortable in providing EOL care because of their professional expertise. The authors also acknowledged that some items on the survey were unclear which made the findings difficult to interpret. Other research by Graham, Ramirez, Cull, Finlay, Hoy & Richards (1996) found that palliative care doctors who felt less competent in delivering EOL care were more likely to experience feelings of burnout than those who were sufficiently trained. Contro et al (2004) suggest when this happens, healthcare professionals resort to behaviours such as emotional distancing or depersonalisation.

Hilden et al (2001) surveyed paediatric oncologists on their attitudes, practices and challenges in EOL care with children who had cancer. The oncologists reported that they had learned to care for dying children through trial and error or through observing other clinicians rather than through formal training in paediatric oncology. In a study by Kaneja & Milrod (1998), 95% percent of doctors in training responded to their survey stating they would benefit from instruction in dealing with death and dying with children. In response to this, Bagatell et al (2002) devised a series of seminars to present to paediatric residents. The seminars covered practical aspects of the work but also addressed the impact of a child's death on the paediatricians and their partners. Exploring the personal impact was deemed "*especially useful*" by the participants which was an interesting finding given the suggestions made about medical training, discussed above. On a critical note, the doctors could have reported positive changes in order to appear more confident in their work

or may have felt uncomfortable to admit facing the topic of death was challenging. However, the programme proved to be a low cost method of covering death education and suggested that doctors wanted to have the time and space to think about the personal impact. This however does not appear to feature in training.

With regards to education available to professionals on experiences of personal grief, Conte (2011) conducted a telephone study to investigate the grief education and support available to paediatric oncology nurses. She found that education available was often non-existent and argued that there needed to be consistent training and support in place for nurses.

Non-medical training

The preparation for working in areas facing death is even more problematic for those working as non-medical professionals such as psychologists and social workers. Papadatou (2009) writes that professionals working in mental health settings are likely to use workshops to gain information on how to work with death and bereavement rather than formal training. Haley, Larson, Kasl-Godley, Neimeyer & Kwilosz (2003) comment on the lack of specialist postdoctoral training on palliative care available to psychologists. They note that *“psychologists lag behind medicine and nurses in establishing relevant education curricula and clinical competencies”* (p. 631).

The lack of death education available during professional training raises important questions around how prepared and resourced individuals are when working in the demanding environments of supporting children with life-limiting conditions. It is clear that there are a number of essential areas that must be considered by those responsible for professional training and which need to be addressed.

Feelings of professional failure

“Death disempowers helping professionals, particularly those of us whose training had led us to believe that we can overcome death by good medical practice” (Fredman, 1997, p. 13).

Papadatou (1997) states that despite children dying in Western countries being relatively rare, healthcare professionals working with children with life-limiting conditions are likely to encounter child death at some point in their career. In working with children who cannot be cured, doctors may view their dying child patients as professional ‘failures’ (Hilden et al, 2001, Papadatou, 1997; Papadatou et al, 2002; Romesberg, 2004) because they are unable to cure. When Fredman (1997) asked doctors and nurses about their roles and responsibilities with dying patients she received a unanimous reply from doctors that they felt a responsibility to prevent death. If they could not prevent it, they were left with feelings of failure. Papadatou (1997) takes the concept of professional failure further, stating that professionals may experience the death of a child to be a “triple” failure. In the first instance because they did not possess the ability to save the child’s life, secondly because of their role in society as an adult, they were not able to protect the child from harm. And in the third instance, they were looked to by the child’s parents and they were incapable of looking after their most precious possession.

In society and in Western culture, we find it unacceptable for children to die. Morgan (2009) feels that children are the hope and future for society and should therefore be expected to survive. Perceptions of the order of the world can be challenged when children die. This is believed to be felt by all healthcare professions, especially paediatricians who experience feelings of failure when facing incurable illnesses (Hynson et al, 2003). It is suggested that the stress involved in working with children who are dying changes the healthcare professionals’ view of the natural order of the world reversing the perception of this order (Oehler & Davidson, 1992). Doe & Katz (2006)

comment on the unnatural nature of a parent outliving their child and Rando (1984) highlights the unfairness of a child dying, that children are being deprived of a full life, which they deserve. It is believed that these experiences of failure may increase professionals' grief responses and feelings of helplessness, sadness and guilt (Morgan, 2009).

2.5.4. Grief & bereavement research

Grief and bereavement research has been well researched over the years, with the development of many models in order to better understand the experiences of bereavement. Notable contributions to this area have been provided by Bowlby (1961), Parkes (1972) Kübler-Ross (1969) and Strobe & Schut (1995; 1999). Grief experiences have been studied in both family members (Klass, 1996; Neimeyer, 2001) and healthcare professionals (Papadatou, 1997; Redinbaugh, et al, 2003; Rhodes-Kropft et al, 2005; Worden, 2002).

Grief experiences of professionals

Experiencing grief is thought to be unavoidable for those working with the dying (Papadatou, 2009). Grief has shown to be experienced by healthcare professionals in different ways and in varying levels of intensity but often with negative consequences (Cullen, 1995; Papadatou, 2001). For some individuals, grief was experienced as a struggle between grieving and maintaining professional behaviours (Davies et al, 1996; Kaplan, 2000) and for others it was the experience of ending a personal relationship with the child and their family (Clarke & Quin, 2007; Papadatou et al, 2002; Papadatou et al, 2001; Rashotte, Fothergill-Bourbonnais & Chamberlain, 1997).

Differences in grief have been shown within and between professional disciplines. In Papadatou et al's (2002) study discussed above, the doctors and nurses who were caring for children dying of cancer experienced differences in the types of losses they grieved for. The doctors grieved for their unfulfilled professional goals and hope to cure the child whereas the nurses tended to grieve for the relationship they had developed with the child.

Smith (2005) also found differences in professional grief. After interviewing nurses, doctors, chaplains and social workers the author found that nurses used each other for support and valued this experience following the death of a child however doctors avoided sharing their grief and managed alone in coping with death. Rashotte et al (1997) in their study found differences within the nursing team in the grief experienced when a child had died. The interviews revealed differences in the quality and intensity of grief reactions related to the relationship that the nurse had developed with the child and their family. The more intense feelings of grief were experienced if an emotional attachment had been formed with the child.

The above studies provided useful insights into different professionals' experiences of grief and highlighted differences between professional groups using both male and female participants. With grief experienced across professional disciplines working with dying children, it is possible that if psychologists had been included in the research, they too would have reported similar experiences. Little research has explored psychologists' experiences when a client/patient dies. An unpublished doctoral thesis has attempted to provide an insight into this area. It is acknowledged that referring to an unpublished document that has not been reviewed may be questionable, however, as there are so few studies that have been conducted, it seemed important to consider the findings. The study showed that junior psychologists who were working with a patient who had died experienced the death as having a lasting impact. The participants sometimes felt alone in dealing with the situation and some felt that they were expected to care but not to feel (Ford, unpublished doctoral thesis, 2009).

Difficulties with grief

Research has shown that some healthcare professionals experience difficulties with grief. Grief responses noted by Davies et al (1996) in their study were described as "grief distress" and "moral distress". "Moral distress" was related to the difficulty in following cure orientated instructions or offering

the child a more comfortable death. “Grief distress” was related to the struggle between expressing their feelings and maintaining professional behaviour of not showing emotion. The study found that the nurses’ grief was compounded by their workplace not acknowledging the impact of the work on the individual.

In connection to the expectations of healthcare professionals, discussed above, grief can be impacted by the behaviours expected of the individual following the death of a child. Kaplan (2000) described an “emotional tension” experienced by paediatric nurses working with dying children. The tension was a struggle to balance feelings of grief at losing a patient with the professional responsibility to manage the situation and provide care competently. Liben et al (2008) propose that healthcare professionals’ grief is hidden and disenfranchised because the individual is not able to acknowledge the loss (Doka, 1989). It is thought that society and their institutions expect them to be strong. The lack of training around death for professionals, discussed above, in conjunction with having to remain strong in the face of death may all impact of the experience of grief for the healthcare professional.

It appears from the literature that grief experienced by professionals is an unavoidable part of the role because of the close relationships formed with children and families. However, this experience is often impacted by expectations placed on the individual by their discipline and perhaps more widely by society. In not having an opportunity to grieve, it is possible that healthcare professionals are at risk of experiencing additional physical and emotional stresses from their work.

2.5.5. Opportunities and rewards from the work

Despite the numerous difficult aspects raised in the research, professionals have identified positive, rewarding, fulfilling and satisfying experiences from their work (Clarke-Steffen, 1998; Davies et al, 1996; Dunne, 2004; Eakes, 1990; Maeve, 1998; Olson et al, 1998; Papadatou et al, 2002; Papadatou et al, 2001; Robson & Beattie, 2004; Rushton, 2005; Woolley et al, 1989).

Papadatou (2009) believes that such experiences appear to protect individuals from the negative impact of being exposed to death and may lead to a change of life priorities, altering their perspectives and values. Research has been conducted to explore the positive changes and opportunities for growth (Attig, 1996; Neimeyer, 1998) and has found an increase in appreciation of life and changed priorities (Tedeschi & Calhoun, 1995; 2004). Yalom (2008) suggests “*that a confrontation with death arouses anxiety but also has the potential of vastly enriching life*” (pp. 75).

Woolley et al (1989) conducted a staff stress and job satisfaction survey with 24 children’s hospice workers and found that participants experienced satisfaction in their job despite times of stress. Rushton (2005) also found that staff working in palliative care with children and families experienced the role as satisfying. Papadatou and colleagues (2002) found from their research that even though nurses and doctors experienced grief in caring for children dying from cancer, they also reported rewards from the work. These rewards included the close and special relationships with the children and their families throughout the process and in the terminal phase of the illness. Papadatou (2009) suggests the rewards associated with palliative care can lead to both personal and professional benefits including an expanded view of the self, which she believes can lead to a greater appreciation of life’s joys. Other growths that Papadatou suggests are greater connection to others, acceptance of own mortality and the sharing of wisdom and skills with others, known as rippling (Yalom, 2008).

Despite reported experiences in the literature of emotional and physical impacts, it is clear that there are also many benefits to the professional in working in this area which may serve as protection from the more challenging aspects.

2.5.6. Managing difficulties in the work

Methods for managing the challenges and dilemmas experienced by professionals have been developed on individual and team levels. Maunder

(2006) suggests that those working in areas of high emotion often develop protective strategies that allow them to cope. In using simple personal approaches such as applying humour to the work (Robinson, 1991; Maeve, 1998; McKee; 1995; Whittle, 2002), using professional strategies such as reflective practice (Maguire & Price, 2007; McCloskey & Taggart, 2010; McNeilly et al, 2006; Souter, 2003), peer support (Davies et al, 1996) and solution-focused strategies (Gupta & Woodman, 2010), professionals have found ways to manage such demanding environments.

Gupta & Woodman (2010) introduced a solution-focused model for a children's palliative care team in order to help reduce stress. Common stressors included feeling unsupported and being reactive not proactive in their roles. Findings from 9 members of the team showed that the cathartic process of sharing stresses and thoughts had led to decreased feelings of isolation and inadequacy. The study showed that nurses had their own useful solutions to problems, which served to empower them in their work and the stress reduction strategy did not require extra funds and appeared to improve staff satisfaction. On-going reviews of the process continued for over two years and showed the pro-active nature of seeking and implementing solutions proved to be a positive strategy for nurses. Such a strategy could be developed with other healthcare professionals to address specific stressors in their team or discipline. From a critical perspective, the study relied on team members rating and sharing their stressors within the group, which may have resulted in participants under reporting their experiences for fear of being judged by their colleagues. One researcher was part of the palliative care team and the other was on secondment from another service, which may have resulted in participants being reluctant to share with a colleague or reluctant to share with a stranger.

Having access to professional support systems has also shown to be helpful in managing the stresses of such challenging work (Beringer et al, 2007; Davies et al, 1996; Maytum, Heiman & Garwick, 2004). In Davies et al's (1996) study, referenced above because of the challenges reported by

professionals, they discovered that being in a supportive work environment and having access to peer support were helpful strategies when the nurses were struggling. Pearson (2010) also found that for nurses, being able to access support from colleagues who had been involved in similar experiences of EOL care for children was beneficial.

Papadatou et al (1999) attempted to better understand the nature and effectiveness of mutual support between nurses who were exposed to the death of children. They interviewed 39 nurses working in oncology and found that nurses used support from their colleagues rather than their friends and they looked to the positive experiences in their work, reframing the deaths of children, "*when a child dies we say, 'There are other children...we lost this one, but the others also need our care, our help'*" (p. 44). This highlighted the importance of mutual support between colleagues and showed how effective support enhanced group cohesion. On a critical note, the two groups were chosen as they both had experience of child death however the nurses came from very different services which made it difficult to tell if the differences in support were based on the individuals, the group or the goals/philosophy of the unit. This could have been improved by using a more homogenous group.

Clinical supervision is also believed to be an important way to help healthcare professionals manage their experiences. Teasdale, Brocklehurst & Thom (2001) identified supervision as a way to help nurses identify their own coping strategies and supportive networks. They found some statistically significant differences with supervised nurses reporting better coping at work and feeling they had better access to support than those who were unsupervised. Reflective practice is another important source of support with specific models being developed for those working in children's palliative care (McNeilly et al, 2006). McCloskey & Taggart (2010), discussed above in relation to staff stress and grief experiences, found that learning through reflection was essential at a personal level for nurses working in paediatric palliative care.

Managing grief

Papadatou (2009) proposes a model, from a number of qualitative studies, to explain elements of grief experienced by professional. She posits that those who experience the death of a patient as a personal loss are likely to grieve; grief offers personal growth to professionals; grieving fluctuates between experiencing grief and avoiding it (see Figure 1); grief overload occurs when there is no fluctuation between the two. Papadatou suggests moving between the two positions to be adaptive and healthy for the professional.

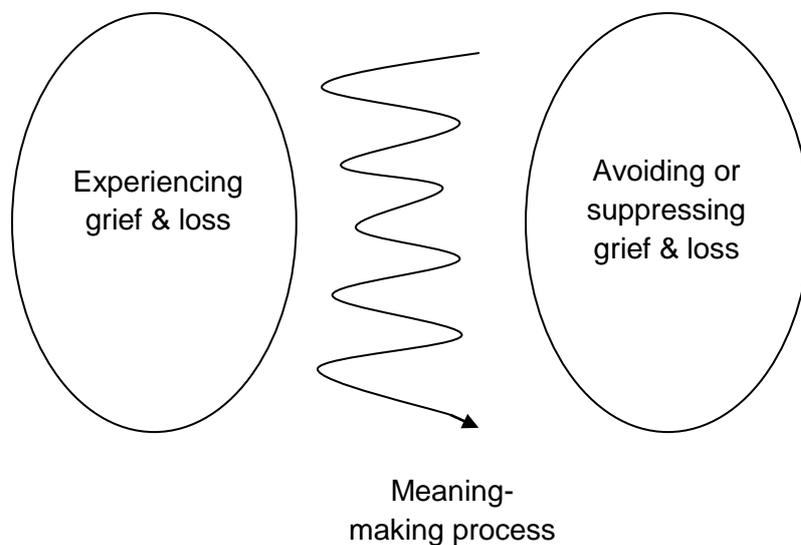


Figure 1 Papadatou (2009, p.140)

Neimeyer (2001) proposes the idea of meaning making surrounding death and explains that healthcare professionals make meaning of a patient's death as they work through the loss. This loss related experience is then integrated into the professionals own life schema. This process is important in the managing and moving forward from the experience and highlights the time needed for professionals to work through their loss, something which discussed above, is not always available to professionals working in this area.

Humour and hope

The use of humour has been referred to in the literature as a method to help manage the more challenging elements of the work (Robinson, 1991). Nurses use humour, as a way to manage some of the difficult aspects of their work (Maeve; 1998, Whittle, 2002) with hospice staff also finding humour to be a personal characteristic that helped them in their work (Woolley et al, 1989).

De Graves & Aranda (2005) conducted an exploratory study to explore the reflections of 14 health professionals (nurses, doctors & social workers) working with children with cancer, for whom were no longer responding to treatment. Using in-depth interviews and qualitative analysis, the study identified master themes of uncertainty and hope in their work. Uncertainty did impact on the professionals' practice however, trying to instil hope in families was important especially when everything else was failing. At all stages of care, the healthcare professionals saw an important part of their role as promoting hope. They saw the children who had survived against the odds as being an important source of hope for the team. The findings were important in highlighting the benefits and rewards from the role and the focus on hope that was important to the professionals. Like other research, this suggests that despite the hardships, the hope that can be drawn from professionals' experiences was an important source of inspiration and protection in a demanding environment. On a critical note, the study only presented the experiences of professionals from one unit and the nurses had more opportunity to voice their experiences over other professionals because they took part in multiple discussions. This may have resulted in some experiences being privileged over others.

Self-aware and self-care

Being self-aware is also important for professionals working in this area. Liben & Papadatou (2011) feel it enables healthcare workers to understand that they are not immune to pain, loss and death, that expertise does not give them immunity to suffering and it normalises their responses in light of their

experiences. They suggest that if professionals are able to recognise their limits and vulnerabilities as well as their strengths, individuals are able to offer the role of knowledgeable guide to the dying child.

Self-care is reported to be another important protective factor for healthcare professionals. McCloskey & Taggart (2010) found that nurses developed a range of positive coping strategies including self-care as a means to manage the challenges of the environment. Vachon & Parkes (1984) also found from their study that nurses reported aids in their work such as taking time for themselves, having a social support network and in being able to discuss their feelings in a confidential manner at work.

