



Portfolio for Professional Doctorate in Counselling  
Psychology (DPsych)

**The Experience of Powerlessness:  
A portfolio of work incorporating an empirical  
research study on Parents' Experience of their  
Child being Diagnosed with Cancer**

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## Preface

This doctoral portfolio consists of three individual pieces of work which reflects my training to become a Counselling Psychologist. The seeds of interest and curiosity in the experience of parents' whose child has been diagnosed with cancer were fuelled by my professional experience in working with a few individuals suffering from cancer during my training. What struck me whilst working with these cancer clients was their bravery and strength, despite the immeasurable hurdles they faced in the battle against this disease.

Cancer is one of the most feared diseases of our time and for a parent being told that their child has cancer can be the worst thing to have ever happened to them. The enormity of distress throughout their child's treatment can significantly interfere with the parents' quality of life and ability to function. It is important for the voices of parents to be heard in order to capture the complexity of their experiences and the richness of this phenomenon. This portfolio attempts to explore the many dimensions of the parents' experiences.

The first part of this doctoral portfolio is a qualitative research study exploring the experiences of parents whose child has been diagnosed with cancer. Secondly, a clinical case study that highlights the complexities and challenges when treating a client with Other Specified Feeding and Eating Disorder. Finally, the portfolio concludes with a publishable journal article based on the main research presented in Part A. Although all three pieces of work are independent, they all focus on the topic of feeling powerless. The experience of powerlessness appears to be defined by the perceived loss of control one has over the situation.

This was one of the themes that was discovered within the parents' narrative. Participants expressed that caring for a child with a life-threatening illness like cancer was closely linked to feeling powerless, which stemmed from not being in control and feeling helpless about their child's condition. This theme is the focus of the publishable article, which reveals how participants faced the reality that they no longer have complete control of their child's cancer. Both pieces of work discuss factors that contribute to why their experience of having a child with cancer evokes feelings of powerlessness (i.e. the significant impact and

struggle to contain issues beyond their control) and explores how they adopt self-protective strategies to appear strong in the face of feeling powerless. In the case study, a client diagnosed with an eating disorder strongly valued the sense of self-control she got when she engaged in restrictive eating behaviours to lose weight. Although this had helped the client's self-esteem in the short term, it made her feel more out of control than before as she felt less energetic, thus reinforcing one of her core beliefs that she was "powerless" and "weak". Using a specialised cognitive behavioural model to treat her eating disorder, the focus of the work was to help her realise that this was a vicious cycle that increasingly focused her self-evaluation on her weight and shape and the perceived consequences of losing control over her eating and weight. Therefore, her restrictive eating behaviours had served as a multifaceted coping strategy to help her feel in control and avoid feeling powerless. An overview of each piece is now presented.

### **Part A: Doctoral Research**

This section of the portfolio is an original piece of research that aims to explore, in-depth, parents' lived experiences of their child being diagnosed with cancer. The essence was to capture how parents make sense of their experiences using a qualitative research design. Semi-structured interviews were conducted with eight participants whose child had a cancer diagnosis and were attending a UK oncology unit within the National Health Service. The empirical data was analysed using Interpretative Phenomenological Analysis which focused on the individuals' meaning-making and revealed key themes across the cases. The findings were considered in relation to existing literature relating to this research topic, whilst highlighting the new knowledge created. The study will go on to reflect insightfully on the limitations of the study and useful suggestions for future research and clinical practice.

### **Part B: Clinical Case Study**

This clinical case study provides an example of therapeutic work with a client who presented with a primary diagnosis of Other Specified Feeding and Eating Disorder. It provides a description of a time-limited therapy and demonstrates some of the challenges and complexities involved when working with this client population. The therapeutic work was informed by a specialised form of CBT developed for the transdiagnostic treatment of eating

disorders. Working collaboratively was a fundamental skill to help create a joint formulation of the client's difficulties and inform the choice of interventions throughout supervision and treatment. This work highlights the key content issues and therapeutic techniques employed to help uncover the client's over-valued beliefs about weight, shape and eating and their perceived ability to control them. The client's belief gave her a strong sense of control and had served to protect her from core beliefs (e.g. feeling powerless, weak), in turn inhibiting the possibility of change. The case study concludes with an evaluation of the clinical work and highlights the key learnings obtained when integrating clinical skills with psychological theory. The work aims to demonstrate my competency in my chosen therapeutic model whilst providing a coherent account of my clinical skills, personal and professional self-awareness. To the reader, it gives an in-depth insight into working collaboratively with a treatment resistant client within the CBT framework and encourages a reflective stance when understanding the role of the client and the clinician in the process towards recovery.

### **Part C: Publishable Article**

The final section of this doctoral portfolio presents a publishable article that is a succinct summation of the larger doctorate thesis outlined in Part A. It focuses on the particular theme of 'Powerless' and is intended to be submitted in the European Journal of Cancer Care. This journal aims to encourage a collaboration between all healthcare professionals internationally working across various sectors of oncology, including psychosocial interventions for patients and family members, policy development and service-user involvement in cancer care, to name a few. It highlights the up-to-date issues affecting care for patients throughout their illness trajectory. This journal was selected because it publishes qualitative literature related to the doctoral research question outlined in Part A that have been widely reported on throughout the doctoral thesis. The current findings hope to provide an insightful contribution to the existing literature already cited within this journal that explores families' lived experiences of childhood cancer.

The publishable piece focused on the theme of powerlessness due to the limited available literature exploring the parents' perspective from an interpretative approach. This article

serves to illuminate the impact that feeling powerless had on the parents' lives and how they strove to cope by suppressing their vulnerable emotions to appear strong in order to facilitate their sick child's wellbeing. The findings are considered in relation to existing literature and discuss implication for clinical practice. The publication of this journal article will serve all healthcare professionals, with particular emphasis to Counselling Psychologists, on understanding the complexities of cancer care and how to assist parents through this difficult process. As interpretative qualitative work in this area is still in its infancy and can provide highly valuable and revealing experiences, it is important to continue on the development of robust methods (such as IPA) for examining, analysing and representing parents' experience of their child's cancer.

### **Personal Reflection**

Over the last four years, my training as a Counselling Psychologist has enabled me to hold the identity of a reflective-practitioner, providing me with the opportunity to reflect on and work through my own processes in order to grow as an individual as well as a professional. Listening to the self is a key element in becoming a Counselling Psychologist and this is facilitated through personal therapy. As a requirement of training, I have found my personal therapy to be fundamental in my development and maintenance of self-awareness, enabling me to establish genuine and congruent relationships with my clients. Overall, I feel I have grown as an individual, appreciating my own individuality by exploring myself on a deeper level. Within my personal therapeutic environment, I have reflected on my experience of being raised by Indian parents and have grown to appreciate the diversity that exists amongst us all. Being aware of the uniqueness of individuals, something that I have become more conscious of since moving to London, has influenced my commitment to the underlying humanistic principles within Counselling Psychology. I hope that this doctoral research can convey the unique stories of the participants and is an opportunity for their voices to be heard.

## **Part A: Doctoral Research**

# **An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer: An Interpretative Phenomenological Analysis**

**Supervised by Dr Jacqui Farrants**

## Abstract

Although the survival rates for children with cancer have improved significantly due to biomedicine advancements, the illness nonetheless is devastating and presents significant challenges for parents. Given that parents have an important role in their child's well-being, it is necessary that we develop an understanding of their experiences to better support them. For this purpose, the aim of the current study was to explicate the parents' lived experiences of their child being diagnosed with cancer. Semi-structured interviews were conducted with eight parents attending a UK oncology unit within the National Health Service. The empirical data was analysed using Interpretative Phenomenological Analysis. Four superordinate themes emerged from the data: "Sense-making", "Powerless", "Relationship with Others", and "A Process of Transformation". The findings revealed how parents strove to find purpose and made sense of their shock of the diagnosis. It also appeared that parents felt a loss of control over their child's condition that impacted their lifestyle. Despite their struggles, participants reported on their need to appear strong and resilient to facilitate their child's coping. Parents conveyed the ways in which their relationships with others, both with the healthcare professional and their social network, affected their experiences of having a child with cancer. The findings indicate how parents seek to re-evaluate their values in life, reconsider future relationships and observe the significant changes to their child during their treatment. The findings are considered in relation to existing literature and discuss implication for clinical practice, as well as the limitations and recommendations for future research.

# Introduction Chapter

## Introduction

This chapter will aim to review the existing literature and ways to help conceptualise the parents' lived experiences of their child's cancer. The chapter will begin by providing a note on the terminology used within previous literature to describe some of the conceptual complexities when describing this population and the relevant findings to clarify the terms used within the proceeding text. I will then provide a brief overview of children's cancer with regard to prevalence rates, with particular focus on parents' experiences. I will then discuss and review the research that has investigated the parents' experience of obtaining and disclosure of their child's cancer diagnosis. Because most of the research related to this title has been dominated by quantitative psychological research, I will briefly review these findings and will then go on to balance this with a review of the findings of qualitative research relating to the specific experiences and views of parents affected by their child's cancer. This will contribute to form an alternative area of knowledge. I will then discuss studies relating to the parents' experiences of caring for their child's cancer, how they search for meaning, the impact of childhood cancer, the support received, and the resilience in parents. The review will conclude by summarising what we know so far and provide my rationale for the current study with its relevance to Counselling Psychology.

When selecting the literature for this review, most of the qualitative studies that I came across were from a sociology framework and drew from a social constructionist movement (i.e. the way we think and talk about childhood cancer as a socially constructed phenomenon). This review focused on empirical psychological research and therefore some sociological findings were excluded since I felt they lacked good-quality empirical evidence. For example, research focusing more on the social constructionist movement (e.g. societal discourses of childhood cancer) was not explored in depth. This is not to negate the validity of sociology related to this research title as it has much to offer to our understanding. However, it is important to go beyond these dominant findings and explore the potential offered from a psychological understanding that is yet to be fully exploited and which can contribute to elaborating the parents' experiences in childhood cancer and help inform

policy and practice related to Counselling Psychology. Furthermore, no exclusions were made with reference to the date of the studies.

## **Terminology**

Much of the existing literature on parents' experiences of their child's cancer frequently refers to 'childhood cancer'. There are a number of ways in which one may define 'childhood'. Some theorists propose it to be a biologically constructed category, others focus on the child's relative lesser ability in a variety of domains, and some have chosen to see childhood as a social construct that has more to do with how people define it (Dixon-Woods, Young, & Heney, 2005). Furthermore, the definition of 'a child' and how one may understand the membership of that category is also not so straightforward as some may use external attributes such as age or highlight the significance of biological influences, whereas others will focus on the complex social processes that help differentiate children from adults. Whilst there is a considerable debate about the concept of childhood, the term 'childhood' was chosen for the purpose of this research as it accurately reflects the studies in this literature review. Most research related to this topic uses the terms 'childhood', 'families' and 'parents' but does not offer a heuristic device that discusses the members in this category, leading to an unclear status. They do, however, report on the age of children (within their eligibility criteria), which varies extensively across the existing literature. When reviewing previous research related to this topic, there is an unreliable age range that authors use when defining a 'child' in (e.g. some studies used children aged 13 and younger, whereas others used 18 years or younger). For the purpose of readability, it will not be useful to define every author's age range. Therefore, the term 'children' in this review refers to people 18 years old or younger as this is the highest age limit that researchers used in the primary texts. To not complicate the text, 'parents' and 'families' also require a heuristic device. For the purpose of this research, 'parents' will be referred to as those who see themselves (or are seen by children) as satisfying a parental role and 'families' will be referred to as members of the family (i.e. parents, siblings, and the sick child) in accordance with most eligibility criteria used in previous research in childhood cancer.

As the aim of this research is to focus on parents' experiences of their child's cancer, my orientation towards this particular phenomenon is generally open and reflects the process

and meaning of events. This is consistent with my epistemological position, which focuses on multiple subjective realities rather than claiming there is one generic truth subscribing to a single objective reality. The epistemological position will be discussed at greater length in the Methodology chapter. In an attempt to convey the findings as presented by previous researchers, I will use their terminology, e.g. 'childhood', because this is what has been used in the primary text to convey their research findings. The quantitative research in this area adopts a realist position and I will not assume these findings to represent the generic truth. Also, it is worth noting that qualitative research that interprets parents' accounts should be treated as narratives and in order to remain close to my own epistemological stance of not assuming the absolute truth, such accounts should not be regarded as serving an accurate and objective reality.

## **Overview of Children's Cancer**

In the United Kingdom, there is an average of 1,600 children (aged 0–14 years) who are diagnosed with cancer each year (Cancer Research UK, 2018). Incident rates of childhood cancers have increased in the UK since the mid-1960s as a result of the improvements in diagnosis and treatment (Cancer Research UK, 2018). Significant biomedical advancements over the past five decades have seen dramatic improvements in the survival rates of children diagnosed with cancer (Kastel, Enskar, & Bjork, 2011), with an average of 82% of children being completely cured (Children's Cancer & Leukaemia Group, 2017). By reducing the rate of mortality, research into childhood cancer has increased interest in researchers and healthcare professionals to explore other areas of the illness. Despite such significant medical improvements, childhood cancer remains the most common cause of death in children from a disease-related illness (Children with Cancer UK, 2017).

Cancer in children is recognised as a 'family disease' simply because it can have far-reaching effects on everyone involved, from the sick child to everyone within the family systems (Slade, 2000). Consequently, it is important to acknowledge the identity of individuals within the family unit, who not only have needs of their own but who can also influence and affect children with cancer (Dixon-Woods, Young, & Heney, 2005). Reflecting the widely held belief in western contemporary cultures that the well-being of children is often associated

with the quality of parenting (Dixon-Woods, Young, & Heney, 2005), McKeever and Miller (2004) found there to be growing pressures on mothers of children with a serious illness to conform to traditional ideologies of care where they selflessly dedicate themselves to protect the welfare of their children. It has been found that parents, although not ill themselves, experience many of the effects of chronic illness, such as alterations to their social identity, a compromising of their ability to function in other roles, and adverse implications on their quality of life (Young, Dixon-Woods, Findlay, & Heney, 2002). For this reason, research investigating the experience of parents who are socially and emotionally adjacent to the child is necessary, as they are recognised as the main source of emotional support for children with cancer (Norberg & Boman, 2008).

### **Obtaining a Diagnosis of Childhood Cancer**

The incidence rates for childhood cancer are low. A general practitioner (G.P.) in the UK will on average see a child with cancer every 20 years (Feltbower et al., 2004). Many of the signs and symptoms of the disease are vague, posing significant challenges for primary-care-led services (such as those operating in the UK) to suspect and diagnose cancer. Furthermore, obtaining a diagnosis for a disease that has low index of suspicion can create significant implications for parents as reported in the qualitative studies below.

A study by Dixon-Woods, Findlay, Young, Cox, and Heney (2001) found the process leading up to the child's diagnosis was a significant period for the parents. In their study, 20 parents were interviewed whose children (aged 4 to 18 years) had received a diagnosis of cancer up to 36 months before the interview. Irrespective of how long it had been since the diagnosis, the time before the diagnosis was highly important for parents as illustrated through the detailed and lengthy accounts they gave leading up to their child's diagnosis. The researchers' grounded theory analysis not only showed a change in the way parents viewed themselves from a 'normal parent' to a 'parent to a child in crisis' but saw this period as one being highly traumatic and filled with suffering.

As described earlier, the symptoms of cancer are diverse and non-specific, and as a result parents are likely to be give 'innocent' explanations for them, including viruses, tiredness,

muscle aches or wanting to get out of school. Dixon-Woods et al. (2001) found that some parents initially attributed their child's symptoms to these explanations which they felt could be managed at home for a few weeks unless the symptoms persisted and worsened, in which case they would warrant a quick investigation from the parents. Similarly, Holm, Patterson and Gurney (2003) also found that parents suspected something was wrong because their child had developed medical symptoms including blood in the urine, earache, vomiting and loss of coordination. Furthermore, parents' intuitive feelings also helped them realise that something was wrong with their child when they observed changes in their child's 'normal' behaviour and emotions (such as their child becoming very quiet). This suggests parents are actively involved in monitoring their child's symptoms and play an essential role in initiating consultations with health services to seek help. Parental accounts such as these add depth to the existing qualitative research by providing important information about children that otherwise would be overlooked or hidden, due to the possible sensitivities surrounding the ethical procedures in recruiting children.