From the literature described above, a number of strategies and techniques were utilised by healthcare professionals as a way to manage in the often challenging environments of working with children with life-limiting conditions. The different approaches emphasised the range of options available to staff on a professional level but also approaches available on a personal level, all of which help to develop an understanding of how working in this area can be well managed.

2.6. Clinical Psychology and children with life-limiting conditions

Clinical psychologists are often now part of paediatric clinical teams and are increasingly involved in supporting children with life-limiting conditions and their families (PPN-UK, 2008). Despite their increased presence in such teams, there is little research that focuses on their experiences of working in these specialist services. It is hoped that through this research, the unique stories of psychologists will enable their experiences to be more fully understood. It is possible that the information that is gathered may then be used by professionals supporting clinical psychologists in their work (clinical supervisors, clinical tutors and those offering training) to develop strategies to best assist them in their role. This could perhaps be used in the development of training programmes to better assist them in their work. The experiences could also be shared with professionals who are about to enter into such

services and who may benefit from hearing about other people's experiences to help prepare them for their work.

2.7. Rationale

A large amount of the available research focuses on medical professions working with life-limiting conditions. Clinical psychologists also work with these children however there is very little research that explores their experiences. The research available has been conducted with professionals working with children who are gravely unwell, often exploring the experiences following the death of a child. There is less research available when working with children for whom death is not imminent but whose condition will shorten their life expectancy. Some life-limiting conditions can be managed and can result in the child experiencing periods of wellness. It would therefore be important to focus on researching the experiences that professionals working in this area might have to share.

Given the development and presence of clinical psychology within general paediatric and paediatric palliative settings, it is reasonable to wonder how psychologists experience working with children with life-limiting conditions. This is an important area of research given the involvement of psychologists in caring for and supporting these children and their families.

Clinical psychologists working with life-limiting conditions are exposed to similar demands in their work as the medical professionals most commonly associated with paediatric care and specialist paediatric palliative care. There is little research that has paid attention to clinical psychologists specifically. Owing to this lack of research, the current study's rationale is to address this gap and to explore clinical psychologists' experiences. This will help to better understand how they make sense of working with children with life-limiting conditions in paediatric settings.

2.8. Aims for the study

This study aimed to gain an understanding of how qualified clinical psychologists in paediatric services make sense of their experience of working with children with life-limiting illnesses.

The specific areas of interest that were explored with participants were:

- The potential impact of the work
- The possible coping strategies utilised in their work
- The support that the participant used/would have liked to have had
- Any changes that occurred for the participant following their experience

This research may enable clinical supervisors and those responsible for training in this field to gain a better insight into these experiences and aid the understanding of what supportive elements individuals use when working in these services.

2.9. Research question

Taking into account the above aims the research question for the study was:

- **What are the experiences of qualified clinical psychologists working with children with life-limiting conditions?**

3. Method

3.1. Overview

This chapter will describe the methodology and design of the research project. Included in this section is an explanation of the method used, the participants selected and the data analysis that was used in the study.

3.2. A qualitative design

Qualitative methods offer the researcher the ability to explore in detail, the rich experiences of human life focusing on discovering knowledge through the participant's subjective experience (Crowe, 1998). This method is advantageous for exploring complex aspects of experience, studying an individual in depth and studying a topic that does not lend itself to quantification (Barker, Pistrang & Elliott, 2002), which were all important in meeting the aims for the study. The experiences of non-medical professionals working with children with life-limiting conditions have been neglected in the research literature. As the introductory chapter highlighted, this is especially true for clinical psychologists who often work in supporting children with such conditions and their families. In trying to explore the experiences of psychologists as close to their lived experience as possible (Elliott et al, 1999), I chose to use a qualitative approach in this study, based on the research aims.

3.3. Why Interpretative Phenomenological Analysis (IPA)?

As a qualitative method was most appropriate to address the aims of the study, the next stage was to contemplate the number of qualitative methods available for use. In deciding which of these approaches would be used, it was important to consider which was most suited not only to the research question but also to my epistemological and ontological position as the researcher. For this study, Interpretative Phenomenological Analysis (IPA) was chosen. The methodology was developed by Smith (1996) and was

deemed to be the most suitable approach for the project based on the following areas:

- IPA has an idiographic approach, which places the focus on hearing the individuals' story and understanding how they make sense of their lived experience (Smith, 2004). IPA's inductive approach enables an individual's perspective of a given phenomena to be explored in detail, which fit with the research question of understanding the experiences of clinical psychologists working with children with life-limiting conditions.
- IPA fits with my epistemological position as Constructivist. IPA does not support the notion of absolute truth or an objective reality waiting to be discovered but instead explores how the individual and society create their own constructions of reality (Raskin, 2002). The theoretical foundations of IPA are hermeneutics (for example Husserl & Heidegger) and phenomenology. Hermeneutics is "*the theory of human understanding in its interpretative aspects*" (Shotter, 1983 p.268) and IPA uses interpretation in order to develop knowledge and understanding rather than the positivist position of obtaining authentic knowledge from sensory experience.
- There was a wealth of support and training available from internal (tutors, fellow trainees) and external (IPA discussion groups, forums, training workshops) sources when using IPA. As well as detailed and structured guidance available to assist researchers in their analysis using the methodology.
- IPA is an established and respected methodology and has been used in health, social, clinical, counselling and educational psychology (Smith, Flowers & Larkin, 2009).

3.4. What about other qualitative methodologies?

There are a number of other qualitative methodologies that could have been used for this research. As with all research, choosing a methodology most

suited to the research inquiry is imperative in obtaining the desired results (Starks & Brown Trinidad, 2007). Therefore, careful consideration was given to grounded theory, narrative and discourse analysis.

Grounded Theory is concerned with building theory around social processes (Glaser & Strauss, 1967) and suggests that data collection and analysis should continue until the point of theoretical saturation has been reached (Willig, 2001). It was felt that owing to this focus on social processes, grounded theory was not suitable for a study exploring the personal experiences of participants. There were also concerns around the practicalities of gathering enough participants to ensure theoretical saturation therefore grounded theory was discounted.

Narrative Analysis was considered as a possible method of analysis for this study. Narrative Analysis focuses on how individuals use stories as a way to interpret their world (Lawler, 2002), which has links with IPA. However, it was felt that narrative analysis would remove the flexibility of emerging themes because of the focus on temporal narratives in the methodology. The available support and access to resources was more limited for narrative analysis and so it was discounted.

Discourse analysis (DA) describes a number of different approaches that focus on language. DA poses that language mediates and constructs the understanding of reality. The researcher rigorously examines the text in order to analyse the selection of discourse that the speaker draws from and positions they adopt (Barker et al, 2002). DA is interested in discourse alone and does not consider sense making (Willig, 2001) therefore this methodology was also discounted.

3.5. Study development

During the development stage of the research, consideration was given to which NHS Trusts would be approached to find participants. It was decided that two large trusts would be used in the study to help protect confidentiality

of the participants. Cambridge and Peterborough NHS Foundation Trust (CPFT) was initially considered in the early study development as they were my employer. South Essex Partnership University NHS Foundation Trust (SEPT) was the second trust considered based on the potential participants the trust could provide and the field supervisor's links with the trust.

In order to establish whether this would be a viable project to recruit to, in the project development (January 2011), an email (See Appendix 7.1) outlining the study proposal was posted to clinical psychologists on the PPN-UK website. The email was sent before ethical approval had been sought and made very clear to potential participants that the project was in development and was not recruiting participants pre-ethics approval. The email also asked psychologists from other trusts to get in contact, especially London based psychologists. This was to establish if other trusts not considered could generate participants. Based on a number of interested responses from GOSH for Children NHS Foundation Trust and none received from CPFT employees, GOSH was used instead of CPFT. As CPFT were my employers it was perhaps better for the impartiality of the study to have selected other NHS Trusts.

3.5.1. Pilot interview

When using IPA, the method of choice for gaining data is through semi-structured interviews (Smith & Osborn, 2008). The pilot interview schedule was devised from information available from the literature, guidance from the supervisory team and from one pilot interview. In order to gather feedback on the interview schedule and the experience of the interview process, a pilot interview was conducted. Following this interview, the pilot interviewee did not believe any alterations needed to be made to the schedule or interview process. This pilot interview was used in the study.

3.5.2. Interviews

Having tested the interview schedule (See Appendix 7.2) during the pilot interview, it was then given to other participants in the study. The schedule

aimed to gain an understanding of clinical psychologists' experiences of working with children with life-limiting conditions including their coping strategies, their access to support and potential changes following their experiences.

3.5.3. Inclusion & Exclusion Criteria

The study aimed to be as inclusive as possible in order to hear the experiences of clinical psychologists therefore there were no restrictions placed on the age, gender, sexual orientation or religion of the participants. It was requested that participants had at least 6 months experience prior to taking part in the interview. This was to increase the likelihood that participants had established support systems in place should topics be raised in the interview that they found distressing.

In order to generate a group of participants that were suitably homogenous, all the participants were required to be qualified clinical psychologists working in a hospital setting with children with life-limiting conditions (see section 2.3. Definition of terms). It was not restricted to clinical psychologists working in paediatric palliative care based settings because personal experience from working in general paediatric settings had shown that clinical psychologists in these settings still encountered working with children with life-limiting conditions. All the participants had to be employed by either GOSH or SEPT.

Exclusion criteria for the study stated that participants had to be working in their role working with children with life-limiting illnesses for more than 6 months (as explained above). The study also set exclusions for participants who were not fluent in English. As qualitative research relies heavily upon language use and the richness of data it was possible that this would be lost through the use of translators. This was not an ideal solution and it was recognised that the research would be excluding the voice of those who did not speak English. This will possibly be a limitation of the study and will be discussed further in the discussion section.

3.6. Ethical considerations

NHS ethical approval was gained from the National Research Ethics Service (NRES) at the Hertfordshire Committee meeting held in Essex (See Appendix 7.9.1. for NRES approval letter). Research and Development (R&D) approvals were granted from both Great Ormond Street Hospital for Children Trust (See Appendix 7.9.2. for approval letter and 7.9.3. for letter of access) and South Essex Partnership NHS Foundation Trust (See Appendix 7.9.3 for approval letter).

3.6.1. Informed consent

Potential participants identified for the study were sent an information pack about the research (See Appendix 7.3.). A reply slip was included in the pack (see Appendix 7.4.) so that participants could consent to taking part. This also enabled them to allocate a convenient time to be contacted if they required additional information about the study. None of the participants requested to speak about the study prior to agreeing to take part. Before the face-to-face interview took place, the participants were given the opportunity to ask any questions. The participants were asked to initial and sign the consent form once they understood and were happy with each of the statements (see Appendix 7.5.).

3.6.2. Confidentiality

It was explained to participants that data collected for the research would be kept confidential. This was achieved by ensuring that any data stored electronically was password protected and an NHS encrypted memory stick was used to transfer data across sites (e.g. GOSH, SEPT building & university site). Participants' identities were kept confidential by replacing their actual names with pseudonyms in the write up and any personal information (e.g. name signed on the consent form) was kept locked away securely at the university site. A number of the SEPT participants had been approached to take part by the field supervisor therefore they were reminded that their

identity was known to the researcher and field supervisor only. The GOSH participants were made aware that only the researcher was aware of their participation in the study.

Participants were made aware that should a transcription service be used, they too would be bound by confidentiality and would have to sign a confidentiality agreement. The participants were informed that the project supervisors and a small group of clinical psychology trainees in a specialist IPA group would be looking at the anonymised transcripts to help with the analysis process.

The participants were informed that research interviews may be conducted with their colleagues in the psychology department without identifying specific individuals. This was shared with the participants to be transparent about the recruitment process. It was possible that this may have resulted in some participants being more guarded in the information they shared due to the often close proximity of working within teams in the NHS. However, it was hoped that participants would feel confident that the information they shared would be treated confidentially and that they felt comfortable to discuss their experiences. The limits of confidentiality were also shared with the participants. It was explained that if they shared anything, which would question their capability to practise as a psychologist, as defined by the Health Professionals Council (HPC, 2010) or the BPS (1995) or if they raised child protection concerns that had not already been shared with the appropriate agencies, information would be shared with the study supervisors.

3.6.3. Consequences of participation

Care and consideration was given to the construction of this study to reduce the potential impact that participants may have experienced in talking about their experiences. Given the sensitive and often distressing nature of working with children with life-limiting conditions, consideration for the participants was at the forefront of the interview at all times. Before beginning the interview, participants were asked to identify an individual who would be able to offer

them support after the interview was completed, should they feel it necessary. The participants were encouraged to pause the interview if they felt they needed some time before continuing and were also made aware that they could terminate the interview if they felt unable to continue. At the end of each interview, the participant was given time to debrief and reflect on the experience of talking about their work, which appeared to help the participant process some of what had been discussed.

All the participants seemed to enjoy the opportunity to talk about their experiences and from a number participant reflections, it was often a rarity for them to have thought through their experiences in detail.

3.6.4. Consequences for the researcher

From my work in paediatric teams during my training I have encountered a number of ill children and their families. I feel this experience has been essential to the designing and carrying out of this project. My previous experiences have helped me to develop coping strategies for myself, which were helpful to draw on when listening to the difficult subjects that were raised during the interviews. My own strategies included accessing support from my friends, family, colleagues and supervisory team.

I was aware during the research of my personal interest in the topic and my previous involvement in paediatric cases. I have remained aware of my own thoughts, feelings and biases throughout this study, attempting to use some of these aspects to enhance my study and my connection with the experience.

3.6.5. Participants relationship to the researcher

I was aware during the research that the participants in the study were either previous colleagues/psychology acquaintances or fellow psychologists. It was hoped that this level of familiarity and connection would aid the interviews rather than hinder the process. As a psychologist I considered myself at times during the interview to be an insider, "*someone whose biography (gender, race, class, sexual orientation and so on) gives her [sic] a lived familiarity with*

the group being researched" (Griffith, 1998, p. 361). However, it is understood that insider/outsider roles are not "*two mutually exclusive frames of reference*" (Olson, 1977, p. 171) but are ends of a continuum that I could move between. There are acknowledged pros and cons to being an 'insider' researcher related to access, intrusiveness, familiarity and rapport (Mercer, 2007). As I could not change aspects such as my gender, profession, age, race etc. I did the best I could in the situation to be mindful of my position in the interview. I have reflected further on these concepts in the discussion section.

3.7. Procedure and data collection

3.7.1. Recruitment

Both NHS ethical approval and local R&D approvals were granted from GOSH and SEPT. The field supervisor approached colleagues within SEPT and gained consent for an information pack to be sent to them. The interested GOSH participants, who replied to the initial email sent using the PPN-UK, were emailed to inform them of the granted ethical approval. They were asked if they would still like to take part and if so, to get in contact so that an information pack and consent form could be sent to them. For an IPA study, it is recommended that at least 5-6 participants are recruited (Smith & Osborn, 2008). In order to gather rich data and to protect confidentiality of the participants, the aim for this study was to recruit 6-8 participants.

3.7.2. Participants

Seven participants agreed to take part in an interview lasting between 1-1.5 hours. Given the specialist nature of paediatric services, it might be possible to identify participants if a detailed description were given therefore basic information about participants has been provided to ensure anonymity. The seven participants were all were working with children with life-limiting conditions and had been in the post for longer than 6 months. The participants worked in a range of services seeing children in in-patient and community settings, with a number of different conditions from general paediatric settings to more specialist services. They were between 29-49

years of age, were all female and White British. The number of years of experience as a psychologist since qualifying ranged from 2-18 years.

3.7.3. Data collection

In the information pack, potential psychologists were offered a telephone call or a face-to-face meeting to discuss participation. The participants were given two weeks to return the consent form. If after this time they had not responded, they would not be contacted again. If during the two weeks they did agree to take part but requested more information, the researcher would cover this during the offered phone call or face-to-face meeting. When the participant was happy to take part, they were asked to look over the consent form, which would need to be signed and collected at the time of the interview. Face-to-face interviews were arranged at a convenient time and place for the participant, which they all requested to be at their place of work.

Before the interview began, participants were given the opportunity to ask questions about the information on the consent form and if satisfied with each statement (e.g. had opportunity to ask questions, anonymised sections of the interview would be shown to members of the university staff and trainees, asked to comment on findings after analysis), to sign and initial the document. This consent form was kept in a locked draw on University of Hertfordshire premises as it contained the real names of the participants. A pre-interview brief (see Appendix 7.6.) was carried out with each participant to share information about the study and provide the opportunity for them to ask questions. Participants were also reminded of the contact details in the information pack of the Independent Complaints Advocacy Service (ICAS) should they wish to make a complaint about the research.

The interviews were audio recorded and lasted between 1-1.5 hours. Once the interview was finished, the participants were debriefed (see Appendix 7.7.) and given the opportunity to reflect on their experience of the interview. They were also given a sheet of support resources including the number to the Samaritans and the BPS (see Appendix 7.8.) if they felt it beneficial to make

contact with them following the interview. Participants were also reminded that once the analysis had been completed, the researcher would contact them and ask for any feedback on the themes that emerged from the data. They were told that they were free to decline in the future, however all participants said they would be happy to comment on the findings.

The interviews were transcribed verbatim. Recordings were stored in a secure electronic file along with back up copies of the files on an encrypted memory stick. Due to the time constraints of the study, a transcribing service was used. The transcriber signed a confidentiality agreement (see Appendix 7.10.) stating they would not discuss the content of the interview. They also agreed to delete the file after transcribing. The electronic transcription files were saved with ID numbers rather than the participant's names to protect confidentiality.