Dixon-Woods et al.'s (2001) study further supports the importance in investigating and understanding the meaning parents give to their child's symptoms. In their study, over half of the parents reported to have been involved in disputes with their doctors who failed to make sufficient use of their resources, which in turn caused delay in prompting a referral. Similar findings have been supported by Edgeworth, Bullock, Bailey, Gallagher, and Crouchman (1996) as well as Eiser, Parkyn, Havermans, and McNinch (1994), suggesting parents' intimate knowledge of their child might put them in a better position than health professionals to identify signs and symptoms of some illnesses (Polnay, 1989). On the other hand, parents who delayed in consulting appropriate medical expertise have reported feelings of guilt and remorse (Comaroff & Maguire, 1981) whilst in other cases anger (Yeh, 2003). A number of studies have reported on strategies parents use to convince specialists of the seriousness of the situation, such as persistence in challenging clinicians, using alternative medicine, visiting Accident and Emergency centres (Dixon-Woods et al., 2001; Holm et al., 2003; Levi, Marsick, Drotar, & Kodish, 2000). As a result of increased awareness to detect cancer early within our social discourse (Arksey & Sloper, 1999) and the potential threat to the child's life, it is particularly important to encourage early detection of cancer and for doctors to seek a second opinion if in doubt (Hamre, Williams, Chuba, Bhambhani,

Ravindranath, & Severson, 2000). To help achieve the UK government's commitment to avoid delays in cancer diagnosis and achieve national waiting times for referrals (NHS England, 2014), it is important for both parents to present to their G.P. with their child's symptoms and for the G.P. to identify suspicious symptoms that may be linked to cancer.

A common feature in the studies that report on delays is that parents feel overpowered by the doctors. In particular, the doctors who threaten their identity as credible advocates who act on behalf of their children and challenge the authenticity of their presenting symptoms that warrant medical attention (Holm, Patterson, & Gurney, 2003). These parents have reported feeling excluded from the world of healthcare professionals (Armstrong, 2003) as well as to have had their experiential knowledge and concerns discounted or not taken seriously, causing further delays and considerable distress and resulting some parents being labelled as 'neurotic' by their doctors (Dixon-Woods, 2001; Holm et al., 2003). Parents' experiences of disputes have been reported in primary care settings (Eiser et al., 1994) and continue when they access secondary care services (Dixon-Woods et al., 2001). Although the anger and distress that parents describe from their unfortunate encounters with professionals occurs at the beginning of their care (i.e. when obtaining a diagnosis), evidence suggests their conflicts are limited to specific individuals involved in their child's care (Dixon-Woods et al., 2001). Nonetheless, parents' perceived inadequacy of medical response does not damage the parents' trust and confidence with other medical professionals, as one would expect. It is likely that parents seek salvation from the field of medicine as their only hope for their child's recovery and begin to focus on their relationships with professionals that occur later in their child's treatment rather than in the earlier stages.

However, there are some limitations in studies that have reported on the parents' experience when obtaining their child's diagnosis. For example, Dixon-Woods et al. (2001) highlighted that some of the children in their study had brain tumours and as this is particularly prone to delays in diagnosis, it may impact the validity of the analysis. As their study adopted a qualitative methodology, and was carried out in only one paediatric unit, their findings cannot be generalised. To my knowledge, very little research has highlighted

the positive relationships parents may experience with medical staff, as most research has focused primarily on the negative experiences.

A few studies have tried to explain why the professional-patient relationship is difficult to negotiate when the parent is convinced something is wrong with their child. Strong (1983), Manning (1992) and Goffman (1967) suggest two types of implicit rules of conduct when a patient interacts with a professional: substantive and ceremonial rules. The former governs the disparity of power between people, i.e. professionals and patients, and the latter expresses the polite, well-mannered interactions amongst people that maintain social order. Strong (1979) highlighted that 'ceremonial order' tends to mask the doctor-patient relationship to maintain harmony, thus making it challenging for patients to directly criticise or 'force' doctors to take their concerns seriously. The powerful influences of ceremonial rules may constrain parents in their ability to initiate medical investigation as their intuitive and experiential knowledge is of low status in comparison to biological symptoms that are prioritised by doctors. This theory suggests parents may have to risk and take on an advocacy role by breaking ceremonial rules. Although the rarity of childhood cancer may make it difficult for a general practitioner to initially detect it (and sometimes parents may be adamant that something is wrong even when in fact it is not), the contribution of parents and their insight should be valued.

### **Disclosure of Diagnosis**

The confirmation of a child's cancer diagnosis can be a pivotal moment in a parent's life and one that is widely documented. Due to possible delays (as previously mentioned) and lengthy investigations, this 'waiting and not knowing' period can cause considerable distress to parents (Clarke-Steffen, 1993). Most parents are not prepared to hear the word 'cancer', irrespective as to whether they suspect the diagnosis or not (Whaley & Wong, 1991). Parents often react with shock as they fear the possibility of the death of their child (Schweitzer, Griffiths, & Yates, 2012) and can recall vivid details of the disclosure for years after the event (Woolley, Stein, Forrest, & Baum, 1989).

Eden, Black, MacKinlay, and Emery (1994) administered a structured questionnaire designed to assess each stage of the delivery of information to 23 parents and found all parents experienced feelings of devastation, deep shock, numbness and anger. As a result, nine couples did not ask for further clarification as they could not hear more bad news and 14 wanted to be alone to help them come to terms with the diagnosis. Their findings suggest the emotional state of the parent determines their ability to hear and comprehend bad news. However, as this study used a questionnaire design it may be prone to social desirability bias where respondents may answer the questions in a manner that is favourable to others, as well as researcher bias where authors create questions to retrieve the answers they desire thus restricting the participants from elaborating on their own experiences. The authors expressed some disappointment with the answers provided as they argued that participants struggled with understanding the language of the questionnaire thus causing more confusion and posing more questions for the families. Consequently, this research design is fraught with limitations, which can impact the validity of the research findings.

Dixon-Woods et al. (2001) furthermore found that parents who struggled with obtaining the diagnosis felt relieved or vindicated knowing that at least it could be treated. However, parents who experienced a quick diagnosis felt shocked, stunned and expressing disbelief. This supports other research findings that have found similar emotional reactions, along with expressions of helplessness and possible loss of control (Binger et al. 1969). In Dixon-Woods et al.'s (2001) study, those parents who suspected something to be wrong but did not share their sense of urgency and concern with medical professionals experienced feelings of guilt and self-reproach for not taking on an advocacy role. The study's findings were analysed using a grounded theory to help identify patterns and achieve theoretical saturation from the parents' narratives. Studies in the experiences of obtaining a diagnosis offer great insight into parents' experiences but employ a retrospective design that is vulnerable to memory biases. Despite the above studies with parents reporting feelings of 'shock', none of them focused on the content, that is, how parents made sense of this shock. As a result, literature could benefit from a study using an interpretative design such as IPA.

## **Quantitative Approaches to the Experience of Parents**

Much of the research to date has adopted a realist position using quantitative methods to help characterise parents' experiences of childhood cancer. These traditional approaches have attempted to look at psychological difficulties among parents whilst their child is in treatment or explore late effects upon completion. As previously mentioned, the disclosure of the child's cancer diagnosis can cause significant psychological distress.

Norberg and Boman (2008) found that parents experienced heightened anxiety and depression up to two and half years after their child's diagnosis compared to healthy controls. They indicated that some parents developed considerable vulnerability in developing symptoms such as those expressed in post-traumatic stress disorder (PTSD), including intrusive thoughts, avoidance and heightened arousal of stress. The outcome corresponds to previous studies of intense stress reported in mothers and fathers (Phipps, Long, Hudson, & Rai, 2005) and vulnerability of post-traumatic stress symptoms (PTSS) in mothers (Brown, Madad-Swain, & Lambert, 2003). On the contrary, a more recent study found parents of children with cancer did not show any evidence of increased PTSS relative to parents of healthy children (Jurbergs, Long, Ticona, & Phipps, 2009). However, Norberg and Boman's study was a correlational study and therefore it is not possible to infer causality between the variables. Furthermore, symptoms of anxiety and depression were measured using self-report questionnaires, which are subject to several limitations such as social-desirability bias, participants misunderstanding questions or the fixed choice questions forcing them to answer with limited flexibility of expressiveness, all of which could impact the validity of the research findings.

Parental psychological distress levels have been shown to decrease as a function of time since the child's diagnosis. Poder, Ljungman and von Essen (2008) conducted a longitudinal study, where parents' post-traumatic symptoms were assessed at one-week, two-month and four-month intervals post-diagnosis and they found a decrease in post-traumatic stress symptomology from 33%, 28% and 22% respectively. In a comprehensive meta-analysis of quantitative literature on the psychological functioning of parents, Pai et al. (2007) found that mothers reported greater distress than fathers post-diagnosis, with mothers reporting

higher levels of family conflict compared to mothers of healthy children. The authors assume that mothers may carry a greater burden of care and management of their child, as previous research has found that mothers spend more time with their sick child (Kazak et al., 1996). Some have postulated that mothers could be exposed to numerous illness-related events, which can create further distress (Best, Streisand, Catania, & Kazak, 2001). Other studies have found the child's illness to be stressful for both parents (Frank, Brown, Blount, & Bunke, 2001). However, findings may not be related to parenting and could be due to gender differences when reporting psychological distress. Although most studies suggest distress to decrease when treatment has finished, a small subgroup of parents experience an increase in levels of anxiety when treatment ends (Grootenhuis & Last, 1997; Bruce, 2006). Some parents report increased levels of worry and fear from the risk of relapse after the end of treatment (Klassen et al., 2007). Pai et al. (2007) continued to explore quantitative studies and found a substantial psychological impact on fathers of children with cancer when compared to fathers of healthy children. From a social ecological perspective, they proposed this could have significant implications on not only the functioning but also the development of the child with cancer.

Several methodological limitations in quantitative research that investigate parents' distress, psychosocial adjustment and family functioning limit the conclusions that can be drawn from such investigations. Most of the studies reviewed by Pai et al. (2007) had fewer than 50 participants in each study group. The small sample size could limit the power of statistical significance found between the groups, thereby reducing the variability of the results to the parents' experiences of their child's cancer. Another limitation is that the majority of quantitative studies have selected parents whose children vary in cancer diagnoses (therefore differing in their treatment procedures), at different stages of prognosis, and children at different ages and development stages, all of which could influence how these factors affect the parents' experiences and limit the generalisation of their findings.

Although the findings shed light on clinically important psychological difficulties, the results must be read with caution as less than half of the studies that quantified the difference between groups reported effect sizes (Pai et al., 2007). Presenting effect sizes could help

improve statistical reporting across studies (Fidler et al., 2005). Furthermore, the applicability of PTSD as a diagnosis and conceptually to parents' experiences has been criticised for failing to recognise differences between receiving a diagnosis of cancer and the experience of trauma more generally (Bruce, 2006). Perhaps the important difference is that the experience of having a child with cancer may unfold over a length of time and is often characterised by multiple stressors (e.g. severity of the disease, prognosis, treatment side effects, risk of recurrence), whereas the sense of threat from a traumatic experience often involves a discrete precipitating stressor (such as war, rape or health-related events like traumatic brain injury) as well as a significant threat to one's own life.

Despite the methodological shortcomings in quantitative research, the findings do attract the attention of practitioners to the psychological difficulties experienced by parents. However, much of the quantitative research has focused more on parents' experiences in terms of identifying and measuring psychopathology and less on understanding the meaning that parents give to their experiences of living with a child who has cancer. Parents and their children are more than objects acted upon by external influences. Instead, they are individuals capable of acting in the world and shaping their responses to it. Some researchers have investigated the impact of parents' quality of life by measuring their subjective well-being to provide an outlook on their experiences (Streisand, Braniecki, Tercyak, & Kazak, 2001). However, the applicability of quality-of-life scales to parents' experiences has come into question, as the items have been produced for other purposes instead of attempting to understand parents' narratives of childhood cancer (Dixon-Woods, et al., 2005; Wright, 1993). The next section will thus focus on studies that have used a qualitative approach to explore the complexity of parents' experiences.

### **Caring for a Child with Cancer**

A growing body of research has used various forms of qualitative methodologies to investigate parents' accounts of having a child with cancer. Young, Dixon-Woods, Findlay and Heney (2002) conducted a highly influential narrative analysis on the experiences of 20 mothers of a child with cancer. The narratives demonstrated the significance of a biographical shift in their perception of certainty and control pre- and post-diagnosis.

Having a diagnosis activated a process that required mothers to alter their self-identity and sense of self as they transitioned from a mother of a 'healthy' child to becoming a mother of a child in 'crisis'. The diagnosis brought with it new responsibilities and role expectations of being a carer and a mother, including the need felt by mothers to be physically close to their child at all times to provide 'comfort' as well as 'keep watch'. The authors theorised that much of the obligation of 'proximity' was associated with the social construction of parenting where parents feel responsible for the physical and emotional well-being of the ill child. The mothers emphasised the special bond between a mother and a child as well as the importance of comforting their child – the authors suggested this may be an expression of parental competence when parents realise they have little control over their child's recovery (Young et al., 2002). Mothers also reported an intense emotional interdependence to cooperate with treatment for their sick child, for example helping to administer medication or assisting with unpleasant treatment procedures. However, these obligations came at a high cost as the mothers had to relinquish their employment and educational commitments. The mothers' own quality of life was compromised, and they reported experiencing 'grief' for failing to fulfil their former aspirations. In addition, other studies have also found that mothers experience guilt as well as regret from their inability to fulfil their maternal obligations towards their other children (Yeh et al., 2000; Sloper, 1996).

To fully understand the role of mothers as carers, Young et al. (2002) draw attention to the feminist theory which suggests that motherhood is a key component that influences a woman's self-identity (Boulton, 1983) and helps them manage their lives (Richardson, 1993). According to this theory, mothers identify with having a strong emotional attachment to their child and carry an expectation of maternal self-sacrifice by putting their child before themselves (Richardson, 1993) and working in line with the child's best interest. Young et al. (2002) define motherhood from a social constructionist standpoint as mothers are socially positioned to be responsible for their child's current and future well-being. Furthermore, the notion of self-sacrifice is a powerful discourse in motherhood that parents have to negotiate. However, this theory does exclude other, largely dominant concepts rooted in psychology such as developmental psychology and how these have shaped the current climate around parent and child development. Nonetheless, this study only explored parenting from a mother's perspective and fails to recognise the role of fathers, or

other partners or step-parents, which is just as important if research is to provide an accurate representation of parents' experiences. In addition, most of the qualitative literature reviewed was "couple centric" and did not report findings of single parents. It is important for literature to include other partners and single parents to broaden the applicability of the findings and uncover new findings.

Although literature on fathers' experiences is limited, a small number of studies are beginning to emerge and are challenging previous presumptions of mothers being the primary caregivers (Brown & Barbarin, 1996). In two focus groups, Jones and Neil-Urban (2003) found all ten fathers appeared to share caregiving tasks with their spouses, welcomed sharing their experiences as well as being heard, understood and comforted, and also reported a growing strength in their marital relationships since their child's diagnosis. This contradicts the common misconception in research that mothers remain responsible for childrearing in western societies (Young et al., 2002). Interestingly, the men challenged medical professionals in an effort to advocate for their children. This provides contrary evidence to the proposition outlined by Dixon-Woods et al. (2005). Jones and Neil-Urban (2003) suggest parents may struggle to dispute with medical professionals as they rely on their knowledge as well as resources; therefore, they have to accept the subordinate and compliant role. This phenomenon may be gender specific as Young's et al.'s (2002) study found mothers did find it difficult to challenge medical authority. Literature on maternal practices of caring for a disable child provides an interesting insight into this area. McKeever and Miller (2004) argued that parents knew when to 'pull back' and suppress their displays of anger by acquiring a feel for the medical game as they recognised that their children's survival was dependent on the services of professionals. Young et al. (2002) concur, stating that parents are not abdicating their authority but are engaging in a relationship (with medicine and clinicians) that is underpinned by their belief, trust and faith.

Fathers, too, find themselves in conflicted roles, particularly as they are perceived to focus on their role as the primary financial provider whilst they try to protect their children and family from pain and suffering (Jones & Neil-Urban, 2003). Although the fathers in their study welcomed the idea of sharing emotions, the fathers did express their difficulty with articulating their emotions and suppressed their feelings from their children and spouse to

appear strong and reliable (Jones & Neil-Urban, 2003). Young et al. (2002) also identified that mothers needed to conceal their emotions in the presence of their children and keep them entertained as they believed it was essential to promote their child's psychological health. In addition, mothers felt compelled to maintain a "cheerful" disposition, whilst remaining hopeful, optimistic and strong to manage their own identity as a parental figure and protect their child from potential worry. Charmaz (1991) coined the term "alert assistants" to describe the mothers who would act in invisible ways to protect their child's identity or helping them to represent themselves as 'normal'. Despite the negative medical effects of treatment, mothers negotiated their relationships with their children by allowing their child to engage in recreational activities and help them 'pass as normal'. Children are not merely passive recipients of care, as they actively co-manage the emotional and biographical aspects of their cancer care with their caregiver.