3.8. Data analysis

The data generated from interviews was analysed using IPA. IPA is a well established qualitative research method used by researchers to gain insight into how a person in a given context makes sense of a certain experience (Smith, 1996; Smith, Jaman & Osborne, 1999; Smith et al, 2009).

3.8.1. Individual analysis

The first stage of the analysis began by listening to each interview and reading and re-reading each transcript in order to become immersed in the data. The second stages of the analysis included noting initial interesting comments, remarks and ideas in the left hand column of the transcript as suggested by Smith et al, (2009). The initial notes were often descriptive or linguistic comments, which were linked closely to the text, developing then into more conceptual and interpretive noting. The right hand column was used to note themes as they emerged. During the analysis attempts were made to 'bracket' (Smith et al, 2009) my own experiences to enable the themes to emerge from the text.

During the third and fourth stages of the analysis, the process became more interpretative rather than merely textual. Attempts were made to search for connections between the emerging themes, enabling themes to come together and begin the clustering process. These clusters of themes then developed into superordinate themes and were given titles that allowed the reader to understand the concept, whilst being grounded in the text. Quotations from the interview that supported each developing theme were recorded to be used in the cross-case analysis at a later stage of the process (see Appendix 7.11. for a section of an analysed interview). Each interview was analysed before moving onto the next interview. Careful consideration was given to bracketing ideas from the previous interview in order to maintain the idiographic commitment of IPA (Smith et al, 2009).

3.8.2. Cross-case analysis

Following the analysis of each separate interview, the next step in the process involved collating all the cases to explore possible patterns. This process was similar to that of the individual cases and all themes from each case were put together in order to examine which themes were connected and which were the most compelling across all cases. Again superordinate and subordinate themes were created for all participants (See Appendix 7.12. for themes for all participants). The transcripts were revisited in order to ensure they were reflective of the participants' experiences of working with children with life-limiting conditions.

3.8.3. Credibility/quality of analysis

It is important in IPA to provide credibility to the analysis (Elliott et al, 2002). In order to ensure credibility throughout the project, guidance was achieved from my supervisors and a small group of clinical psychology trainees. Both my supervisors audited my analysis to provide reliability. One supervisor is an expert in IPA methodology and has supervised a large number of student's dissertation projects. The field supervisor completed her clinical doctorate dissertation using IPA on trainee psychologists' experiences of working with

clients who had died and is also a qualified psychologist who works with children with life-limiting conditions. Feedback from meetings with both supervisors confirmed the clarity of my analytic process and they agreed they could follow my analysis from initial ideas to final themes. In contributing their own ideas, this helped me with the analytic process however I recognised my own interpretative stance on the data I was presented with.

In order to generate support and advice from a peer group, a small number (3-4) of trainee clinical psychologists from the University of Hertfordshire formed an IPA group. During these meetings, I took anonymised sections of the interview transcripts that I had analysed in order to have the process audited by others. There is some question as to how helpful this process is given the 'double hermeneutic' of IPA research and the constructivist position of this study. However, it was felt important to have both credibility and transparency in the analysis process.

On completion on the analysis, themes from the interviews were shared with each of the participants and they provided their comments. Owing to the 'double hermeneutic' of IPA, Smith (2004) challenges member checking. However, member checking is believed by others to be important in establishing credibility (Lincoln & Guba, 1985). Participants were asked to be honest in their feedback and to feel free to fully agree with the presented results (see 5.6. What they thought, for the participants comments).

3.9. Researcher reflexivity

Owning one's own position is important in qualitative research (Elliott et al, 1999) and my epistemological position has already been discussed above. Being self-reflexive is an important requirement of the researcher and requires an understanding of the thoughts, beliefs, knowledge and experience that they bring to the research. It is not possible for the researcher to adopt a position of a 'blank slate', however it is possible to shelve their own previous attitudes and beliefs in order to better connect with the experience of the participant. This process is referred to as "bracketing" and by the researcher maintaining a

self-reflexive position it enables them to share in the experiences of the participant. I attempted to “bracket” my own thoughts and experiences and remain self-reflexive throughout the study.

4. Results

In this chapter the findings from the analysis of seven clinical psychologists' experiences of working with children with life-limiting conditions are presented. Three master themes emerged from the analysis:

- ***The meeting of two different worlds: When psychology and medicine converge***
- ***Nobody is immune: Facing the challenges of life-limiting conditions***
- ***Balancing the rough with the smooth: Finding a way to manage***

The superordinate and subordinate themes for the study are summarised in Table 1. Each of the master themes and the sub-themes will be expanded and discussed in detail in this chapter. For an illustration of which themes were present in each of the seven interviews see Appendix 7.12. In line with a constructivist theoretical framework, it should be noted when reading this chapter that the results from this analysis are one possible interpretation for this group of clinical psychologists' and their experiences. Due to the 'double hermeneutic' of IPA (Smith & Osborn, 2003), this analysis may have created similar or different themes for another researcher.

It is recognised that given the level of depth when analysing using IPA, it would not be possible to present all the experiences and opinions of the seven participants. Their descriptions were full and plentiful and through a thorough analysis I have attempted to give the reader an insight into their experiences and how they made sense of the medical world they had become part of.

To substantiate my interpretations from the analysis, extracts from the interviews have been used, which have been amended for readability. Small hesitations, utterances such as 'um' and repeated words have been deleted. Additional information is represented in square brackets for the reader for the

times when the participant made reference to a topic raised earlier in the conversation or where meaning had been inferred. Three dots (...) have been used to represent where text has been deleted for readability or where there is continuation of the text e.g. when the quote was taken from the middle of the participant's dialogue. The names of participants have been changed along with any identifying information to ensure confidentiality.

Superordinate & subordinate themes
<p>The meeting of two different worlds: When psychology and medicine converge</p> <ul style="list-style-type: none"> • Flexing to fit: Adapting to medicine • We do success not support: The lack of support in medical culture • Psychology offering something unique: Team benefits • Let's not waste any more time: Feeling the pressure of illness
<p>Nobody is immune: Facing the challenges of life-limiting conditions</p> <ul style="list-style-type: none"> • "You can't stop yourself being affected" • This is normal for us: Becoming desensitised to illness • "This could be me": Identifying with families
<p>Balancing the rough with the smooth: Finding a way to manage</p> <ul style="list-style-type: none"> • Strategies for surviving • Support in all shapes and sizes • Looking for a light in the gloom

Table 1 – Superordinate & subordinate themes

4.1. The meeting of two different worlds: When psychology and medicine converge

The coming together of two apparently very different worlds, united in working together with children with life-limiting conditions, was both a challenge and an achievement for all seven participants in this study. The first superordinate theme presents the psychologists' reactions to being confronted by the medical world.

A number of participants talked about being faced in their paediatric clinical work with very different experiences to those experienced in their psychology training, where they worked predominantly in mental health settings. In the physical health world medicine is constructed as holding the position of power, with doctors and nurses typically exercising an expert knowledge. Participants experienced the power of medicine in their work and felt that they needed to mould themselves to fit into that world. This needing to fit in was a response to medicine being the dominant model, medical staff being the dominant professionals and psychology being the minority in the hospital setting. The participants felt that because they were on the medics 'turf', they needed to be the ones to adapt. The participants faced a number of challenges in adapting, on a range of scales in their work. The larger challenges included facing medical culture, perceived by the participants to be less accepting of support and less inclined to discuss the emotional impacts of the work. The smaller scale dilemmas included adapting to the physical environment and the speed of working in the medical setting.

The accounts reflected psychology as offering unique contributions to the paediatric teams. Some participants' accounts reflected attempting to cascade their skills to the medical teams in the hope they would be absorbed and infiltrated into the environment. Sharing their skills seemed to serve the purpose of showing other professionals what psychology could bring to the team. This enabled the psychologists to feel that they were offering

something of value, which helped them to carve a role for themselves in the team.

4.1.1. Flexing to fit in: Adapting to medicine

'Flexing to fit in' represents the adaptations that participants felt they had to make in order to fit into the medical world. Having been trained in mental health settings, a number of changes to clinical practice and behaviour were viewed necessary to carry out work successfully in a paediatric setting. These changes included not having designated therapy rooms, working at a faster pace and having to be the 'expert'. Interestingly, the participants mostly commented on adapting to medicine (medical staff and the medical environment) rather than adapting to the child's illness.

From the participants' perspective, responsibility to fit in rested predominantly with the psychologists, being the minority discipline, rather than the medical staff. Differences between participants in how much they had changed and how comfortable they felt in adapting themselves were evident. A sense of powerlessness in just having to change was apparent for most participants, feeling they had to bend to fit into the dominance of the medical environment.

...It's still, even now, after all these years, sometimes it's really uncomfortable. I would much rather not have to speak to people in corridors where...people are walking around. I'd much rather have a private room I can take someone to in a clinic but I have to accept that I'm not always going to be able to do that, but I still find it uncomfortable, I still don't like it, and I think it limits what you can do... (Alison)

Alison's extract highlights the changes she had to make to fit into the environment. Referring to the adaptations repeatedly as "*uncomfortable*" suggests her uneasiness at having to adopt new behaviours and having "*to accept*" indicates the lack of control she perceives in her situation. In my view, this can be understood in the context of medicine often being given priority in a paediatric environment and psychology being perceived to be less

important. As medicine is dominant in the environment, the psychologist has to be flexible to move with their culture. The psychologist therefore is the one required to change and Alison acknowledges and succumbs to this position because she feels that she has little, if any, choice.

Georgie's account illustrates the differences and subsequent changes that she makes to her clinical practice as a result of the environment.

...I think the...boundaries were a bit different...there could be more of a dipping in and out approach...it's not...setting up a one hour appointment, and coming along, meeting, and agreeing...what you're going to talk about in that session, and then finishing and then agreeing the next session... (Georgie)

For Georgie, her training did not fit with her job in a paediatric setting. For example, she felt that her mental health training had prepared her for a world where she set up weekly appointments, worked within set boundaries, conducted therapy in a protected space and time and measured outcomes and progress. Georgie's experience of children "dipping in and out" of therapy reflected literature documenting the typical needs of children with life-limiting conditions (Craft & Killen, 2007). The medical setting did not enable Georgie to practice in the way she had become accustomed. Perhaps this was something that she felt on a larger scale, psychology not fitting in with the medical world. Georgie over time became more comfortable with the adaptations required of her and reached a place that felt more jointly negotiated.

"...it [hospital ward] is a bit of a goldfish bowl, people can observe things that maybe you wouldn't want people to see...if it was happening in your own home, people wouldn't be aware of, and so I think sometimes...if parents seem distressed or upset, they maybe...more quickly referred to psychology or actually that's not what the family want at that point...quite a few times I've been along and they've [said] 'no, I'm fine, I don't want that' "...(Grace)

Grace's account also highlighted the difference of the in-patient paediatric setting and the impact on her work. She reflected on the unusual environment of the hospital ward, likening it to "*a goldfish bowl*" where families were on display. The families, when in the hospital, were under the spotlight therefore any suggestion or hint of distress and they were "*quickly referred to psychology*". Grace's observation and acknowledgement of the more visible environment enabled her to recognise that perhaps the family did not want or need psychology involvement at that time. She could appreciate the inescapable nature of the setting for the family and held this in mind when contemplating their behaviour. Being able to physically see distress appeared to promote anxiety in the medical staff. Grace made sense of this experience as the staff referring families to psychology quicker than they would if perhaps they were seen on a more outpatient basis.

...they [doctors] want you to behave in a way that makes sense to them, they want you to occupy the expert position, and that for me isn't something that was part of my training, and neither is it part of my work, and that I think it takes a while for them to get used to me in that respect... (Ellen)

Ellen's extract highlighted a more opposed response to the medical professional's desire for her to change. The words "*a way that makes sense to them*" presented the doctors needs for her to fit in with the medical culture in a manner they understood. Ellen made the doctors "*get used*" to her way of working rather than taking on "*the expert position*". Instead she made adaptations in relation to the pressures of working with shortened lives and the different physical environment such as working in rooms with beds. She highlighted how psychology could stand up to medicine rather than bending to fit in. This was an example of how in some services over time, medicine was adapting to the presence of psychology. Ellen's account was more forceful in making the doctors see her as different to themselves but other participants found over time that the medical team were forming a more collaborative relationship with psychology.

4.1.2. We do success not support: The lack of support in a medical culture

'We do success not support' represents the attitudes to support, expressed by medical colleagues and experienced by the participants in the study. 'Success' refers to the general attitude of 'fixing', 'mending' and 'doing' expressed by the medical staff. Attitudes towards support for themselves as medics and for psychologists in the team included both explicit questioning of the need for support and more implicit positions of not being able to ask for or acknowledge needing support in their roles even when facing sad and stressful situations.

The following three extracts reflect the difficult and eventual failings of support groups/supervision implemented for medical staff by psychology.

...sometimes people want it [supervision] but then they don't know if they're allowed to have it, or what will other people think if they have it, and that kind of thing, so actually they can see the value in it for themselves but there's that kind of ... whether that's the peer pressure or just a cultural thing...will it be seen as a sign of weakness if you go...(Nicole)

Nicole's extract focused on the difficulty for medical staff in accessing support via supervision. She experienced this as frustration, trying to offer help in difficult situations but meeting barriers related to "weakness". She expressed enthusiasm in providing support for the staff team however, this seemed to be slipping away with each obstacle she faced. Nicole hypothesised the need to be strong at all times as a "cultural thing" for the medical staff. The suggestion was that they wanted it and did "see the value in it for themselves" but either they were not "allowed it" by their profession or they denied it to themselves.

...we sort of decided to...discontinue it I think because people weren't being allowed I think to be freed up to come, be able to express things, and have a bit of time out afterwards...(Jane)

Jane's extract echoed Nicole's in medical staff not "*being allowed*" to attend a support group. Jane raised issues of pressures on the ward with time and staffing. The nurses wanted to attend and Jane reflected levels of vicarious traumatisation from events they reported witnessing on the ward. However, there was a cultural failure in the system to acknowledge that staff should be given time to process and seek help at these difficult times. For Jane, this was disappointing and a challenge to her professional responsibility. As a psychologist, her role was to provide support to those experiencing distress. She saw the nurses were traumatised by their experiences but was unable to offer support, she was helpless.

...Well I've got a proposal [for a psychosocial group] but it's been sat on someone's desk for about a month... we'll see, I think we're meant to be starting it soon... (Anne)

Anne's psychosocial group for the ward staff was designed to offer staff alternative ways to think about children with an emphasis on using the space as a means of support. She felt it was important but her reflection at it being "*sat*" on a desk for a month already, suggested the lack of importance of support systems at a more senior level. Her words "*we'll see*" and "*we're meant to*" highlighted the intended plans but a suspicion that it might not come to fruition. Anne seemed to almost expect to be let down as though she had resigned herself to the inevitable disappointment she was about to face. I wondered if Anne thought that a proposal for a medical group would sit on a desk for a month.

...it's [child dies] happened now and move on...I think sometimes doctors find it is quite tough for them. I mean they have a role where they're the ones you know in charge of the treatment and that must be hard when someone dies...other people often want them to be there to explain...what's going on... but I think often there isn't so much space for reflection... (Grace)

Grace perceived the doctor's role as difficult when a child died and she showed appreciation for their challenging position in the team. Experiences of the other participants reflected feelings of frustration (Nicole), helplessness (Jane) and disappointment (Anne) in wanting to support medical colleagues in their experiences. Grace experienced the situation as sad and showed sympathy for the doctor's position when a child died. She made sense of their response by connecting it to the pressure of the environment and not having the "space for reflection". Having this understanding seemed to help her when the doctors were matter of fact in stating that a death had occurred and they should move on. She could then better tolerate this approach to death because she had her own explanation for their behaviour.

*...unless you've worked in those roles, it's probably quite hard to appreciate exactly what it is like, so sometimes we used to wonder...isn't this interesting, we provide support, no one provides support for us, there definitely seemed to be an answer which was along the lines of... it's just a psychology job, just get on with it, you know, how hard can it be?
(Georgie)*

Georgie's extract reflected medical staff comments and presented a failure from the team to understand the emotional demands of the role of working as a psychologist in an oncology service. The question "how hard can it be?" conveyed Georgie's surprise at the lack of understanding of her role. She experienced this as a lack of support from some of her medical colleagues, which perhaps led her to utilise her psychology colleagues more because they could better understand how hard the role could be. Looking at Georgie's words "it's probably quite hard to appreciate exactly what it is like", she appeared to try to understand the medical staff's point of view. It is possible that Georgie was attempting to appreciate why the medical team may not understand her role and the potential impacts. It is also possible that Georgie was making excuses for their comments because she felt she must just fit in with the environment, adapting to the medical culture to "just get on with it" (see subtheme 4.1.1. - 'Flexing to fit in').

4.1.3. Psychology offering something unique: Team benefits

A sense of offering something unique was felt to some extent by all participants in the study. By using the word 'unique', I am trying to reflect the participants' desire to give something special to the team that only psychology could offer. It appeared that searching for uniqueness was a method for psychology to carve a purpose for itself in an environment where others may have struggled to understand or value the contribution of the discipline. In 'offering something unique' they could 'earn their place' in the medical world. It is likely that in a mental health world, the role and contributions of psychology would have been better understood therefore in a medical team, the participants needed to make their role more explicit.