It is necessary to include fathers of children with cancer in studies (Kazak, 2005), as the sociocultural aspects of the healthcare system in the UK can perpetuate the gender roles that exist with the child's care. A few insightful qualitative studies in fathers' experiences of their child's cancer have reported that fathers often felt they 'missed out' on communication, felt like 'outsiders' in the family, and received treatment information second hand (Chesler & Perry, 2001; Faulkner et al., 1995). As a result, these issues could affect healthcare professionals and how they deal with the experience of fathers. These difficulties could be exacerbated by fathers' non-domestic role obligations and the choices they make (e.g. continuing to work in the midst of ongoing medical and family crisis or letting their wives take the caregiving responsibilities). Williams (2002) found how the differences in gender are often implicated when a child becomes ill, as everyone 'just accepts' mothers to take on an active role as a child and household caregiver. Fathers, on the other hand, tend to avoid expressing their intense feelings or use the demands of their work lives as opportunities to distance themselves emotionally from the illness or minimise the significance of the diagnosis (Chesler & Perry, 2001; Reay, Bignold, Ball, & Cribb, 1998).

It is clear that parents undertake a complex set of roles when parenting and caring for a child who has cancer. The cost, energy and skill involved are strategically managed to facilitate their own and their child's well-being. The end result serves as a demonstration of

parents' adequacy, especially when they have little control or power over the illness. However, parents positioning themselves as optimistic and strong, or the media portraying families heroically overcoming cancer with successful coping strategies, could oppress those families that struggle to cope (Rolland, 1997). More qualitative research that elucidates the many dimensions of parents' experiences could help contribute to the understanding of this phenomenon. Capturing the perspective of parents could inform clinicians' practice when helping parents to fulfil their roles and recover their identities as 'adequate' parents.

### **Searching for Meaning in Childhood Cancer**

As discussed, parents' response to the diagnosis can be profound and one that varies from shock to denial. In the face of a diagnosis that is often perceived as a fatal condition (Schweitzer, Griffiths, & Yates, 2012) and the prognosis being distressingly uncertain, parents undertake a reordering of meaning to help them make sense of what has happened. A qualitative study of Iranian children with cancer and their mothers was conducted to identify the psychological challenges they experience with a view to revealing their needs when caring for a sick child. Reisi-Dehkordi, Baratian and Zargham-Boroujeni (2014) interviewed 34 children and 32 mothers and analysed the results using thematic analysis. The problems experienced by mothers were categorised into five main domains: spiritual, psychological, communicational, knowledge and care-related. One of the main problems reported by mothers and children was that they tried to address questions like 'why me?' and felt disconnected with God as a result of the diagnosis, whilst some mothers attributed their child's illness to God's 'divine punishment'. Other researchers have also reported on parents engaging in narratives when trying to question their illnesses with questions such as 'why me' or 'why now' (Pill & Stott, 1982; Tuckett, 1976). Literature on caregivers who suffer from physical health problems has revealed that spirituality gives people hope and helps them express themselves fully during difficult times (Pierce, Steiner, Havens, & Tormoehlen, 2008).

In Dixon-Woods et al. (2001), parents wondered if they were to blame for exposing their child to substances during pregnancy or early childhood that would increase their vulnerability to getting cancer. Indeed, Yeh (2003) interviewed 32 Taiwanese parents and

found parents attributed their child's cancer to their own carelessness in caring, providing an unhealthy lifestyle or the possibility of a genetic inheritance. Parents who were more religious instead explained cancer as a result of their past sins or as God's punishment.

It is clear that people's understanding of health and illness is subjective as it varies depending on personal experiences, culture and social circumstances (Armstrong, 2015). The individual's perception of the meaning of their illness could have implications on how they behave with regard to their child's sickness, and how they engage in treatment, especially when we consider the sociocultural differences amongst cultures. For example, Yeh, Lin, Tsai, Lai, and Ku (1999) found that parents who attributed religious beliefs to the cause of their child's cancer had decided to drop out of their child's treatment in order to search for alternative, religious explanations for their child's illness. Therefore, it is imperative that we understand the individual's meaning-making as it highlights the subjectivity of the role undertaken by parents of children with cancer.

### **The Impact on Parents**

A growing body of qualitative literature has begun to emerge that can serve to help reconsider and develop an understanding of parents' experience when a child has a cancer diagnosis. Research into the psychological and social effects of a child's cancer diagnosis has continued to draw heavily on the psychopathology of the families' experiences and has conceptualised their experiences on 'maladjustment' and 'coping' (Eiser, 1994), while ignoring what is it like for parents to live with a child diagnosed with cancer. As discussed earlier in the chapter, much of the focus has been on the rates of depression, anxiety, coping and post-traumatic stress disorder symptoms amongst parents. Conversely, some qualitative literature surrounding this topic has also addressed positive aspects of the parents' experiences (e.g. personal growth), despite parents being negatively impacted by the disease.

A longitudinal study by Woodgate (2006) explored the narratives of 39 children and their parents in Canada. During the course of the study, each parent was interviewed more than once to validate the themes, mothers being interviewed 117 times and fathers 46 times. In

addition, parents were observed at various sites at the hospital as well as at different points in time. The author described that the core narrative present amongst all accounts was 'life is never the same', which represented their meaning of the story, the interpersonal impact and the language used to describe it. Children receiving a diagnosis of cancer was a major life experience for parents and for the child, as they learned that their world changed forever from an idyllic state to one that was no longer perfect. Embedded within this core narrative were three subthemes: parents experience of multiple losses and ultimate fear of losing their sick child that added to their suffering; families' need to move on and remain resilient; and how parents worried about the risk of relapse and stressed that cancer continued to shape their lives (even if their child was in complete remission). The significant losses that families experienced, such as their unique qualities that connected each other, made surviving the ordeal of cancer more difficult to deal with as their lives were forever different. Although this study illuminates the longevity of the negative effects of childhood cancer on families and children, the findings cannot be generalised to all parents due to the qualitative methodological approach.

Another qualitative study by Bjork, Wiebe, and Hallstrom (2005) aimed to elucidate the families' lived experiences at the diagnosis stage. They interviewed 17 families (parents, children and siblings) using a descriptive inductive design with a hermeneutic phenomenological approach. Their experiences were clustered into two themes, 'a broken life world' and 'striving to survive'. When a child of the family was newly diagnosed with cancer, the family's once secure, safe and well-known world was replaced by fear, uncertainty, chaos and loneliness. More specifically, parents reported an immediate threat to their child's mortality and felt their emotions were 'locked in' as their thoughts ruminated over their child's diagnosis. Parents took on a humble outlook on life as new priorities were set and the family became more important than ever. The families strived to survive immediately after receiving the child's diagnosis in order to feel hopeful, gain as much control as possible to reduce the chaos, and be close to other people to reduce feelings of loneliness. Their positive attitude helped them to cope with feeling powerless in not being able to control their child's illness. Such phenomenological results cannot be understood as universal truths (Dahlberg, Drew, & Nystrom, 2001) but they do deepen the understanding of the family's experiences. Particularly, for example, as it has clinical

implications, to help paediatric oncology nurses and psychologists reduce chaos or loneliness experienced by families at the time of their child's diagnosis.

A similar study was later conducted by Bjork, Wiebe, and Hallstrom (2009), using the same qualitative methodology, to interview parents during the course of the child's cancer trajectory: when the child was diagnosed (findings as above); during the child's cancer treatment; after the treatment was completed. From the 11 families interviewed, the central theme focused on the everyday struggles that families experienced as much of their life was prioritised around the sick child during treatment. Parents, in particular, reported feeling drained and exhausted by the constant demands of the illness; deprived of their normal home life as they felt 'locked up' and isolated during hospital stays, disconnected from the high turnover of hospital staff and also yearning for their life to return to normality (e.g. they felt happy when returning to work). As a result of their child's illness, families experienced a change in their perception about life as they began to appreciate their relationship with others, the support they received from others (even though parents did not always take up the help that was offered), and had a more hopeful outlook about the future.