...so it's quite helpful in that way that we can help contain some of the anxiety that perhaps the paediatricians feel, or the clinical nurse specialists feel, when they are up against some quite challenging experiences. I think that's a helpful role, to help tolerate the level of worry that can be around...(Jane)

Jane used the concept of 'containment' (Bion, 1962) in her account, a process that is prominent in psychotherapy. Stemming from childhood development where the parent acts as a container for an infant's distress and anxiety, containment in a therapeutic sense can develop an individual's capacity to tolerate distressing thoughts and feelings for themselves. Here Jane reflected on offering her unique skills in being able to help contain the emotions of the team. Jane worked away from the ward and in her unique external position, removed from the drama of a situation and not "up against" it, psychology could offer a means to manage and help "tolerate" distress. Jane felt this helped the staff team to better understand the support she could offer, which made her feel wanted and helpful when she visited the ward.

...she's [client] just feeling quite physically unwell...when we were talking about going like this...it felt more about just lacking of energy...she had a sense of hope that things would improve as she felt physically better,

and so through the conversation I guess the physical illness side became more of a picture of why she's like she is...(Grace)

Grace's account highlighted the unique position of the psychologist in a paediatric setting, having space and time just to talk. Other participants spoke about the importance of taking time to reflect and ask questions, which contrasted with their view of the medical approach of rushing in to respond and fix. Grace had been asked by the girl's parents to speak with her because they were concerned about her mental health while in the hospital. Grace experienced this as having a privileged position. She saw that in comparison to the medical staff she had time and space to ask questions and felt lucky to not have been pressured to act. Grace could share with the girl's parents that she was "*just feeling physically unwell*", which she felt was important in reducing the anxiety of the family and the ward staff.

...I think the thing I like about it is if you think of the role of psychology being that often we take that external perspective on things, we kind of try and be slightly removed...just to try and look at things from a different perspective, I think that's the real strength from the job...(Nicole)

Nicole's account mirrored the experiences of other participants, being in a position to provide a unique perspective in the team. In being "*external*", "*slightly removed*" and approaching from "*a different perspective*", Nicole implied that medical professionals can get too close or only have one way of viewing a situation. She experienced this position like Grace as one of privilege and "*strength*". Psychology training promotes the importance of holding multiple views and using a biopsychosocial approach (Engel, 1977) when contemplating an individual's difficulties. The participants emphasised the merits this approach had in providing a team who were likely to think in only one way with alternatives. This in turn made the psychologists feel like a valuable and constructive part of the team.

...people are worried about what they're [the ill child] worrying around or what they're depressed about, or something. When you meet with them

it's just quite often the normal stuff that other young people would be saying, aside from the fact that they are having needles stuck in them all the time, or they're in and out of surgery...(Anne)

Like both Grace and Nicole's extracts, Anne reflected on the different perspective that psychology could offer to the team. They all experienced the role of offering a different way to approach a situation as adding value to the team. In giving their psychology knowledge away, the participants were hoping the medical team would become more accepting of psychology and perhaps incorporate the ideas into their practice. This was perceived as psychology's attempt to infiltrate the medical world. Anne highlighted the unique position as the psychologist to take a step back. She was able to 'see' the girl who had just broken up with her boyfriend rather than relating her experience to illness as other members of staff or the family may have done.

4.1.4. Let's not waste any more time: Feeling the pressures of illness

'Let's not waste any more time' represented four participants' experiences of time pressures within services supporting children with life-limiting conditions. The consequences of medical staff delaying their actions were likely to have a more significant impact compared to psychology postponing their involvement with children and their families. However, as psychology was part of the team and the medical environment, participants found they too were being pulled into the "boiling pot".

...everything about CF [Cystic Fibrosis] feels rushed anyway...they're not going to live as long and we've got to get through lots more things and we've got to make sure that you do everything you need to in a small amount of time...it just feels like they all grow up so quickly and they have to go to adult services and it's a manifestation probably of the wider experience of having CF. You can't hang around...(Ellen)

Ellen's extract clearly illustrated the need to move quickly when working with children with CF. There is an indication in the way that she speaks, in one

long sentence, that there is no time to pause, not even for breath. This is perhaps connected to CF and that the children she was working with did not have as many breaths left as well children did. Ellen compared the transition from children's to adult services for individuals with diabetes and CF and expressed amazement at the speed that CF children are pushed through the system. In relation to other situations, Ellen was more determined not to change her professional self (e.g. not taking the 'expert' position) however, the pressure aspect was a dilemma that she had to adapt to. She had no choice but to fit in with the medical environment and their perception of illness in not being able to "hang around".

...I think with the pressure of a life limiting illness...that kind of context, everybody feels even more urgency, so if this child is only going to live into middle adulthood, so 30/35...you don't want to see them wasting their childhood or their teenage years when they could really be enjoying themselves...(Jane)

Jane's extract too reflected the pressure for all professionals to respond given the shortened life expectancy of the children in their care. She described the ward environment as a "boiling pot", which conjured images of the life-limiting condition adding additional heat to the 'fire' under professionals.

...Work at a much faster pace, which is mirroring their [doctors] pace, and which is constantly difficult as a psychologist, having to be much more working to their time schedules...(Alison)

Alison's reflections illustrated the medical team's approach to responding to illness and the changes she had to make as a psychologist to fit into the team, "mirroring" their world. The need to work to their schedules was "constantly difficult" however, she too was supporting children with life-limiting conditions and their families and had little choice but to respond.

...It's hard because you're in a helping profession and sentimentally you're here to help and then this huge voice of pressure, help!, so it's

really difficult to feed that back but it's about short term discomfort for long term gain really...(Nicole)

Nicole's extract provided a contrast to the other participants in that she was exposed to the pressure to respond but attempted to fight against it. Her words suggested being torn between an instinctive rush to help and a less automatic standing back until the right time. Nicole often commented on the desire for medical staff to get everyone involved and help whereas her professional approach was not to overload families at a difficult time. She responded to the pressure by directly challenging it because she saw the "long term gain" in her tactic. Nicole was perhaps different to the other participants because she had been in her role for a shorter period of time. Her newness may have made her more enthusiastic and determined in her position to force the medical team to adapt to her way of working rather than for her to adapt to their pressures. It was possible that she felt a need to 'start as you mean to go on', stating her position with the team in the hope that they would better understand her approach.

The participants' accounts were interesting and their attempts to make sense of the medical world may have been a way to better understand the different environment. This may have enabled them to feel more comfortable with the changes that were evidently required of their professional selves when based in a hospital setting.

4.2. Nobody is immune: Facing the challenges of working with life-limiting conditions

The second superordinate theme presents the struggles faced by all professionals working with children with life-limiting conditions. The word 'nobody' highlights that no person is able to escape the difficulties. This included the medical staffs that were not constructed as being permitted to be vulnerable.

All the participants experienced challenges in their work especially in facing death with children and their families. They acknowledged and gave in to the prospect of the work being sad and at times very upsetting. In this acceptance, they seemed able to recognise their struggles, which subsequently allowed them to move forward in their work.

Participants recalled experiences in their work that appeared to fall at extreme ends of the 'connection continuum'. At one end was 'overly connected' to the children and their family situation. At these times, the participants overly identified with their plight and became heightened to symptoms of illness in their own bodies and those of their children/families. The other end of the spectrum was being 'disconnected' to the situation. Participants experienced times when either they or their medical colleagues appeared to cut off from their connections with the family. It was perceived by the participants that this disconnection was detrimental to providing good support to children and families in their care. There was an attempt for psychology to stay mindful of disconnection. The disconnection was interpreted by the participants as a subconscious process for both psychologists and the medical team. However, psychologists then became aware of the process after the event in comparison to the medical team who were less conscious of the process.

4.2.1. "You can't stop yourself being affected"

'You can't stop yourself being affected' indicated the struggles for everyone when working with children with life-limiting conditions. Participants reflected on the effect of an illness on the child and their family however, they also considered the impact on themselves and their medical colleagues. In confronting life-limiting conditions, the participants experienced this in a number of different ways including hopelessness, frustration, shock, sadness and feeling de-skilled.

...It was frustrating in some ways...I think I felt quite a lot of pressure from the other professionals and his parents to make him feel better, so he would be happier...there's a very real problem here that wasn't going

away, and I think he was facing that...he'd kind of hit that point where things start getting worse. So...it made me kind of doubt myself I think in my professional skills, and like what am I meant to do here?...(Anne)

Anne was affected in a number of different ways when working with a teenager with a form of muscular dystrophy. She was frustrated, under pressure, doubting her professional skills and feeling hopeless. Anne's professional confidence seemed to erode in the face of physical illness, which perhaps reflected the physical erosion of the boy's body that Anne was working with. Both Anne and the boy were faced with a "very real problem that wasn't going away" and she felt unable to offer anything that could make a difference. The expectations from his parents, other professionals and possibly expectations she put upon herself were that she would be able to help reduce the boy's distress. However, Anne felt this was impossible and made sense of her position as powerless. This resulted in her questioning her own competence and made her doubt herself.

...I think it [presentation] was about death and dying and then in that meeting someone said this girl just died...and then they said the name, and I was really taken aback, but also found it really difficult to carry on the session because it was like, wow, I wasn't expecting that...(Grace)

The potential for hurt hit Grace unexpectedly, emphasised by "wow", when she heard during a training session that a girl she had worked with had died. Despite working in the area for some time, the impact in hearing the news had still caused Grace to be "taken aback", perhaps because it had been unexpected. This extract captures the sense of not being able to escape from bad news in the hospital environment. She is conducting a training session on death and is then hit with the news of a child dying. There is almost no choice but to be affected.

...I think particularly in paediatrics you get a sense of the paediatric team becoming like another family almost...the multi-disciplinary team often

feel quite a closeness and so sometimes those boundaries are ... they become a bit enmeshed, kind of leads into difficulties as well I think because there's a lot of pressure generated or a lot of anxiety generated in the system as a whole...(Jane)

Jane's extract focused on the effects for the hospital team in working with children with life-limiting conditions. The staff developed such "closeness" in their relationships that they often became "another family" to the child, opening them up to emotional vulnerabilities just as their biological family would experience. The medical team were affected by their experiences as Jane's extract highlighted. However, there were few participants who spoke about the impact for the medical team.

4.2.2. This is normal for us: Becoming desensitised to illness

In contrast to the theme above, 'becoming desensitised' was another experience faced by the medical staff and to a lesser extent psychologists working with children with life-limiting conditions. 'Desensitised' because this represents when someone becomes emotionally insensitive due to over exposure or repeated shocks (The Free Dictionary,n.d.). The four participants' who either perceived desensitisation in their colleagues or recognised the phenomenon in themselves suggested that the response came from a familiarity ('becoming') of working in settings used to witnessing suffering. The professionals then became less affected by their experiences as they became 'normal' in their clinical practice.

The participants made sense of their experiences in becoming desensitised to illness for themselves as different to the process for doctors. The participants reflected that with experience, sometimes situations became 'normal' for them. This had prevented them from fully empathising with the family's experience, which induced feelings of remorse. The medical staffs were perceived by the participants to be unconsciously desensitised to their experiences. They made sense of this as some members of the team

become hardened to their work which they felt was problematic for the team and the care they provided to children and their families.

For Nicole, the perceived lack of sensitivity from the medical team was “disgusting” to her. From her perspective it appeared to be the medic’s way of managing especially in the face of death.

...there are so many deaths, that there isn't really proper thought given to it, and I think that's a real problem...when deaths do get discussed...sometimes the tone of the conversation and the way that people carry themselves in that conversation is actually pretty abysmal and disgusting to be honest, it's disrespectful to what's happened, but there isn't that culture of giving yourself time to sit and think about it...(Nicole)

Nicole’s extract highlighted her experience of a stark difference between psychology and medicine in the managing of emotions. Her words “*abysmal*” and “*disgusting*” showed her displeasure and annoyance in how deaths were talked about in the team. Nicole felt that because deaths were commonplace in the setting, there was a desensitising to the experience because it had become the norm. Nicole wanted the child’s death to be treated with respect. Nicole wanted to have “*time to sit and think about it*”, which may have included the use of a reflective space to give time and thought to the child and the professionals’ experiences. Her own views of being respectful clashed with her experience on the ward, which resulted in her feeling anger and frustration.

... the medical doctors are talking oh well they've got this, this treatment, blah blah...it's not going very well...they might end up palliative...it is all talked about in that way, and I guess that's where you do get drawn into that...but it's trying to make sure you keep that awareness ...(Grace)

Grace's use of the words "blah blah" highlighted her experience of how common an occurrence it was for doctors to see sick children. There was a temptation for Grace to be "drawn into" the factual medical language of her colleagues in thinking about children on the ward. This was interpreted as her at times flexing so much to fit in that she became like the doctors. However, in other situations when she can stand up to the dominant discipline, she was able to "keep that awareness". Grace seemed to be likening herself to the doctors sometimes and at other times distancing herself from them and their practice. Grace perhaps felt guilt for sometimes being "drawn into" talking about the illness rather than thinking about the child and their family. This acknowledgment appeared to be important in recognising her behaviour and was interpreted as Grace admitting to sometimes failing to 'see' the child behind the illness but trying to change her behaviour in the future. Grace's extract also highlighted the different constructions of ill health in the medical environment.

...In the particular specialty I work in, this is what they do day in day out, so they [doctors] are just working with a group of children who they know...something like seven will probably die, so that is part of their world...(Alison)

Alison's extract also highlighted the 'normal' experience for doctors but in this case, the 'normal' experience was death. Alison seemed to make sense of this experience by relating it to the common occurrence of deaths within her specialty. Alison showed understanding for the doctor's position, which she had perhaps adopted over time in order to facilitate working alongside them.

...these people, these families, are really having to deal with such challenging issues, I think it becomes so normal for this part of your job, that it's through conversations like this when you're almost confronted by, oh gosh, yes, actually, it is really hard for them to deal with...(Georgie)

In contrast to the other extracts, Georgie focused more on herself becoming desensitised to illness in comparison to the others who generally made reference to the medical team. When Georgie reflected on how she had found talking about her work in the interview, she acknowledged that what was “so *normal*” for her was different to the experience for the family. Georgie was struck by this realisation and “*gosh*” suggested that she, like the medics, was unaware of her detachment but the interview had brought it into her consciousness. In using the interview as a reflective space, Georgie became more aware of her clinical practice, which emphasises the importance of reflection in this type of work for maintaining connections.

4.2.3. “This could be me”: Identifying with families

In contrast to the subtheme of desensitisation above, there were experiences when the participants overly identified with children and their families. Three participants reflected their experiences of becoming hypersensitive to illness. They experienced concerns for either the health of their families or themselves, especially when they were new to their role. In working closely with illness and the impacts, the participants had taken on the guises of the individuals they were working with.

...I've said to them [trainee] it's totally normal to diagnose yourself with literally every disease that comes through the door... (Ellen)

...I remember seeing once a buggy that's the same as my buggy at home and...just feeling a lot more vulnerable I guess...you could relate to the situations a lot more... my daughter, her tummy looks big...kind of worrying about that... has she got a lump?... (Grace)

Both Ellen and Grace’s extracts emphasised how their experiences with families made them turn the situations inwards on themselves, generating concerns for their own health and that of their family. In witnessing the vulnerability of life in their work, both participants appeared to be facing the fragility of their own life. Working with death exposed Ellen and Grace to

concepts of existentialism and their own mortality. They both worked through these anxieties after being in their roles for a period of time. I wondered if all the other participants had experienced something similar in the early days of working with life-limiting conditions but over time they had forgotten this. Ellen and Grace used humour to perhaps make light of their initial reactions however, there was seriousness in their experience that for me felt important to hold on to. It made me wonder how newly recruited psychologists might experience the transition to a hospital setting and the impact it might have on their thoughts and feelings about health. Ellen was a healthy woman and Grace had a healthy child but I wondered how the identification with children and families might change if the psychologist or a member of their family was also experiencing a serious illness.

Interestingly, Grace reported experiences in her work when she became drawn into talking about serious health conditions in a similar way to her doctor colleagues, discussed above in section 4.2.2. This is normal for us. She felt she had become desensitised at times when seeing illness on a regular basis. However, her comment here emphasised the potential for dichotomy in psychologists' experiences. Grace could be desensitised at times but then could overly identify and experience hypersensitivity to illness and the health of her own children at other times.

...you just think this could be me, it can happen to any of us, I think that's the thing with health conditions, anyone can just have one (Anne)

Anne emphasised the non-discriminatory nature of illness in that "*it can happen to any of us*", exaggerating feelings of vulnerability and helplessness. The possibility that this could happen to anyone perhaps contributed to the participants becoming more thankful for their own good health and that of their families, discussed further in the theme below.

The challenges in working with life-limiting conditions were perceived by the participants to be felt by all professionals however, the differences in how the

psychologists and their medical colleagues responded to their experiences were quite different.

4.3. Balancing the rough with the smooth: Finding a way to manage

The third superordinate theme presents the ways in which all seven participants found ways to manage in the context of working with children with life-limiting conditions.

As already discussed in previous themes, all participants described the 'rough' they encountered in their work, feeling helpless, overwhelmed, pressured and positioned in a culture lacking support. During the analysis, it became apparent that all the participants had specific ways to balance the difficult daily experiences ('rough') with something more positive ('smooth'). There were a number of different ways that participants achieved a balance in their work. For some, it was reminding themselves of the skewed perspective of the hospital and the rarity of the conditions they were seeing in their work. For other participants it was focusing on positive stories from the families they had worked with or the importance of having a life outside of the hospital on which to draw strength. The tactics shared by the participants had been developed over time to help prevent them from becoming emotionally impacted or overwhelmed by the nature of their work.