Although previous research has focused on exploring the family's lived experiences and has provided some insight into experiences of childhood cancer, it seems nonetheless that more research is required to illustrate parents' experiences in particular. A methodological limitation that reflects the current qualitative research studying the families' experiences could limit the conclusions that can be drawn from 'family' studies. Research conducted on 'families' has interviewed a heterogeneous sample (e.g. parents, siblings and the sick child), so there may be a risk of over-emphasising the findings gathered from a particular subset of the population. The current findings may risk over-representing those findings from one group of participants over others, preventing the generalisation of findings to only parents, and potentially questioning the validity of the findings. Therefore, it is clear there is a need for a more homogenous sample to capture and attend to a particular subgroup (i.e. parents) and provide a more faithful representation of the parents' experience of childhood cancer.

A few qualitative studies that have focused on only the parents' experiences have become a welcome addition to the literature. In an Iranian study by Jadidi, Hekmatpou, Eghbali, Memari, and Anbari (2014), the experiences of 18 mothers and four fathers whose children suffered from leukaemia were explored using semi-structured interviews. Using content analysis, parents' experiences were categorised into eight subthemes: *Insolvency* (parents feeling completely hopeless as they could not find a solution to their child's disease); *Knapsack of the Problems* (the socioeconomic problems and family issues parents had to face); *Cancer Secrecy* (parents avoided disclosing the disease to the sick child and instead attributed it to other health conditions like anorexia), *Trust of God* (their only source of support and sense of hope came from God and prayer), *Self-Sacrifice* (parents' complete devotion to support the child during treatment), *Adaptation* (support from friends, relatives and prayer helped parents to adapt to their child's condition), *Medical Malpractice* (errors in treatment or failure to diagnose earlier), and *Hospital Facilities* (availability of facilities to the patients). Most importantly, the authors argued that the main theme to emerge across all parents' account was 'parents a dead-end life'. All parents described the profound impact their child's cancer had had on every aspect of their life and felt as though their lives were being ruined by the disease. Parents were overwhelmed with feeling completely hopeless about their future and struggled to tolerate the haunted images that came when thinking about their child's death.

Research has also found that the diagnosis and treatment of children's cancer can impact parents' marital relationships. Some studies have assessed marital quality since their child's diagnosis. A descriptive, retrospective study on 35 couples reported a decrease in their marital satisfaction within the first year of diagnosis but noticed an increase in their marital strength after two to three years of diagnosis, as assessed by two questionnaires that measured parents' marital quality before and after their child's diagnosis (Lavee & May-Dan, 2003). During their first year, parents reported a deterioration in their sexual life because the majority of their time was invested in their child's needs. Despite the improved marital quality over time, the findings should be interpreted with caution as the authors selected stable couples that attended a family retreat. Another quantitative study on 164 Taiwanese mothers and fathers showed instead significantly higher levels of distress and marital dissatisfaction in mothers during the first two months of their child's diagnosis, whereas

fathers' perception of marital satisfaction did not differ across the illness age (Yeh, 2002). On the contrary, Brody and Simmons (2007) interviewed eight fathers during their child's treatment phase and found that the majority of fathers described their relationship with their partners as having strengthened as they spent more time with their wives and depended on each other for support. However, fathers also conveyed their sense of isolation as their wives spent more time with the sick child, leading to interpersonal friction in the couple.

Communication between couples is an important factor that can impact parents' relationships. Mothers' communication with their spouse appears to facilitate their ability to cope with their child's cancer as it contributes to a decreased sense of burden and improves their spousal relationships (Shapiro, Perez, & Warden, 1998). Similarly, Lavee and Man-Dan (2003) found parents were more satisfied in their marital communication and reported to have strengthened their trust after going through their child's illness.

Furthermore, disruptions in communication can occur from parents being separated due to their child's cancer treatment, if one parent is far away from the family's city of origin. Parents indeed have reported that geographical distance can make it difficult for couples to communicate (even via telephone), especially when they want to express important issues regarding the child's illness or treatment (McGrath, 2001a).

Studies investigating the impact of childhood cancer on parents' relationships do, however, have several limitations and findings should be interpreted with caution. The above studies did not detail factors that could influence the marital communication, e.g. how long the couple were married, pre-existing conflicts, the number of children living at home. While the research can suggest that there is a relationship between communication and parents' relationships, most of the studies (i.e. Shapiro et al., 1998; Lavee & Man-Dan, 2003; Yeh, 2002) were correlational in design, thereby the two variables could only be inferred as associations and not causal.

Overall, quantitative and qualitative studies report considerable variability on marital quality over the course of a child's cancer trajectory (Long & Marsland, 2011). Themes to

emerge from qualitative studies highlight both marital strain (McGrath, 2001b; Reay, Bignold, & Ball, 1998) and improvements to the relationship (McGrath, 2001b; Brody & Simmons, 2007). Despite the demands of treatment that could affect marital quality, qualitative literature has also reported on parents' increased sense of connectivity (Enskar, Carlsson, Golsater, Hamrin, & Kruger, 1997) and the key emotional support that parents express to receive from their spouses such as childcare, financial support, and household responsibilities (McGrath, 2001a, b).

### **Support for Parents of Children with Cancer**

The adequacy of support parents receive from healthcare professionals and others in their social network has been shown to play an important function in mediating the parents' experience of their child's cancer. The experience of support received from healthcare provisions, educational services, community support and workplace environments can have implications for the psychosocial adjustment of parents and can affect their ability to care for their sick child (Von-Essen, Enskar, & Skolin, 2001).

Von-Essen, Enskar and Skolin (2001) conducted a study aimed at describing parents' and nurses' perceptions about the aspects of care and assistance that parents perceive to be important when caring for their sick child. Their content analysis on 114 parents revealed that the majority of parents perceived good care to involve meeting socially competent staff, who were polite and helpful, and receiving honest information about their child's treatment and prognosis. Outside of the hospital care, parents mentioned their need for more emotional support from those people they trust (e.g. friends, relatives, professionals) and instrumental support (e.g. receiving assistance with practical matters like bills, baby-sitting and transportation). However, a third of the parents mentioned that they did not require any assistance. Although the design of this study could be considered robust, it recruited participants that met a wide inclusion criterion (e.g. no limit in time since diagnosis, children with different conditions, different stages of prognosis) that led to a sample of parents with diverse experiences with respect to their child's illness. Research from a more homogenous sample is needed that explores whether the provisions of good care and assistance have an impact on the parents' well-being.

Kastel, Enskar, and Bjork (2011) instead explored parents' experiences of information delivered during their child's first year of cancer treatment. Parents reported that information was not always well adjusted to their needs by clinicians, as most parents were in shock having discovered their child's diagnosis and struggled to absorb large volumes of information. Some parents instead wanted to receive information instantly, whereas others found this problematic and traumatic and required more time to assimilate the information. The authors stressed the importance of considering parents' preferences when receiving information, so that clinicians could help them feel confident, secure and able to cope with the situation. Similarly, Yiu and Twinn (2001) draw a link between providing relevant information to parents and increasing their sense of control whilst reducing insecurity. Increasing dialogue and helping parents understand the diagnosis and treatment can facilitate their successful participation in their child's care by increasing their power and emotional readiness (Corlett & Twycross, 2006; Holm, Patterson, & Gurney, 2003). Such efforts are not exclusive, as clinicians are required to manage cultural differences and language barriers if they are to adjust to the parents' needs and beliefs (Eichner & Johnson, 2003).

Several studies are furthermore beginning to show how organisational aspects of healthcare provision can potentially undermine or support parents. For example, Atkin and Ahmad (2000) explored how parents cope with a child suffering from a chronic illness like sickle cell disorder and they drew on a qualitative methodology to conclude that parents criticised health professionals for their lack of knowledge and concern for their child's condition. The incompetent and unsympathetic approach made it more difficult for parents to care for and cope with their child's condition. These findings were replicated in Reisi-Dehkordi, Baratian and Zargham-Boroujeni (2014) with a sample of 32 Iranian mothers of children with cancer who, through semi-structured interviews, reported that healthcare professionals had inadequate knowledge regarding their children's stage, treatment complications and disease prognosis. In the complex and intensely emotional context of childhood cancer, it is particularly important to identify such problems, as they can threaten (and at times destroy) parents' trust in clinicians (Davies, Salmon, & Young, 2017). Indeed, research in advanced palliative healthcare has stressed that a trusting relationship between the clinician and

patient, a practical and emotional environment for family and friends, as well as a supportive staff can mitigate caregivers' sense of powerlessness and helplessness (Milberg & Strang, 2011).