Having support was a key strategy for the participants in managing in the role as psychologists and all seven placed value on having 'support in all shapes and sizes'. Participants felt able to share their experiences with other professionals thus lightening the emotional load on themselves. This made it less likely that they would become overly distressed or impacted by their work. There was comfort in seeking support from other psychologists who had similar experiences, generating a sense of being contained and understood. There was also value placed on support from friends and family who were more removed from the situation but able to offer solace all the same.

4.3.1. Strategies for surviving

'Strategies for surviving' represented the many different practical methods employed by each of the seven participants in surviving the demanding nature of their work. For some, the strategies were conscious techniques however, for others it became apparent when questioned that their strategies were more automatic. The tactics used were often practical and included gaining a perspective on the prevalence of illness, making changes in their careers or utilizing personal characteristics such as humour.

...people with CF give each other germs, beautifully, there's nothing more toxic to a person with CF than another person with CF. Here's some lovely germs and I've been brewing them from me, for you, and here's some more in return...(Ellen)

Here Ellen reflected on a CF clinic she was part of in her service. She often spoke about her experiences in a humorous manner. It seemed to be part of her character but was interpreted also as a way to protect herself against the seriousness and often sadness of the children's conditions that she came into contact with.

...the number of children with cancer...is like 1,000 a year, it's really small, but you don't see that because you're here, and you see all these children on the ward, and so that...put things in perspective...try and un-skew that perspective a bit by doing things that are more in context...(Grace)

Grace reflected again on the unusual nature of the hospital (see 4.1.1. Flexing to fit in) and the skewed perspective in seeing ill children all the time. It was as if the lens that Grace viewed her life through had changed colour since working in the hospital, perhaps from rose tinted when in the 'outside' world, to a dull grey when inside the hospital world. She talked about when she was pregnant she found it hard to have perspective which was interpreted as the general worries she had for the health of her unborn child. However, in trying

to hold onto the “*really small*” number of cases in the country, she was able to “*unskew*” her vision and think about the number of children living with cancer.

...working with quite complex families...there's quite a lot of distress, I think there's a potential to maybe need a break at some point from that, might not mean changing the type of service, it might just mean changing the job...(Anne)

...I think this probably has actually been a strategy for me, to change specialities as well...I want to look at my other interests because actually the balance is not quite right, and so I think probably, yes, moving around has been a bit of a protective strategy...(Georgie)

Both Anne and Georgie described their strategy for surviving as changing their role. They both expressed a desire to stay within the service but to perhaps try working with different conditions. Georgie’s extract suggested that she had been less conscious of her approach, “*I think probably, yes*” but that on reflection it had been helpful in protecting her at work.

4.3.2. Support in all shapes and sizes

‘Support in all shapes and sizes’ represents another strategy that all seven participants utilised in managing their role within the hospital. However, this strategy was sufficient enough to warrant its own theme. The participants reflected a number of times during the interviews on finding solace in support from fellow psychologists, medical colleagues, family and friends. The support received by participants was then able to be reciprocated to children, families in their care as well as colleagues.

...I think it's just using people around you and relying on the expertise of others as well, go to people, using your colleagues, supporting them equally...(Anne)

...I've found the most support within the individual specialisms so each team I belong to are very supportive, you're able to form close

relationships, and they're very good at backing you up with the medical stuff...(Ellen)

Both Anne and Ellen's extracts highlighted the need for the support of surrounding professionals, both psychologists and medical, in helping them to manage in their roles. Anne reflected on managing the sometimes 'rough' isolated nature of her work with the 'smooth' of having her colleagues to rely upon. The support to the participants bolstered them to then provide support to others.

...definitely use of supervision helped to try and I guess contain things for me, so I was then able to do that for the families on the ward, but also ward staff as well...(Georgie)

...I'm lucky that I...sit in a room with other psychologists I think that's really helpful...(Jane)

...there's a group of us...who sit in the same office, and we've got quite good at talking to each other about difficult situations so I would feel I could go and say to one of them this has been a horrible experience on the ward, and talk to them about it, and that's quite supportive...we understand that world together, so that's very helpful...(Alison)

Georgie, Jane and Alison all reflected on the help they received, in having support from psychology colleagues to manage their experiences. Georgie described the demands placed on her to respond quickly to people approaching her on the ward. She was bolstered by the support from her supervisor who provided containment for her, which then enabled her to reciprocate the support to others. Jane and Alison both gave specific examples of needing the support of psychology. Jane felt that she was "lucky" to be surrounded by other psychologists, which was interpreted as her being in a fortunate position which was not always a given when working in a paediatric environment. Jane and Alison felt that it was important sometimes

in being within their own profession. In speaking with someone who knew what they were going through, it enabled them to feel completely understood.

...I think I've always been lucky...I've always had good professional supervision and to feel supported by...professionally by the people around me... But I think also, personally, I have good friends and family... (Nicole)

Interestingly, Nicole also refers to being “*lucky*” when reflecting on support. This was interpreted as having professional support is never a guarantee but instead is down to luck. This could have been experienced by Nicole as a potential for uncertainty when a change in supervisor or colleagues could end her good luck and leave her feeling unsupported. This perhaps led her to appreciate her support more, not taking people for granted because she was aware that it could be taken away. Nicole’s extract did highlight the importance of support not just from colleagues but also from her family and friends. She talked about her husband as being key to keeping her grounded in her work and in having both the support system in work but also when at home, Nicole was bolstered. This enabled her to manage the stresses of the role and maintain an emotional equilibrium.

4.3.3. Looking for a light in the gloom

‘Looking for a light in the gloom’ represents four participants’ need to have something positive to draw upon when working in a dark and sometimes dismal environment. This sub-theme is subtly different from 4.3.1. Strategies for surviving focused on the more practical aspects of managing however this sub-theme focuses on the emotional and deeper level processes used in order to find a balance in the role. The ‘light’ is used to describe a beacon of radiance or hope that the participants could illuminate whenever they felt the need. It provided a guiding brightness that prevented them from becoming lost in a world of sadness and death. For some this was thinking of positive endings in their work, holding on to feelings of being valued by their team and for others it was looking for a light in their personal life.

...I get to see a lot of normal happy healthy...children kind of enjoying themselves and that is really nice because it's a lovely tonic from this hospital where you're kind of reminded that this is not the usual situation, it is some people's reality and it can be really horrible, but you know, there's lots of lovely things with children as well... (Georgie)

The light that Georgie found in the gloom of her work came from her life outside of her job. She described seeing healthy children as a “*lovely tonic*”, balancing out the rough experience of always meeting children who were ill. Looking at the words Georgie used, “*tonic*” conjures up images of being restored, invigorated and refreshed, a pick-me-up for the body, mind and spirit in spending time with healthy children. Georgie, like other participants in their accounts, reminded herself that the hospital environment was “*some people's reality*” but not the experience of the majority which served as a reassurance.

In facing the struggles with families and at times the death of children, the participants were able to look for the positive impact that these experiences had on their lives and positively re-frame the difficult events.

...I do find that I go home and I'm more thankful or grateful and I enjoy more I think than I would if I didn't work...but I just think that you have a bit of perspective around stuff and the way that interacts with me is that I feel grateful for my family... (Jane)

For Jane, the gloom in her work was illuminated by the light of her own family. In her words “*more I think than I would if I didn't work*”, she reflected that if she worked elsewhere or not at all, she would appreciate her home situation less. The contrast of the gloom at work seemed to make the light of her home life seem even brighter for Jane. The contrast between the two environments served to bring “*perspective*” to her world and highlighted her fortunate position that others working elsewhere might not feel so readily. I wondered if having her own positive family experiences enabled Jane to be more empathic in her work with children and their families.

...its been quite a positive experience because the medical team that I work with, they're very receptive to psychological ideas... so in many ways, that's quite nice because you're doing relatively new work with people who are really interested in what you're doing, so its had real positives...(Alison)

Alison found her light from the medical team that she worked with. The value and interest displayed by her medical colleagues was important to her especially in being the only psychologist in the team.

Anne and Ellen did not have children of their own but instead their extracts illustrated how they found light in the gloom from the children and families they were working with:

...I think it's just because these families have a lot of strength...they're so resilient and a lot of parents say this, and I just feel like I give up, but I look at them and they're so strong, that it just makes me stronger, and I think actually you just look and see what people cope with...and it's amazing...so I think for that its probably made me a little bit more motivated... (Anne)

...Going on a paediatric ward and seeing kids playing, yes, they've got tubes in their nose and they're not well, not really as bad, not for me anyway, because there might be some change, there might ... there's a possibility of something...(Ellen)

Anne found her light by drawing illumination from the families that she provided support to. Her words highlighted her admiration for the families in how “*amazing*” she felt they coped with the challenges of illness. Her repeated use of the words “*strength*”, “*strong*” and “*stronger*” conveyed an image contrary to a typical image of a child with a life-limiting condition. Ellen’s extract highlighted the gloom in seeing sick children but she saw the glimmer of light in the “*possibility of something*”. Ellen had a sense of hope for “*some change*”, which acted as her light in the gloom.

4.4. A final reflection...

Alison was the final participant in the study and when asked at the end of the interview if there was anything else that she thought was important to tell me about her work, she made a final comment. I felt this 'gem' (Smith, 2011) shone a light on the phenomena of working with children with life-limiting conditions.

...there is something very positive as well about that sort of experience... it can be very rewarding and particularly the work I do, you do see the flip side of it, you do see families who've been through the most horrendous experiences coming out the other end...really impressive families sometimes who pull through and children who are just amazing, they pull through, extraordinary experiences, and how that really shapes their lives and changes the way they view the world, and that's a very positive side so I always balance that up, there are really difficult times but there are also these amazingly positive experiences...(Alison)

5. Discussion

This final chapter will consider the findings from the study in the context of the research question and will make reference to the existing literature. As the analysis generated areas for discussion that had perhaps not been anticipated, some additional literature not raised in the introduction has been incorporated into this section (Smith, Flowers & Larkin, 2009). A methodological critique of the project will then be presented, followed by implications for clinical practice and potential areas for future research. Concluding comments, final reflections and participant feedback will draw the study to a close.

5.1. Clinical psychologists' experiences of working with children with life-limiting conditions

The objective of the study was to explore clinical psychologists' experiences of working with children with life-limiting conditions. There were four areas of interest in the study. Below the results will be discussed in relation to the experience of the participants and the more specific areas of interest:

- The potential impact of the work
- The possible coping strategies utilised in their work
- The support systems used/would have liked to have had
- Any changes that occurred following their experiences

5.1.1. The impact of the work

The study found that participants were impacted by their work with children in positive and more challenging ways. This fits with previous research that highlights the potential for distress (De Graves & Aranda, 2005; Kushnir et al, 1997; Oehler & Davidson, 1992; Papadatou et al, 1994; Vachon & Parkes, 1984; Woolley, Stein, Forrest & Baum, 1989) but also the rewards and growth

from such work (Davies et al, 1996; Maeve, 1998; Neimeyer, 1998; Papadatou et al, 2002; Yalom, 2008). All the participants reflected some level of impact on themselves in their role with an acceptance that it would be difficult not to be affected by the work. It appeared to be an experience they had little control over and instead of trying to prevent it they instead developed strategies to manage it (see 5.1.2. The coping strategies below). There was also a perception from the participants' accounts that other professionals working in the environment were also impacted by the work.

Impact was portrayed for participants in different ways. For some, it was experienced as overly identifying with families and becoming hyper sensitive to health issues. This experience included diagnosing themselves and their family members with serious health conditions or feeling vulnerable about the possibility that a family member may become ill. This supported anecdotal evidence from Stedeford (1994) who proposed that professionals identify with patients and experience increased anxiety for the health of those close to them following experiences in their work. Other impacts on the participants were feelings of helplessness in not being able to change medical health concerns for children and their families, which was found in other research (Downey et al, 1995; Papadatou et al, 2002; Raeside, 2000; Wells, 1996). The experiences of helplessness in this study and previous research had both been connected to feeling unable to reduce suffering. The death of children was also another impact for psychologists in their work. The findings reflected the potential for hurt in their roles and the feelings of shock and sadness when children they had worked with died.

The results of this study showed that the impact on some individuals had led to them becoming desensitised to the suffering of children and their families. This impact was experienced by participants as being a more medical trait however, one participant bravely admitted that as a psychologist she had recognised becoming desensitised herself at times. This desensitising was a possible result of being surrounded by ill children on a regular basis and the

suffering of families becoming 'normal' to professionals. These findings suggested that doctors and sometimes psychologists could become less sensitive in their work, which in turn could have an impact on other members of the team and the children and families receiving care. Research has shown that healthcare professionals working with dying patients may detach themselves from the dying as a defence against anxiety (Menzies-Lyth, 1959), which Papadatou (2009) suggests is often reinforced in professional training. It is also possible that becoming desensitised was a way to manage the stress of the role, reported in the research to be an extremely stressful area of work for medical professionals (Knazik et al, 2003; O'Connor & Jeavons, 2003; McCloskey & Taggart, 2010). It raises important questions in how desensitisation is recognised and managed amongst healthcare professionals. This is especially important given the potential impact that desensitisation could have on the work of a psychologist e.g. offering therapy and support to children, families and staff teams. A clinical psychologist is perhaps in a more advantaged position in the multi-disciplinary team, given their access to supervision and reflective practice, to be able to consider this issue. This could have implications for clinical practice and will be discussed below.

It appeared that psychologists were not the only professionals impacted by the work but other members of the team were also affected. A few participants presented their perceptions of the impacts to the medical team, often the nurses. They reflected on the close connections of the nursing staff with children and their families. The participants felt that this position of closeness opened up the nursing team to negative impacts if a child became close to death during their care. It is possible that the nurses in the accounts were experiencing "emotional tension" in their work with children and their families (Kaplan, 2000) and were perhaps struggling to balance their feelings at losing a patient with their professional responsibility to manage the situation as shown in previous research (McCloskey & Taggart, 2010; Vachon & Parkes, 1998). The participants also perceived the doctors to have been impacted by the work but they did not express this. This may again be explained by

doctors becoming detached or avoiding dwelling on the experience as Papadatou (2009) suggests. The constructions of different relationships in each profession (psychologist, doctor, nurse) showed what was perceived by the participants to be allowed and not allowed. The nurses were seen as being able to have close relationships with children. Doctors were constructed as more distant, giving advice on treatment but not as personally connected to the children and their families. The participants as psychologists appeared to fit in the space between the two medical positions, trying to maintain professional boundaries but recognising the emotional impacts and personal connections from working with children with life-limiting conditions. The participants made sense of these experiences as being part of their professional cultures where different disciplines followed the different expectations of their roles.

Unlike the research conducted with medical professionals the participants in this study did not appear to make sense of their experience of death as professional failure (Behnke et al, 1984; Hilden et al, 2001; Papadatou, 1997; Papadatou et al, 2002). It is possible that because as psychologists they had not been trained to prolong life but to instead relieve emotional suffering and distress, they had very different experiences when a child died. There were suggestions from a number of participants that doctors however, may have experienced the death of their patients as a failure, which is in line with previous research. Participants perceived doctors as wanting to move on after the death of a child rather than reflect on the experience possibly owing to these feelings of failure in their role and not wanting to dwell on the event.

While the participants did acknowledge emotional impacts, this study did not find support for physical impacts such as chronic fatigue, irritability, headaches (Downey et al, 1995; Raeside, 2000), high stress (Woolley et al, 1989) or burnout (Aiken et al, 2002; Craft & Killen, 2007; Gunderson, 2001; Maslach, 1982; Pines & Aronson, 1988) as other research found. It is possible that participants did not want to reveal these experiences during the

interview however, it is also possible that the difference between the previous research and the current study is related to the differences between professional disciplines. The emphasis on support and supervision from psychology training may have provided the participants in this study with the skills and strategies to manage stresses in the workplace. The medical professionals in the previous studies may have lacked this support. The importance of support discussed below was recognised by all the participants in this study would suggest this was essential in managing difficult experiences. The individual strategies for coping that each participant employed may also have served as protection from detrimental effects to both physical and psychological well-being. This finding has clinical implications, discussed in detail below and suggested that challenging impacts can be managed well in the setting without leading to stress or exhaustion.

Despite the difficulties, the results also found the experiences of the participants to be rewarding in their work, which previous research has also found (Clarke-Steffen, 1998; Davies et al, 1996; Maeve, 1998; Olson et al, 1998; Papadatou et al, 2002; Papadatou et al, 2001; Robson & Beattie, 2004; Rushton, 2005; Woolley et al, 1989). Such experiences are believed to protect professionals from the negative impacts of being exposed to death (Papadatou, 2009), which appeared to fit for the participants in this study. Participants were impacted in an encouraging way by becoming more appreciative and thankful of their own families (also see 5.2.1. The coping strategies below). They were also positively impacted by the strength and resilience of the families they worked with. In being part of success stories, when children battled through difficult experiences, participants were able to take away something constructive from their work which served as a motivation to maintain the position. The positive success stories described by participants are perhaps related to working with children with life-limiting conditions rather than working with children who are about to die imminently. This research allowed for experiences of resilience and wellness to be heard which are perhaps different to other studies which only reflect on the

experiences of working with dying children (Clarke-Steffen, 1998; Hilden et al, 2001; Papadatou et al, 2002; Raeside, 2000). It was important to understand how psychologists made sense of children being unwell but also to hear their experiences of children living positively with their conditions. This allowed for different experiences to be shared and provided insight that could be explored further in future research.