Furthermore, the role of patient amenities within hospital services can undermine the parents' attempts to care and provide a 'normal' life for their sick child. For example, children receiving poor quality hospital food can raise parental anxiety as it can hinder their caring role and can interfere with promoting a healthy diet during their child's recovery (Dixon-Woods, Young, & Heney, 2005).

Support from family, friends and the wider community can help contribute to the parents coping with and adjusting to their child's cancer. In an Australian study, Schweitzer, Griffiths and Yates (2012) analysed interviews from nine mothers, two fathers and their children twice over a 12-month period using Interpretative Phenomenological Analysis (IPA). Some parents reported on the positive support received from friends and family, which assisted them both emotionally and on a practical level. Other parents instead commented on the accommodating support they received from their colleagues at work (e.g. allowing flexible working hours), whilst others felt relieved to take time out from their child's treatment by going to work. The authors highlighted how one couple from an Asian ethnicity felt their child's illness helped them challenge their perceptions of feeling "different" from the majority Caucasian Australians and as a result, they felt more integrated and accepted in society. As this theme only emerged in one couple and did not reoccur for the whole group, such findings cannot be generalised to all parents who were recruited. Furthermore, the authors mentioned that most interviews were undertaken with other family members being present, which may impact the validity of the data as interviewees may answer questions less truthfully or more favourably in front of others. After reading the primary text, the quality of the interpretations provided little beyond the description of the participants' accounts, and I felt the findings lacked interpretative value. Smith, Larkin and Flowers (2009) stress that IPA is always interpretative and that often researchers can be too cautious when presenting their analyses. Although one's interpretation of findings is subjective, it is however important in order to produce better quality IPA work in an

attempt to make sense of what the participants have said and strengthen the validity of qualitative research.

## **Resilience**

As discussed, previous studies have generally focused on multiple psychological distress and demands that parents face when their child has cancer. It is essential that efforts are made to reduce parental distress as research shows that parents' mental health can affect the sick child's and siblings' quality of life (Kazak & Baraket, 1997; Barrera, Boyd-Pringle, Sumbler & Saunders, 2000). Consequently, it is just as critical to promote positive psychosocial outcomes as it is to reduce the negative psychosocial risk. A body of research has indeed examined how individuals adapt and cope with adversities by examining the resilient properties of families and factors promoting positive outcomes.

Resilience is described as the ability to withstand or bounce back from adversity (Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). However, research has struggled to measure resilience because of a lack of consensus and variability in defining it. One theory argues resilience is defined by inherent characteristics (e.g. self-esteem, optimism) which enable individuals to thrive when confronted with adversity (Conner, 2006; Richardson, 2002). Another theory instead conceptualises resilience to be an evolving process that is inferred by the amount of risk and positive adaptation one experiences following trauma (Luthar, Cicchetti, & Becker, 2000; Rutter, 2006). This evolving process, for example, could be parents adjusting to a new lifestyle, symptoms, maintaining family normalcy during adversity, as well as evolving social support (Rolland & Walsh, 2006; Brody & Simmons, 2007). The final school of thought dominating current literature suggests that resilience should be defined as a positive psychosocial outcome or the absence of psychological distress (Southwick et al., 2014) as resilience is often evident after the experience of adversity (Mancini & Bonanno, 2009). Due to the different perspectives, resilience research has adopted various methodologies and included multiple constructs (like optimism, hope, coping, meaning-making) across a range of client populations, making it difficult to compare research results and precluding techniques such as meta-analysis (Molina et al., 2014).

Rosenberg et al. (2013), for example, conducted small group interviews with 18 bereaved family members, predominately parents, of children with cancer to develop an integrated model for understanding factors of resilience. Their thematic analysis of the parents' responses to their child's cancer experience echoed existing resilience theories. Some family members described their resilience as being built on the foundation of inherent characteristics (e.g. pre-existing social support, recognising cancer being 'out of their control'). Furthermore, they also found resilience to be a process evolving over time as some caregivers described modifiable factors to help them feel resilient (e.g. social support from medical care teams or from local and wider community, changes in their hope and coping strategies or spirituality). As a result of their cancer experience, family members highlighted positive psychosocial consequences as an indicator for resilience (e.g. post-traumatic growth, recognising meaning behind their experience, returning to normalcy). Although parents had lost their child to cancer, they described that the overarching factor for their resilience was the legacy that their child left behind which gave them a sense of purpose to continue in life. Furthermore, all caregivers expressed that there is no single definition for resilience, as it is unique and subjective to one's experience.

This qualitative study later informed Rosenberg, Starks, and Jones's (2014) cross-sectional mixed-method study investigating how well the parents' subjective opinion on resilience aligned with quantitative measures of resilience. The authors administered several quantitative questionnaires to identify factors of resilience to a separate cohort of 88 parents whose child had survived cancer and compared these results to 21 bereaved parents. After completing the questionnaire, parents were asked to write about how their child's cancer had impacted their current lives. They found that 63% of non-bereaved and 52% of bereaved parents were considered "resilient" and had significantly higher personal resilience resources and significantly lower distress scores. However, the authors concluded that only 50% of non-bereaved and 62% of bereaved parents had all three inventory scores aligned with the authors' subjective perceptions of resilience. The research findings indeed underscore the challenges in measuring resilience in parents, and this is a key construct in psychosocial care that can often be recognised by clinicians but difficult to measure.

Research also suggests that those who experience adversity or a serious illness may also experience a positive life change such as new personal strength or increased family closeness and this has been described as post-traumatic growth (Phipps et al., 2015). It has been found that both parents of childhood cancer survivors experience significantly higher frequency of post-traumatic growth than parents whose child has other illnesses like diabetes (Hungerbuehler, Vollrath, & Landolt, 2011). Phipps et al. (2015) carried out a comprehensive assessment of the adjustment in 305 parents of children with cancer and compared these results to 231 parents of healthy children who were demographically similar. Using a structured diagnostic interview, they found PTSD scores in parents of children with cancer were low and did not differ from the comparison parents. Their findings demonstrated the resilience of parents of children with cancer by showing no elevated levels of PTSS rates in contrast to the comparison group. Surprisingly though, they found that parents whose child received a diagnosis five or more years ago showed significantly lower levels of PTSS levels in comparison to parents of healthy children. This supports previous literature suggesting that parenting a child with cancer may increase one's resilience as parents undergo a process that strengthens their ability to adapt and cope with stress (McCubbin, Balling, Possin, Frierdich, & Byrne, 2002). Phipps et al.'s (2015) findings further support this suggestion, as parents of children with cancer reported significantly higher post-traumatic growth scores than parents of healthy children. Indeed, Schweitzer, Griffiths and Yates (2012) further support the presence of parental growth from children with cancer as they found in their study that parents experienced a new appreciation of life and the importance of maintaining close relationships with family members. In particular, they also found that parents appeared to perceive life with optimism when seeing their child return to a sense of normalcy in their daily activities.

### **Rationale for the Current Study**

From this literature review, various themes have emerged highlighting the psychological and existential challenges of parenting a child with cancer. Traditional, quantitative approaches in studying parents' experiences have emphasised the devastating and wide-ranging impact a cancer diagnosis, its prognosis and treatment can have on parents. However, it is important for future research to not limit the dimensions of parents'

experiences or represent them as pathological or deviant (e.g. labelling them with PTSD, depression, maladjustment) as this limits the meaning parents themselves give to their world. The existing quantitative literature in childhood cancer has identified many weaknesses in design methodology that unfortunately limits the conclusions that can be drawn from the current evidence and limits our access to interpretative perspectives that illuminate how parents' make sense of their experiences.

Placing more attention on the subjective accounts of the individuals through rich qualitative data can contribute much to the understanding of parents' experiences. The new and emerging qualitative research on parents and childhood cancer has identified important themes such as the parents' meaning of their child's cancer, the impact of the experience on parents, the support parents receive, as well as the parents' resilience in overcoming this adversity. However, much of this literature has been disappointing in its quality and quantity. Previous research (both quantitative and qualitative) has focused heavily on individual concepts such as parents' ability to cope and adjustment, and has often suffered from poor research design and interpretation (offering little beyond description). Furthermore, much of the existing literature in this area has been researcher-orientated, focusing on what the researcher deems important to explore. Although this body of work has drawn practitioners' attention, it risks providing only a partial account of the parents' experiences (Dixon-Woods, Young, & Heney, 2005). Attempts to capture the depth of their experience and restore the focus to understanding parents' experience has been welcomed by recent literature (Schweitzer, Griffiths, & Yates, 2012) and I intend to continue in this direction. To my knowledge, only a limited number of qualitative studies have been conducted relating to my research topic in the United Kingdom (UK), especially within the structure of the National Health Service (NHS).