5.1.2. The coping strategies for working with life-limiting conditions

The study found that all participants had developed a range of coping strategies in order to help them in their work with life-limiting conditions, which supports previous research (McCloskey & Taggart, 2010; Papadatou et al, 1999). Coping was managed by balancing the challenging experiences of the role with the positive experiences at work and in their personal lives. Some participants were more aware of their coping strategies than others, which indicated both conscious and automatic strategies (e.g. see Grace's feedback on the results below, p.194) used by individuals in the study. As all participants reflected on their coping techniques, it highlighted the importance of having ways to manage the difficult and often demanding environment in the hospital. This supports existing research highlighting the benefits of having developed coping strategies to manage the challenges of the setting (De Graves & Aranda, 2005; McCloskey & Taggart, 2010; Vachon & Parker, 1984; Whittle, 2002).

As discussed above, the participants acknowledged the potential for personal impact from their work. While they could not control for this, they were able to help manage the level of impact. Some participants used humour as a balance to the seriousness of the children's conditions, a strategy found to be helpful to other professionals in this line of work (Maeve, 1998; Robinson, 1991; Whittle, 2002). Other participants described making changes to their environment as a way to protect them from difficult experiences. Moving jobs was a form of control that the participants could exert over their situation. In

having a break from the environment, this acted as a defence to the potential distress and fatigue of the work. This supports the research that suggested taking time away from challenging working environments can help to manage stress (Vachon & Pakes, 1984). It also supports research from Clarke & Quin (2007) who found that professionals working in paediatric palliative care utilised strategies such as needing “*to take a break every so often*” (p. 1229) to help manage the emotional demands of the role. Focusing on good experiences in their work was another strategy that the study found to be important to participants. In keeping a perspective on the difficulties experienced by families but also the more positive outcomes, this enabled some participants to feel more motivated in their work.

The findings from the study also showed that participants reminded themselves of the offerings and contributions that psychology could make to the medical team. This acted as another coping strategy in their role, helping them to create a more defined role for psychology within the medical world and enabling them to feel more integrated into the team. Despite feeling they had to force their integration into the team at times, participants felt their colleagues were generally accepting of their input.

5.1.3. The support systems used

Support systems were utilised by all participants in the study and the findings showed the importance of having support in their role. This echoed findings from other research studies that have shown support to be helpful in managing the stresses of the environment (Beringer et al, 2007; Maytum et al, 2004). Davies et al (1996) found that nurses working with children facing the end of their lives used peer support and accessed family and friend support, which were all acknowledged as helpful by the participants in this study. The most utilised members for this study’s participants were fellow psychologists. Having support from psychologists enabled the participants to feel they were understood by someone who had very similar experiences and training to

themselves. Participants felt that in being supported and contained, they were then able to reciprocate this to the families they were working with. This finding supported previous research which emphasised the importance of a caring and supportive environment for professionals in order to create a similar environment for patients (McKelvey, 2006).

Findings from this study suggested that generally participants felt they had access to sufficient support. This contradicts a number of other research studies that found paediatric care staff had not always felt supported in their roles (Clarke & Quin, 2007) or felt they lacked support from their supervisors and institutions (McKelvey, 2006). Accounts from this study revealed that participants had supervision or groups within their own discipline that were supportive. The participants faced difficulties however in offering support. They wanted to offer help to their medical colleagues by running staff support groups. Despite previous research showing that having space to think about the personal impact and discuss thoughts and stresses being helpful to medical staff in children's palliative care teams (Bagatell et al, 2002; Gupta & Woodman, 2010) the psychologists' efforts were often in vain. It appeared that nurses were unsure if they were allowed to attend and doctors were rarely present. The perceptions of the participants were that medical staff had less time and space to access support in their role. The participants made sense of this as different healthcare professionals fitting in with the culture of their profession. For the medical staff this culture was interpreted as being focused on maintaining professional behaviour at all times and remaining strong. Stedeford (1994) suggested that in accessing staff support, professionals might have felt judged as inadequate, which may explain these findings. The perceived differences between psychology and medicine in accessing support could also be connected to professional training. Supervision is a form of support, integral to clinical psychology training and practice with clear guidance and minimum standards are set out by the professional bodies (BPS, 2008; Fleming & Sheen, 2003). Supervision is a requirement of psychologists' clinical practice and focuses on reflection as well as more

practical aspects of case management (BPS, 2008). The participants may have regarded accessing support as typical practice however this was not the same for medical professionals, which may have been experienced by psychologists as unusual.

The study suggested that the priority for support was often at the bottom of the senior management's agenda. Despite the obvious demanding nature of the work and the potential for negative impacts on the individual, support groups were not prominent at an organizational level (e.g. Anne's interview – support group proposal sat on a desk). This echoed McCloskey & Taggart's (2010) research that concluded that attention needed to be paid to staff support on a wider level especially given the potential for staff to internalise emotions. Participants in this study experienced the lack of support for medical colleagues as frustrating and a difficulty that existed within the wider culture of the hospitals where they were based. It is possible that psychologists could have a more prominent place in pushing the support agenda for staff teams given their training and theoretical understandings of emotional distress and stress. A psychologist could facilitate staff support but the staff team must also want and understand the value of support, which appears to require a much larger medical culture shift in thinking.

5.1.4. The changes to the self

The participants' experiences in their work led to a number of changes to the self and their clinical practice. The findings showed that some participants had altered themselves more than others. Some participants were more content to make changes and adapt to the environment with other participants more protective over their professional identity and their clinical practice.

Some changes to the self were connected to the impact of the work, already discussed above. The personal changes from their experiences had aroused for some, their sensitivity to ill health for themselves and their own family.

Worden (1991) suggested that in working with the dying, individuals may become more anxious about their own mortality or feared losses, potentially those of their children, which may explain the findings from this study. A more positive change for the participants was their increased appreciation of their family and their relationships following their experiences at work. It is possible that the participants' experiences with ill children, facing an early death led them to re-visit their own life priorities. Papadatou (2009) suggests that experiences in palliative care lead to more appreciation for the common joys of life, which seemed to be evident here. The participants may then have decided consciously or subconsciously to take a more "life is too short" approach, putting more time and effort into their personal relationships and family lives than perhaps they would have otherwise.

Yalom (2008) wrote that death can enrich an individual's life, which may explain the participants' gratefulness for their own families. Doe & Katz (2006) proposed that when exposed to situations where children die before their parents and without the opportunity to live the life they deserve (Rando, 1984) professionals face challenges in their understanding of the world. In being faced with these challenges, the participants may have developed greater feelings of appreciation for their own families. The findings suggested they became more thankful, perhaps in response to the unacceptable nature of a child dying (Morgan, 2009) and the unfairness of the situation.

Findings from this study showed that all the participants in the study felt that they had to adapt themselves in some way to fit into the medical world. For some individuals this was more comfortable than others and the degree to which people had changed differed across the participants. The changes that occurred often included fitting into the environment by altering elements of their practice such as having conversations in corridors and not having structured times and boundaries in settings. These changes for the participants were challenging but seeing limited support for colleagues and responding to the pressures of illness were the biggest difficulties for the

participants. Perhaps the challenge in not having support for all staff was difficult given their own beneficial experiences of having space and time to reflect. And the challenge of facing pressure may have been related to wider societal pressures to respond to the needs of a child with a shortened life expectancy. The participants experienced the medical world as very different to the mental health world where they had completed their training. Mental health work was described as more suited to an outpatient model of care but often participants were working in inpatient settings so they had little choice but to adapt. It is possible that other psychologists entering into this role for the first time may benefit from additional training either during their clinical doctorate or as part of their continuing professional development (see clinical implications below). Psychologists may also benefit from an insight into the medical world, which this study goes some way towards providing.

The findings showed that some participants attempted to stand up against the medical culture and became more assertive or more challenging towards doctors in explaining and standing by their decisions. This was interpreted as their attempt to illustrate to colleagues how as psychologists they might approach things from a different perspective. The participants may have been unused to questions regarding their practice and their professional decisions if they only had experience of mental health settings. At other times participants felt that they had no choice but to respond to the environment especially when feeling the pressure of working with life-limiting conditions. In these situations there was no choice but to give in. The participants balanced their experiences of the environment by making changes to themselves and their practice in some areas but then remaining unchanged and defiant in others. This was interpreted as an acceptable compromise.

5.2. Strengths and limitations

The IPA approach enabled the rich and diverse experiences of each participant to be explored whilst recognising the co-constructed sense making

between the participants and myself as the researcher (Smith et al, 2009). Although each account presented in this project is one possible interpretation of the participants' experiences (Elliot et al, 1999), with different or similar themes generated by another researcher, it is hoped that these interpretations give a voice to the experiences of the participants, previously unheard in the research literature. IPA is an idiographic approach and therefore does not suggest that the findings from these participants should be generalizable or transferable to other clinical psychologists working with children with life-limiting conditions. Instead, this approach offers additional knowledge to the already existing knowledge available (Smith & Osborn, 2008).

It was important to consider my role as a fellow psychologist as well as a researcher and how this might raise challenges to the interview process (Mercer, 2007). The insider/outsider experience appeared to allow the participants to feel relaxed during the interview, with some participants commenting on this feeling at the end of the meeting. I hope that my 'insider' position (Griffith, 1998) as a trainee clinical psychologist helped the participants to feel more able to share their experiences honestly with me, which seemed evident from some of the difficult topics that they raised during the interviews. Although I attempted to separate my own thoughts and ideas during the process, it was possible that owing to my 'insider' position, I assumed elements of the participants' accounts. My position served as both enabling but perhaps also a hindrance and was however, unavoidable. I was also aware that I had worked previously in a paediatric setting and had some exposure to working in a medically orientated environment. While attempting to bracket my own thoughts and beliefs, I acknowledge that my experiences are likely to have impacted on my interpretations of the participants' accounts in some way.

All seven participants in the study were female, White British and were working in hospital settings with children with life-limiting conditions, which provided homogeneity in the sample as recommended by Smith, Flowers &

Larkin (2009). Although the participants were representative of clinical psychologists employed by the NHS (BPS, 2007) it is important to consider the views of those not represented in this group. The experiences of male psychologists working in this area have been neglected as have psychologists from other ethnic backgrounds. This could be considered a limitation of the study therefore it would be useful to have a better understanding of these under represented groups, which could be an area for future research. There were differences between GOSH and SEPT with the former being a specialist children's service and the latter offering more generic paediatric services. There were also differences in the numbers of employed psychologists between the trusts and possibly access to support which could have impacted on their experiences. However, it was felt that protecting the confidentiality of participants by recruiting from two different NHS trusts was of paramount importance.

The participants self-volunteered for the study, which has been taken into consideration. It is possible that the participants who agreed to take part had experiences or comments they wanted to share in comparison to those that did not volunteer. There were also psychologists who offered to take part in the study but were employed by trusts that were not included in this research. The current participants were employed by NHS trusts in the South of England therefore it may be important in the future to cast the participant net further a field to gather psychologists' experiences from other geographic locations.

5.3. Future research

The limitations of the study, discussed above, have generated areas for possible future research. Given the amount of research that has been carried out in the area of medical professionals working within palliative care or with dying children, it would be important for more research to be carried out with other healthcare professionals including psychologists. There is also a gap in the research for professionals working with life-limiting conditions rather than

in paediatric palliative care. Although it did not emerge as a key theme in the data for this study, it is likely that working with children who are not expected to live into adulthood would be a different experience to working with children who are not expected to live through childhood. This was perhaps linked to some of the positive experiences shared in this study where psychologists supported children in times of illness and wellness. It would be important to hear more experiences from psychologists working in areas such as CF where the child would experience periods of wellness and would often survive into adulthood.

As noted in the limitations section, it would be interesting for future research to explore the experiences of male psychologists or those from different ethnic backgrounds to better understand their experiences in this work. It would be interesting to conduct research with participants working in a different part of the country. Both NHS trusts in this study were based in the South East of England where they may have had experiences specific to trusts in this region. It would be useful to conduct a future study perhaps in other locations, including more rural settings.

5.4. Implications for clinical practice

The findings from the study have generated a number of possible implications for clinical practice. Although there are considerations that would be applicable to other disciplines, the implications below will focus more on those relevant to psychologists rather than the wider medical team. This is because the research question wanted to address the gap in knowledge regarding psychologists whereas there is already literature for other healthcare professionals, largely doctors and nurses working in the area, already discussed in the introduction chapter.

One of the important implications from the study was the adaptations needed to adjust from mental health settings to physical health settings. Psychologists working in medical settings often do not have experience of physical health environments as participants highlighted, with clinical training often taking part in mental health settings. It may be important for teams employing psychologists in paediatric settings to provide additional support or training to help those new to the area to adjust to the environment. It may also help to make explicit to psychologists the adaptations potentially needed to fit in with the medical world in order to help with this transition. There may also be a wider implication for clinical psychology training courses across the country in preparing trainees to work in physical health settings. Training programmes may cover modules on working in health settings with some placements available in hospital environments. It may be of benefit for training courses to provide additional experience to trainees who express an interest in working in health settings before the end of the course. This may be possible in a third year elective placement where the trainee would be given the opportunity to experience the differences of the medical world.

The second implication from the study was that working with children with life-limiting conditions could be a demanding experience often impacting emotionally on all those involved in their care, including psychologists. The impact of working with the children was unavoidable, which has implications for the importance support. The participants often utilised supervision or support from their colleagues whilst at work. They also had personal coping strategies such as having interests separate from their professional lives suggested by Stedeford (1994) as important. It may be especially important for supervisors to encourage psychologists to find their own strategies and promote self-care more in this role than perhaps in others. There were individuals in this study who felt the environment was either isolating or pressured at times, which made support more challenging. It may be important for supervisors of psychologists to place more emphasis on support

systems and for consideration to be given to support at a senior management level, which may include psychologists.

The third implication, from the experiences of the participants in this study, relates to the challenging but rewarding nature of the work. The participants' positive reflections of working with life-limiting conditions highlighted that their roles were of personal and professional benefit. This has implications for those psychologists who have previously been put off working in the area or for those who are currently training but had fears about working with such conditions. The participants' accounts provided reassuring experiences in their role that could serve as encouragement for others. In comparison to research carried out with other professionals working in paediatric care, participants did not report feeling burnout (Aiken et al, 2002; Craft & Killen, 2007; Gunderson, 2001; Maslach, 1982; Pines & Aronson, 1988), being overly stressed (Papadatou 2000, 2001a, 2001b, 2002, 2009; Vachon & Parkes, 1984; Woolley, Stein, Forrest & Baum, 1989), depressed or majorly impacted by their work. These research findings may have raised concerns for psychologists contemplating this area of work however, the current findings suggest these negative impacts were less common in their work. The results also highlighted that clinical psychologists are well placed to work with children with life-limiting conditions, their families and the teams that support them because of their personal and professional skills.

A fourth implication for clinical practice relates to the issue of desensitisation within the team. Psychologists could be the professional most suited to addressing concerns of desensitisation in the team owing to their training and use of reflection in supervision and clinical practice. This provides them with the necessary skills and theory to assist team discussions around the process and possibilities for change. It may therefore be an important role for the psychologist in addressing such issues and to help facilitate thinking and new ways of working.

5.5. Conclusion

This study aimed to explore the experiences' of clinical psychologists working with children with life-limiting conditions, an area previously neglected in the research literature. It was hoped that the study would provide a unique contribution to the knowledge base and in using an IPA approach , in-depth experiential accounts of seven clinical psychologists can help to better understand the experience of working with such children and their families.

The main findings from the study highlighted the differences for the participants in working in the physical health world compared to working in mental health settings. This was an experience very different to what their training had prepared them for. Mental health and physical health were two seemingly different worlds. Participants found they had to adapt to the medical world by altering aspects of both their professional and personal selves in order to fit. For some individuals this was struggle, with a need to protect their identity as a psychologist and stand up to the demands made by medicine. And for others, the adaptations enabled them to find a place in the team, which resulted in a more comfortable coming together of the seemingly different disciplines. There was a general sense of psychology having to fit into the medical world rather than medicine adapting to psychology, which participants had learned to tolerate to more or lesser extent over time. A balance seemed important in their work with all participants needing to find equilibrium in their experiences. There were a number of challenges that participants experienced in the hospital environment but these were counteracted by the positive accounts and reflections that arose from their work.

The findings have implications for clinical practice. It may be important for newly qualified clinical psychologists or those already qualified but looking to change settings and work in paediatric environments, to have additional

support or training. This may help to prepare psychologists for potential changes to their personal and professional selves, which may be required when working in a physical health world. The participants did not report burnout or high levels of negative emotional impact as other studies have found. This may be reassuring for those contemplating working in the field that previously had concerns about detrimental impacts.

5.6. My closing thoughts

My journey throughout this project has been one of intrigue and reward. I have felt privileged to hear the individual experiences of each participant and hope that I have done justice to the accounts that they shared with me. I feel that I have been able to give a voice to the often unheard experiences of this small group of people.

At the time of writing this I had some experience of paediatric settings but not of working with life-limiting conditions. I had a multitude of questions before starting the project and feel that my research has provided me with answers to some of my initial curiosities. Interestingly, I have just started my final clinical placement in paediatric palliative care and wonder if my experiences of being immersed in the physical world will be similar to those of my participants. I am looking forward to finding out.

5.7. What they thought

Following analysis, Smith & Flowers (2007) recommend carrying out validity checks of themes with participants. Each of the seven participants were contacted post interview and presented with the superordinate themes and their sub-themes. They were provided with a description of each theme and asked for their comments. Six participants responded with their thoughts, one participant was unobtainable.

“I certainly connect to the ideas of your themes. In the first theme, though, you mention that medical colleagues don't have access to the support that psychologists do...one of the things that always strikes me is that in our dept psychologists provide staff support to the MDT and also facilitate debriefs after a child death. However, who is there to do that for us? The answer is that no-one currently does - I've never been fortunate enough to attend a debrief for a child I worked with, unless I was running it, which brings up all kinds of issues...” (Georgie)

“The meeting of two approaches is a nice way of summarising these ideas - I have observed in my new post psychology becoming involved with the cases that don't fit neatly into the medical box...I like the way this [“Nobody is immune” theme] reflects the dichotomous experience that psychologists in this field can become desensitised to serious illness but on the other hand can also really identify and acknowledge 'this could be me or my family'...Recently I have had the situation arise several times where parents have been referred with mental health concerns after crying when being told their child requires cardiac surgery - I feel that a conversation I have a lot is that what is routine to the medical team is not to a family, and normal responses are often pathologised” (Anne)

“...I found it very easy to get a sense of the 2nd [Nobody is immune: Facing the challenges of life-limiting conditions] and 3rd [Balancing the rough with the smooth: Finding a way to manage] superordinate theme and felt it fitted with my experiences. In particular, in the 2nd theme - the split experienced of on the one hand becoming more desensitised to illness and on the other feeling 'vulnerable'. In the 3rd theme - it was interesting to have the range of coping strategies pointed out - which I use, but not really sat down and thought about before” (Grace)

“Had a look at this, mostly all the themes resonate with me, but particularly the third theme” (Jane)

“I particularly connect with the 1st and 3rd themes and what is discussed in these sections. In considering the title of the first theme I feel that it is not just

psychology and medicine, the divide is mental health and physical health, where everything feels very different, almost like a parallel universe where things look similar but are not the same...The 3rd made me reflect about how some services are set up with a lot of isolation from mental health colleagues ...this has to be balanced out somehow” (Ellen)

“I found the themes you suggest very interesting and all 3 certainly do seem relevant from my perspective. I have been working in this field for a while so found myself wondering if the second and third themes would be equally true for psychologists working in mental health services, or whether they are different when you are working with physical health difficulties?” (Alison).

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7. Appendices

Appendix 7.1. Interview schedule

Qualified clinical psychologists' experience of working with children who have life-limiting illnesses. A qualitative study.

Before starting, go through pre-interview brief (Appendix 8) with participant reminding them of confidentiality unless chief investigator believes the disclosure compromises fitness to practice guidelines (BPS & HPC) or children protection issues, which have not been shared with the appropriate agencies.

Introduction questions relating to the background of the participant and their experience.

1. To begin, I wondered if you could tell me a bit about yourself as a professional? (To build rapport with the participant)
 - a. What brought them to clinical psychology?
 - b. What was their experience prior to training?
 - c. What course & year?
 - d. The development of their career?

2. Can you tell me a little about yourself now as a professional who is working with children with life limiting conditions?
 - a. Where are you working?
 - b. How long have you worked here?
 - c. What stage are you in your career?
 - d. What brought you to this post?
 - e. What conditions do you typically work with?

3. Prior to working in this role, had you had any experience of working with children with life limiting conditions?
 - a. personally
 - b. professionally
 - c. If 'yes' - what was that like for you?
 - d. If 'no' – what was that like to not have any previous experience?

4. Thinking about a child that you wish to talk about today, can you tell me a little bit about them without revealing too much information that might compromise their anonymity?
 - a. Their age, gender, diagnosis? May need to explain condition
 - b. What brought them to be seen by psychology?
 - c. How is/was the therapy going?
 - d. How long do you intend/did you work together?
 - e. Are/were you working with the family also?

5. Can you describe your experience of working with children with life limiting illnesses?
 - a. How do you make sense of this experience?
 - b. What is it like for you personally/professionally?

Questions related to coping with their experiences.

6. Are you able to get support when working in this role?
 - a. Social – friends, family etc
 - b. Work based – colleagues, supervision, support groups etc

7. Could you tell me a little about how you manage the experience of working with children with life limiting conditions?
 - a. What, if anything, helps you to manage the experience?
 - b. What, if anything, gets in the way?

8. Do you think there is an impact on you when working with these children?
 - a. In your personal life?
 - b. In your professional life?

Questions relating to support available to the participant.

9. Are you aware of any support systems that are available to you e.g. via your workplace, other organisations?
 - a. Have you ever used them?
 - b. If 'yes', were they helpful/unhelpful? Why?

10. I wondered if there are any other support structures that would be helpful if they were available to you while working with these children and their families?

Questions relating to potential changes following the participant's experience.

11. Do you think the experiences of working with children with life limiting conditions has had any lasting impact on you?
 - a. As a psychologist
 - b. Personally

12. If so, are there any ways in which you are a different person now?
 - a. Why do you think these changes have occurred (if at all)?

13. Do you think your experience of working with children with life-limiting illnesses has had or will have an impact on you as a supervisor or as a practicing psychologist?
 - a. If 'yes' why do you think this may be?

14. Do you think your experience has had an impact on your desire to stay or leave this area of working?

15. Has your understanding of your experience working in this role changed over time?

a. If so, how?

Drawing the interview to a close.

16. As we are reaching the end of our interview together, I wondered if there is anything else that you feel would be important for me, or other people to know about your experience?

17. Any there any questions that I haven't asked that you were expecting?

18. How have you found talking about your experience today?

Appendix 7.2. Initial email on PPN-Network UK

Afternoon all,

I am a second year Clinical Psychology trainee studying at the University of Hertfordshire and am currently putting together my thesis proposal. I would like to study - How do Clinical Psychologists experience working with children who have life-limiting illnesses?

I would like to carry out semi-structures interviews with qualified clinical psychologists who have experience of this work and would be happy to come and meet with you in work to complete the interview. My initial plan would be for the interview to last approximately 1 hour and interviews would be likely to take place between May - September 2011. The interview would involve questions around personal experiences, the impact of these experiences and strategies and support used in this type of work. As I work in Hertfordshire and am employed by Cambridge & Peterborough Mental Health Partnership NHS Trust (CPFT), I would like to ask for volunteers for the research to be employed by either CPFT or South Essex Partnership University NHS Foundation Trust (SEPT). Applying to two trusts makes the ethics application easier however, I would like to hear from any interested Clinical Psychologists outside of these areas, especially London based trusts, as there is a possibility of opening up the search area.

I will be supervised by Dr Debbie Ford, a Clinical Psychologist working in Luton Paediatrics and Dr Pieter W Nel, Consultant Clinical Psychologist and Academic tutor based at the University of Hertfordshire. I would be grateful if anyone who would be willing to participate and give me an hour of their time to respond off list, to protect confidentiality.

I look forward to hearing from you, Becci Davenport

Appendix 7.3. Information sheet for participants

Qualified clinical psychologists' experience of working with children who have life-limiting illnesses. A qualitative study.

Dear

You are being invited to take part in a research study. This sheet contains information about why the research is being done and what participation would mean for you. Please take time to read it carefully and do ask us if there is anything, which is not clear or if you would like more information.

What is the purpose of the study?

My name is Rebecca Davenport and I am a second year Clinical Psychologist in training at the University of Hertfordshire and I am conducting this research for my 3rd year Doctoral research project.

I am currently investigating qualified clinical psychologists' experiences of working with children who have life-limiting illnesses. For my project I am looking to recruit 6 to 8 people who have experienced therapeutic contact (e.g. in a group, family or individually) with children with life-limiting illnesses. The definition of life-limiting conditions "are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers" (taken from Association for Children's Palliative Care).

The project aims to develop an understanding of how individuals process their experiences. The hope is that the research helps those who offer supervision and training to psychologists working with children with life limiting illnesses to better understand this experience. This may help to develop the support systems that are made available to individuals.

Why am I being invited?

You are being invited to take part in this study because you are a clinical psychologist employed by South Essex Partnership University NHS Trust (SEPT) or Great Ormond Street Hospital for Children NHS Trust (GOSH). You may also be from these trusts and have already expressed an interest in the project following an initial posting on the Paediatric Psychology Network UK (PPN-UK) in January 2011. For the study we ask that you:

- 1) Are a qualified psychologist who is working in a hospital setting with children with life-limiting illnesses
- 2) Have been working in your current post for at least 6 months
- 3) Speak English fluently

Do I have to take part?

No, you do not have to take part. It is your choice whether you decide to participate or not. If you do wish to take part, you will be given a copy of this information sheet to keep and you will be asked to sign a form giving your consent. Even after signing this form you are free to withdraw from the study at any time without giving a reason.

What will happen to me if I take part?

We will ask you to take part in one digitally recorded interview, which will last around 1 - 1½ hours. This will involve meeting with the chief investigator at your work place to talk about your experience of working with children in your clinical practice. Dr Mandy Byron (Joint Head of Paediatric Psychology at GOSH) and associated line managers (SEPT) have given permission for those interested to take part in the study during working hours. You will be contacted at a later date, if you consent, to ask to verify the transcript of the interview and if you wish to, comment on the research findings. You may decline this offer without giving a reason.

What are the possible risks or benefits of taking part?

We do acknowledge that talking about your experiences may be difficult. If there are any questions that are especially upsetting, you do not have to answer them. If you decide to take part, we will ask you to identify someone that you could speak to (e.g. your supervisor) following the interview if you felt it necessary. We will also provide a brief information sheet of local resources available, which may be helpful. We hope that you will enjoy sharing your experiences and that the research project will allow you to have space to reflect on your story. We hope that that information we gather will help clinical supervisors and those providing training to better understand the experiences of working with children with life-limiting conditions and to develop support systems for those working in this area.

What will happen to the results of this research study?

The results from the study will be written up in a PhD thesis for the purposes of gaining a Doctoral qualification in Clinical Psychology. The findings hoped to be shared in academic publications and/or presentations however, any information will be made public following this research will be fully anonymised.

You will be asked if you would like to comment on the analysis of your interview to help with the accuracy of the results but you can decline your involvement.

Who has reviewed the study?

The study has been reviewed by the East of England Research Ethics Committee (Essex) to protect your safety, rights and well-being. This study has been reviewed and given a favourable opinion with no raised objections on ethical grounds.

As the research project is also part of an academic commitment, it has been subjected to a formal and a peer review by the University of Hertfordshire's Doctoral Programme in Clinical Psychology.

Who is supervising the project?

The project is being supervised by Pieter W Nel, Academic Tutor at the University Of Hertfordshire & Consultant Clinical Psychologist (contact details below):

Dr Pieter W Nel

University of Hertfordshire

Health Research Building

College Lane, Hatfield

Tel: 01707 286322

p.w.nel@herts.ac.uk

What if there is a problem?

If you are worried about anything relating to the study please contact the chief investigator (Rebecca - 07825 447423) who will try to answer any questions. If you remain unhappy and wish to complain formally you can contact the project supervisor (Pieter - 01707 286322, details above).

Will my taking part in the study be kept confidential?

All personal information collected during the study will be kept strictly confidential and quotes used in the write up will be fully anonymised, as much as possible, in order to protect the confidentiality of participants. Your name and other identifying information will be kept securely and separately from the digital recording and the data-analysis. Due to the time constraints, an approved transcription service will be used to transcribe your interview. Your recording will be labelled 1, 2, 3 etc. to maintain anonymity. The transcribing service will sign a confidentiality agreement.

Some anonymised sections of the data collected for the study will be looked at by authorised individuals from the University of Hertfordshire (Sponsoring organisation).

These individuals will be:

- 1) A small number (5-6) of clinical psychology trainees in a specialist research group. They will look at some anonymised sections of the interview transcripts during the analysis stage of the project. This helps the chief investigator to check the consistency and validity of the analysis.
- 2) Representatives from the academic and professional assessment bodies will also look at some anonymised sections of the data. This is necessary in order to assess the quality of this doctoral research project.

All the individuals who look at sections of the data will all have a duty of confidentiality to you as a research participant.

Your recording and any identifiable data relating to your participation will be destroyed following receipt of my degree (expected September 2012). The written thesis will be kept for 5 years post research project submission (June 2017). This is in accordance with the University of Hertfordshire's 'Good practice in research' guidelines.

Are there any reasons where confidentiality may be breached?

All participants in the study will be regulated by the British Psychological Society (BPS) and the Health Professions Council (HPS) due to your professional role. If participants disclose any behaviour during the interview which could call into question their fitness to practice as a clinical psychologist, according to professional conduct guidelines written by the professions regulatory body (HPC) and the professional body (BPS), the chief investigator may judge it necessary to inform an appropriate third party without formal consent.

If participants disclose information during the interview relating to child protection concerns that have not already been shared with the appropriate authorities, it would also be necessary for the chief investigator to disclose this information.

Please see the following documents for more information relating to fitness to practice and safeguarding physical and mental well-being:

BPS Professional Practice Guidelines 1995 – Division of Clinical Psychology

[http://www.bps.org.uk/sites/default/files/documents/professional_practice_guidelines - division of clinical psychology.pdf](http://www.bps.org.uk/sites/default/files/documents/professional_practice_guidelines_-_division_of_clinical_psychology.pdf)

HPC Standards of Proficiency – Practitioner Psychologists (2010)

[http://www.hpc-uk.org/assets/documents/10002963SOP Practitioner psychologists.pdf](http://www.hpc-uk.org/assets/documents/10002963SOP_Practitioner_psychologists.pdf)

HPC Standards of conduct, performance and ethics (2004)

<http://www.hpc-uk.org/assets/documents/10001BFBSCPEs-cfw.pdf>

Further information and contact details

If you have any additional questions or any concerns during the study, please contact the chief investigator (details below) or research supervisor (details above). If you are interested in potentially participating in this study please fill in the reply slip included with this information sheet and return to Rebecca Davenport via email.

Should you wish to complain about this study, contact the Independent Complaints Advocacy Service (ICAS) who can support individuals wishing to pursue a complaint about the NHS (see [http://www.pohwer.net/how we can help/independent.html](http://www.pohwer.net/how_we_can_help/independent.html))

The contact details for the areas covered by this study are as follows:

- ICAS Essex Tel: 0300 456 2370
- ICAS North London Tel: 0300 456 2370

Thank you for taking time to read this information. Kind Regards,

Rebecca Davenport - Chief Investigator/Trainee Clinical Psychologist
University of Hertfordshire r.davenport@herts.ac.uk Tel: 07825 447423

Appendix 7.4 Reply slip for participants

Please complete and return by email to the chief investigator -
r.davenport@herts.ac.uk

Name.....

1. **I am not** interested in participating in this project.

2. **I may be** interested in participating in this project and meet the criteria

stated above but I require more information. I consent to you

contacting me (please complete information below).

2. **I am** interested in participating in this project and meet the criteria

stated above. I consent to you contacting me (please complete

information below).

Details (if you have ticked statement 2 or 3):

Telephone number:

Email address:

Suitable days & times for contact:

Appendix 7.5. Consent form

Qualified clinical psychologists' experience of working with children who have life-limiting illnesses. A qualitative study.

Please initial

1. I confirm that I have read and understood the information sheet for this study (V2 19/08/2011). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	
3. I give permission for the research interview I take part in to be recorded.	
4. I understand that anonymised sections of the data collected by this research will be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research project. All will have a duty of confidentiality to you as a research participant.	
5. I understand that anonymised sections of the data collected by this research will be looked at by clinical trainee psychologists in a specialist research group to help with the consistency and validity of the analysis. All will have a duty of confidentiality to you as a research participant.	
6. I understand that quotes from my interview may be used when the findings of the study are reported but that these quotes will not contain any information that could be used to identify me.	
7. I agree that anonymised quotes from my interview may be used in any publications.	
8. I agree to be contacted for my comments on the findings of the study. I am aware I can decline my involvement at any time.	
9. I agree to take part in the above study.	

Name: Participant Signature: _____ Date: _____

Name: Researcher Signature: _____ Date: _____

Appendix 7.6. Pre-interview brief

1. Discuss the purpose of the study

- Experiences of clinical psychologists working with children with life-limiting illnesses.
- Giving a voice to clinical psychologists working in these services.
- Sharing experiences with tutors, supervisors and other psychologists to help build support systems and develop understanding for those working with children with life-limiting illnesses.

2. Plan for interview

- Interview will last for approximately 1.5 hours.
- All interviews will be digitally recorded.
- Participants will all be asked similar questions.
- For the participant to feel able to share experiences and provide examples.

3. During the interview

- You do not have to answer the questions and if you want to pass over questions this is your choice.
- You can ask to stop the interview and take a break if you feel this is necessary.
- You can ask to stop the interview and not continue if you feel this is necessary.

4. Breaching confidentiality (BPS & HPC)

- Remind participants if they disclose any behaviour during the interview, which could call into question their fitness to practice as a clinical psychologist, according to professional conduct guidelines written by the professions regulatory body (HPC) and

the professional body (BPS), the chief investigator may judge it necessary to inform an appropriate third party without formal consent.

- If participants disclose information during the interview relating to child protection concerns that have not already been shared with the appropriate authorities, it would also be necessary for the chief investigator to disclose this information.

5. Protecting your confidentiality

- Your personal details are known only to the chief investigator.
- Your personal details will be kept in a locked cabinet at the University of Hertfordshire.
- The digital recording of the interview will be kept in a password protected file on the chief investigator's computer and recordings will be transcribed by a service bound by confidentiality.

6. After the interview

- If you have any questions following the interview, you will be given time to discuss these with the chief investigator.
- The chief investigator will provide you with a list of support services and useful contact points to take away after the interview.

Appendix 7.7. Interview debrief

7. Discuss the purpose of the study

- Experiences of clinical psychologists working with children with life-limiting illnesses.
- Giving a voice to clinical psychologists working in these services.
- Sharing experiences with tutors, supervisors and other psychologists to help build support systems and develop understanding for those working with children with life-limiting illnesses.

8. Plan for interview

- Interview will last for approximately 1.5 hours.
- All interviews will be digitally recorded.
- Participants will all be asked similar questions.
- For the participant to feel able to share experiences and provide examples.

9. During the interview

- You do not have to answer the questions and if you want to pass over questions this is your choice.
- You can ask to stop the interview and take a break if you feel this is necessary.
- You can ask to stop the interview and not continue if you feel this is necessary.

10. Breaching confidentiality (BPS & HPC)

- Remind participants if they disclose any behaviour during the interview, which could call into question their fitness to practice as a clinical psychologist, according to professional conduct guidelines written by the professions regulatory body (HPC) and

the professional body (BPS), the chief investigator may judge it necessary to inform an appropriate third party without formal consent.

- If participants disclose information during the interview relating to child protection concerns that have not already been shared with the appropriate authorities, it would also be necessary for the chief investigator to disclose this information.

11. Protecting your confidentiality

- Your personal details are known only to the chief investigator.
- Your personal details will be kept in a locked cabinet at the University of Hertfordshire.
- The digital recording of the interview will be kept in a password protected file on the chief investigator's computer and recordings will be transcribed by a service bound by confidentiality.

12. After the interview

- If you have any questions following the interview, you will be given time to discuss these with the chief investigator.
- The chief investigator will provide you with a list of support services and useful contact points to take away after the interview.

Appendix 7.8. Participant resources

Provision of Counselling for staff in the NHS

There are many NHS trusts that provide in-house counselling services for their staff team to offer emotional support. To find out more information on which services are available to you through work, contact your occupational health department.

National organisations

Samaritans – Open 24 hours a day

Telephone 08457 909090

jo@samaritans.org

To find a private counsellor or psychologist, these are suggested websites that might be helpful:

The British Psychological Society

www.bps.org.uk

British Association for Counselling & Psychotherapy

www.bacp.co.uk

Appendix 7.9. Ethical approvals

7.9.1. NRES approval letter



National Research Ethics Service

NRES Committee East of England - Essex

East of England Rec Office 1
Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597693
Facsimile: 01223 597645

Reissued 26/09/11

01 September 2011

Miss Rebecca Davenport
Trainee Clinical Psychologist
Health Research Building
University of Hertfordshire
College Lane,
Hatfield
AL10 9AB

Dear Miss Davenport

Study title: Qualified clinical psychologists' experiences of working with children who have life-limiting illnesses. A qualitative study.
REC reference: 11/EE/0265

Thank you for your letter of 21 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to the East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		21 June 2011
Evidence of insurance or indemnity		02 August 2011
Interview Schedules/Topic Guides	Appendix 2 Interview Schedule 2	19 August 2011
Investigator CV	Version 1.0	21 June 2011
Letter from Sponsor		22 June 2011
Other: Academic Supervisor CV	Version 1.0	21 June 2011
Other: Field Supervisor CV	Version 1.0	21 June 2011
Other: Initial Interest Email	Version 1.0	21 June 2011
Other: Participant Resources	Version 1.0	21 June 2011
Other: Transcribing Agreement	Version 1.0	21 June 2011
Other: Debrief	Version 1.0	21 June 2011
Participant Consent Form: Appendix 5	2	19 August 2011
Participant Information Sheet: Appendix 8 - Pre-Interview Brief	2	19 August 2011
Participant Information Sheet and Reply Slip: Appendix 4	2	19 August 2011
Protocol	2	19 August 2011
REC application	Version 3.1	21 June 2011
Response to Request for Further Information	Email from Rebecca Davenport	21 August 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

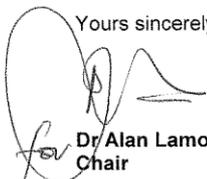
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EE/0265 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Alan Lamont
Chair

Email: Suzanne.emerton@eoe.nhs.uk

Enc: "After ethical review – guidance for researchers" [SL-AR2]

CC: Professor John Senior
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Appendix 7.9.2. GOSH R&D approval



Great Ormond Street Hospital for Children 
NHS Trust

Miss Rebecca Davenport
Cambridge and Peterborough NHS Foundation
Trust
Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Research and Development
Great Ormond Street Hospital for Children NHS Trust
and Institute of Child Health (UCL)
30 Guilford Street
London WC1N 1EH
T: 020 7905 2698
F: 020 7905 2201

03/10/2011

Dear Miss Rebecca Davenport

TITLE: Psychologists working with children with life limiting illnesses

R&D Number: 11BS16

REC reference number: 11/EE/0265

Funder: Own Account

Sponsor: University of Hertfordshire

This project has been granted Management Approval by the R&D Office.

Approval Conditions:

Your research study must adhere to the Department of Health's Research Governance Framework. For more information please see the attached leaflet, further information can be found on the Department of Health website at www.doh.gov.uk.

The PI must inform the R&D office of any changes to the start and end dates of the project, or if there are any changes to the protocol, personnel or ethical status. At the end of the study the PI will be sent a final report form to complete and return to the R&D Office.

During your study you should remember to send in Annual Progress Reports to your Funder and the Research Ethics Committee that provided ethics approval for your study.

If you need statistical support you can contact the Statistical Support Service
<http://www.ich.ucl.ac.uk/ich/html/education/sss/intro.html>.

Attached is a checklist of documentation which you should keep on file. These documents

R&D Approval: 11BS16-Miss Rebecca Davenport

should be retained for 25 years. All patients entered into this study must be registered on the hospital PIMS system.

Yours Sincerely


pp

Subhir Bedi
Senior Research Governance Co-ordinator

Carbon Copy: (PI) Dr Mandy Byron

R&D Approval: 11BS16-Miss Rebecca Davenport

Appendix 7.9.3. GOSH letter of access



Great Ormond Street Hospital for Children 
NHS Trust

Ms Rebecca Davenport
Trainee Clinical Psychologist
Health Research Building
University of Hertfordshire
College Lane Campus
Hatfield AL10 9AB

3/10/2011

Dear Ms Davenport

Letter of access for research

Study: R&D Ref 11BS16

Title: Psychologists working with children with life limiting illnesses

This letter confirms your right of access to conduct research through **Great Ormond Street Hospital for Children NHS Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **3rd October 2011** and ends on **31st September 2012** unless terminated earlier in accordance with the clauses below.

The information supplied about your role in research at **Great Ormond Street Hospital for Children NHS Trust** has been reviewed and you do not require an honorary research contract with this NHS organisation.

You are considered to be a legal visitor to **Great Ormond Street Hospital for Children NHS Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Great Ormond Street Hospital for Children NHS Trust** you will remain accountable to your employer/educational institution **Cambridge and Peterborough NHS Foundation Trust** but you are required to follow the reasonable instructions of **Dr Mandy Byron, Consultant Clinical Psychologist** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Great Ormond Street Hospital for Children NHS Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Great Ormond Street Hospital for Children NHS Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Great Ormond Street Hospital for Children NHS Trust** premises. You must observe the

same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer/educational institution is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Great Ormond Street Hospital for Children NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

We wish you well with your research.

Yours sincerely



Nima Sharma
Research Governance Co-ordinator, Great Ormond Street Hospital for Children NHS Trust

cc: **R&D office at Great Ormond Street Hospital for Children NHS Trust**
Silvija Moss, HR Advisor, Cambridge and Peterborough NHS Foundation Trust

Appendix 7.9.4. SEPT R&D approval letter

Providing Partnership Services in Bedfordshire, Essex and Luton

Our Ref: CM/djt

10 November 2011

PRIVATE & CONFIDENTIAL

Miss Rebecca Davenport
Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Research Governance
Disability Resource Centre
Poynters House, Poynters Road
Dunstable, Bedfordshire, LU5 4TP

Telephone: (01582) 709072
Fax: (01582) 709057

Chair: Lorraine Cabel
Chief Executive: Dr Patrick Geoghegan OBE

Dear Miss Davenport

Re: Psychologists working with children with life limiting illnesses (reference no.: RGG: RGG-2011-01/09)

Thank you for submitting your research application to the South Essex Partnership University NHS Foundation Trust (SEPT). The research governance committee reviewed your project on the 27th October 2011. I am pleased to confirm that the group has approved the project.

In receiving this letter you are accepting that your study must be conducted in accordance with the research governance framework and in line with the Trust's policy on research conduct processes (CLPG19), health and safety and data protection guidelines. If you are unsure about your obligations in relation to these three areas, please contact me immediately. Throughout the course of your research you will be sent monitoring forms and audits. It is important that you fill these in and return them. A failure to do so may result in your approval being withdrawn.

Additionally, brief details of your project (title, aim and project lead), may be posted on our internal website to give other staff a flavour of the research currently taking place in the organisation. Details of research funded by pharmaceutical companies will not be added but all others may be used, unless you notify me of your objection.

If it should be necessary for any researchers to access SEPT, who are not current employees of SEPT, for the purposes of this research project, they will be required to have a Letter of Access issued beforehand. Please advise this office of any external researchers who may need a Letter of Access at your earliest convenience.

At the end of your study, please forward a copy of the final report to me, together with presentations or publications relating to the project so that I can keep an accurate record of the outcomes of research in our area.

Cont'd

www.SEPT.nhs.uk



South Essex Partnership University 
NHS Foundation Trust

We wish you every success for your study. Please do not hesitate to contact me if you require any further assistance during the project.

Best wishes.

Yours sincerely



Cherie Morgan
Research Assistant to
Prof G A Kupshik
Joint Chair of Research Governance Approvals Group

Cc by email:
Dr Rasha Mechaieil, SEPT
Dr Debbie Ford, Local Collaborator, SEPT

Appendix 7.10. Transcription Agreement

REC Reference 11/EE/0265



TRANSCRIBING AGREEMENT (Version 1): 21st June 2011

Doctorate in Clinical Psychology
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non disclosure agreement is in reference to the following parties:

Rebecca Davenport ('the discloser')

And

HW Secretarial Services ('the recipient')

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and destroy any copies of the recordings they were able to access provided by the discloser.

Signed: *H. Williams*

Name: H. WILLIAMS (HW Secretarial Services)

Date: 20/10/11

Qualified clinical psychologists' experience of working with children who have life-limiting illnesses. A qualitative study (V1) 21/06/2011

Appendix 7.11. Audit Trail – Georgie (Interview 2)

Initial themes from interview 2:

Working with rare conditions	Is it ok for psychology to need support?
Working with the unknown	Drawing on the personal
Medicine not yet available	Feeling unprepared for death
Micro & macro involvement	Little appreciation of the impact
Differences of team working	
Integrating psychology in the team	
Developing a presence	
Variety offers protection	
Not thinking is protective	
A change can be protective	
Getting things off your chest	
The importance of support	
Using indirect support	
Being contained enables containment	
Professional detaching	
Becoming desensitised to death	
The fears for the family	
No choice but to adapt	
Implementing boundaries	
Having to hear the fears	
Illness changes everything	
Helping children to think about health	
The potential for hurt	
Remembering the positives	
Support can be one-sided	
Support lacking priority	

Detailed description of Georgie's interview

Georgie found the experience of being in a medical world very different to her psychology training. She made sense of her working environment as unknown and uncertain for herself and also for the children she saw who often had very rare disorders where medicine had yet to catch up in its understanding of the physical problem. Georgie had experienced the work to be more emotionally challenging when she had first started but over time had developed strategies to prevent her becoming overwhelmed by the nature of the work. She made sense of children's deaths as a rarity and often reminded herself of the skewed, unusual nature of the hospital environment. She used positive stories of children she had helped or experiences from her relationship with her own children to maintain a connection to hope and good health.

At times Georgie found herself detaching from her work. She made sense of this experience as the routine occurrence for her in meeting sick children and their families. However, a stark contrast occurred for Georgie when she was faced with the families' emotions and the sadness of their situation. She was then able to reconnect with the experiences of the family, which was important to her in maintaining sensitivity and empathy in her work.

Georgie offered support to staff teams and experienced a lack of reciprocation for psychology when they required support in return. She made sense of this experience as other professionals' not recognising the potential impact for psychologists. She felt that other professionals constructed psychologists as being strong in the face of adversity and not in need of support. This left Georgie with questions about the inequality of support for staff, experienced as frustrating and unfair.

Georgie (interview 2) - Developing themes

Superordinate theme - The meeting of two worlds: Psychology and medicine coming together		
Emerging theme (clustered)	Subordinate theme	Quotation
<p>Working with rare conditions Working with the unknown Medicine not yet available Micro & macro involvement</p>	<p>The uncertainty: Working without answers</p>	<p>“...the unknown and uncertainty is massively prevalent in all that we do...” (lines 138-141)</p> <p>“She has no name for her condition...it's not a simple case where there's a diagnosis, so even if the diagnosis was really bad, at least you've got an understanding... (lines 431-437)</p>
<p>Differences of team working Integrating psychology in the team Developing a presence</p>	<p>Attempting to integrate</p>	<p>“...some of the language has been incorporated by other professionals” (lines 192-194)</p> <p>“...developing another language... it allows a potential for joint working and...also contributes to be a valued member of a truly multidisciplinary team...” (lines 198-202)</p>
<p>No choice but to adapt Implementing boundaries</p>	<p>Flexing to fit in: Adapting the self</p>	<p>“...a dipping in and out approach...it's not setting up a one hour appointment...”(lines 223-225)</p> <p>“Very different to anything I really felt trained to do,...things like that just didn't really fit, it didn't seem to apply in this setting” (lines 253-255)</p> <p>“because of your ongoing presence in the ward, people being able to come up and talk with you that was something quite new for me (lines 273-275)</p>

Superordinate theme – Balancing the rough with the smooth		
Emerging theme (clustered)	Subordinate theme	Quotation
<p>Getting things off your chest The importance of support Using indirect support Being contained enables containment</p>	<p>The importance of support</p>	<p>“...someone in our department has a role of thinking about social events so...in an indirect way, kind of some team bonding does help, we can support each other better, we get to know each other better” (lines 623-626)</p> <p>“My colleague. I'd say...she was probably the greatest source of support. Supervisor. Partner. And friends” (lines 656-657)</p>
<p>Remembering the positives Drawing on the personal</p>	<p>“A lovely tonic”</p>	<p>“I get to see a lot of normal happy healthy...children enjoying themselves and that is really nice because it's a lovely tonic from this hospital...” (lines 543-545).</p> <p>“there are families I've worked with who have been completely traumatised...but then have come out the other side... thinking about that is really nice...” (lines 549-554)</p>
<p>Variety offers protection Not thinking is protective A change can be protective</p>	<p>A change is as good as a rest</p>	<p>“...people don't tend to stay, in palliative care jobs more than a few years” (lines 537-574)</p> <p>“...I think it is partly a protective thing, to not think about it all the time, day in day out, and could probably drive you a bit mad” (lines 780-787)</p>

Superordinate theme – Facing a challenge: Dilemmas for the Psychologist		
Emerging theme (clustered)	Subordinate theme	Quotation
<p>Support can be one-sided Support lacking priority Is it ok for psychology to need support? Little appreciation of the impact</p> <p>Feeling unprepared for death Having to hear the fears The potential for hurt</p> <p>Becoming desensitised to death Professional detaching</p>	<p>“How hard can it be?” – Needing but not always getting support</p> <p>The potential for hurt</p> <p>A step too removed</p>	<p>“...who does that for us in terms of debriefs or why don't we have a staff support system?”(lines 640-641)</p> <p>“...it definitely did feel one way in terms of the provision ...I think it has felt at times quite one sided...”(lines 661-667)</p> <p>“...we provide support, no one provides support for us...”(lines 689-690)</p> <p>“...the more you kind hear the story and so on, the more potentially you can get hurt...”(lines 485-486)</p> <p>“...you do experience a great deal of sadness yourself in the child's death...”(lines 778-779)</p> <p>“...it might be a horrific experience and how that would feel both to her and to me...” (lines 473-474).</p> <p>“...to see people within that really raw emotional... times like that you're reminded of just how much it means to people” (lines 525-527)</p> <p>“...if you don't remind yourself that whilst this is normal for you...to this family there's this thing that they don't want to deal with, and is highly unusual for them...” (lines 787-789)</p>

Appendix 7.12. - Superordinate themes for all participants

Super-ordinate themes	Sub-ordinate themes	1. Anne	2. Georgie	3. Grace	4. Nicole	5. Jane	6. Ellen	7. Alison
The meeting of two worlds: When psychology and medicine converge	Flexing to fit in: Adapting to medicine	✓	✓	✓	✓	✓	✓	✓
	We do success not support: The lack of support in the medical culture	✓	✓	✓	✓	✓	✓	✓
	Psychology offering something unique: Team benefits	✓	✓	✓	✓	✓	✓	✓
	Let's not waste any more time: Feeling the pressure of illness				✓	✓	✓	✓

Nobody is immune: Facing the challenges of life-limiting conditions	“You can’t help being affected”	✓	✓	✓	✓	✓	✓	✓
	This is normal for us: Becoming desensitised to illness		✓	✓	✓			✓
	“This could be me”: Identifying with families	✓		✓			✓	
Balancing the rough with the smooth: Finding a way to manage	Strategies for surviving	✓	✓	✓	✓	✓	✓	✓
	Support in all shapes and sizes	✓	✓	✓	✓	✓	✓	✓
	Looking for a light in the gloom	✓	✓			✓		✓