The National Institute of Clinical Excellence's (NICE) 'Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer' (2005) recommends that all parents of a child with cancer should have access to expert psychological support to help assess their psychological and social needs during key points on their care pathway. Counselling psychologists (who have had appropriate training and support) are now expected to assess parents' needs and coping skills and provide psychological and emotional

support. However, results from a survey reviewing the psychosocial care available to patients and their parents across the 21 childhood cancer treatment centres in the UK (currently run by a professional body called the UK Children's Cancer Study Group, responsible for the organisation of treatment and care of children with cancer in the UK) found the poorest areas of staff provision were within counselling and psychological support (Mitchell, Clarke, & Sloper, 2005). They found the ratio of patients to psychosocial staff was significant, and very alarming, varying across centres between 132:1 to 1100:1. The results indeed reflect the difficulty practices have in knowing 'when' and 'how' to implement this care as the authors found an absence of psychological assessment and support across centres.

The above results mirror the findings from Macmillan's report, *Worried Sick: The Emotional Impact of Cancer* (2006), which points out that 61% of carers who need emotional information, advice and support do not receive it due to the difficulty in gaining access to it. The guidance covered by NICE is an important development to recognise and advocate for the significance of psychological support for parents across their child's illness trajectory. The role of a counselling psychologist should be to provide psychological therapy to parents who would like support with the wide range of emotions they may experience (e.g. uncertainty, anxiety, trauma, distress) in the hope of improving their well-being. As far as I am aware, there are no NICE guidelines recommending a specific intervention (e.g. CBT) to treat parents of children with cancer. Due to the growing concern for effective programme planning and psychosocial support for parents, it is thus necessary to carry out more qualitative research to develop an idiographic understanding of parents' experiences and so accurately reflect their needs to inform clinical practice within counselling psychology in the UK (Biggerstaff & Thompson, 2008).

Current qualitative literature suggests that cancer in a child can challenge the very essence of the parental role and threaten parents' identity (Young, Dixon-Woods, Findlay, & Heney, 2002; Chesler & Perry, 2001). Although the survival rates for some childhood cancers are as high as 82%, previous literature suggests that parents will remain as cancer 'survivors' as they learn to adjust to their altered self-identity and struggle to accept that they may not be able to fulfil their obligations to always protect their child from an unpredictable, life-

threatening illness like cancer. By attempting to understand and gain knowledge about what parenting is like from the individual's perspective, it may be possible to help parents to fulfil their roles and regain their identities as 'adequate' parents. For the future, this may be valuable to help inform and develop treatment interventions for parents and caregivers so that counselling psychologists can focus on what matters to the client.

### **Aims of the Current Study**

The current study aims to elucidate parents' lived experiences of their child being diagnosed with cancer. The focus is to capture a more detailed and nuanced analysis to understand this phenomenon from the parents' perspective by gaining an in-depth understanding of their experience. As well as providing parents with an opportunity to voice their experiences and offer a platform to be heard, this research hopes to expand the growing body of existing qualitative work by presenting an interpretative study to enrich our knowledge surrounding this phenomenon, and hopefully inform clinical developments for treatment options. With the establishment of NICE guidelines recognising the importance of psychological support for parents throughout their child's cancer trajectory, it is hoped the study's findings could help counselling psychologists working with parents by giving them an opportunity to understand what it is like to have a child with a potentially life-threatening illness such as cancer.

# Methodology

## Introduction

This chapter will address how the study attempts to answer the research question: how do parents make sense of their experiences of their child being diagnosed with cancer. The aim of the research was to provide an understanding of what it is like to live through and make sense of the experiences of parents who have a child with cancer. The study adopted a qualitative methodology of Interpretative Phenomenological Analysis (IPA). This chapter will begin by explaining the rationale for adopting a qualitative research design and then my epistemological standpoint, which informed my choice of methodology. A detailed description of the procedural steps will then be outlined to ensure that this is a rigorous, valid and ethically sound piece of research.

## Rationale for Adopting a Qualitative Research Design

To my knowledge, only a limited number of qualitative studies have been conducted relating to my research topic in the United Kingdom (UK), and this present study aimed to contribute to the current literature on the parents' experiences of their child's cancer.

Current research in the UK has utilised quantitative approaches and these have dominated the field with regard to parental experiences in childhood cancer. Therefore, it was vital that the research methodology used in the current study was exploratory in nature. The orientation towards these experiences within a qualitative methodology is generally open and process-focused, thus enabling in-depth analysis and creating new knowledge for a phenomenon that is poorly understood. Therefore, this study will not look for a cause-effect relationship (i.e. through a quantitative methodology) and will oppose the positivist position which has prevailed among mainstream psychology and which reflects a belief in an objective reality (Langdrige, 2007).

Qualitative methodology aims to explore a rich and diverse account of the individuals' subjective experiences (Willig, 2008). As this study explores the experiences of parents who have a child with a life-threatening illness, a qualitative methodology will be deemed the

most appropriate approach in providing an in-depth understanding of the human phenomenon from the individuals' unique frame of reference, as it presents itself to them (Dallos & Vetere, 2005).

Through the vast array of literature that has explored the experiences of childhood cancer on parents, it was assumed that individuals would construct their world in a unique way that is personally meaningful to them. Therefore, a qualitative research design would be more appropriate than a quantitative approach, as it would seek to engage with the data to gain new insights into the ways in which each parent constructs meaning in their unique world. The rich quality and texture amongst the responses will help identify and embrace the similarities among and differences between the individuals (Willig, 2008).

The findings will hopefully work towards developing a coherent body of knowledge to inform and guide support for parents who play a critical role in the care of their children. Although the research was to improve clinical practice and help the development of psycho/sociological treatment to support parents in the future, another aim was to give participants the opportunity to share their experiences and be heard. Both aims can be achieved through a qualitative research design.

It is important for researchers to be aware of their own epistemological positions, as this can help identify and clarify our own fundamental assumptions about knowledge. Adopting a qualitative approach felt more natural and personally resonated with my own epistemological viewpoint (please see 'Epistemological Position' below) as well as my own values and purpose to create meaningful data (please see "Personal Reflexivity" later). Furthermore, throughout my experience as a Trainee Counselling Psychologist, I have conducted in-depth interviews with my patients to reflect and focus on the human subjective experiences and this naturally aligns with the practice of a qualitative research design. My clinical skill-set has enabled me to work in a highly collaborative manner with my patients and it was hoped that I could draw upon these to achieve promising results for my research and make it an enjoyable experience.

Despite the diverse epistemological positions available, Willig (2012) stresses that the general rubric of qualitative research is to be concerned with the meaning of peoples' experiences and how they make sense of them.

### **Epistemological Position**

Epistemology is a branch within philosophy that has helped humans to question what knowledge is and how it can be acquired to make sense of the world around us (Cardinal, Hayward, & Jones, 2004). It is the epistemological position that informs the methodology which is defined (by Silverman, 1993) as the general approach to studying research topics. To evaluate research in a meaningful way, it is essential to know what its objectives are and what kind of knowledge it aims to generate (Willig, 2013). By stating explicitly the epistemological position of the research one would then use this to guide the selection of the research methodology and presentation of findings (Madill, Jordan, & Shirley, 2000).

It is often difficult to declare one's affiliation with an epistemological label, as Willig (2012) highlights that it can be a challenging task to acknowledge and directly express our assumptions about the world. It is important for the qualitative researcher to acknowledge their own beliefs, assumptions and experiences, as both the participants' and researchers' interpretation of events contribute to the process of making sense of the findings. To understand my own position, I reflected on my own therapeutic practice with my clients and what I thought was important when my clients narrated their subjective experiences. During therapy, I feel my clients consider their subjective accounts to be important and an integral part of understanding the phenomenon, rather than being concerned with the objective truth. When I work with clients' often overvalued and sometimes unusual beliefs, I try to understand the impact this belief has on their life rather than arguing to what extent their beliefs are a true reflection on reality and how "accurate" they are. With this in mind, I do believe that the events that take place in the individuals' life exist, but I also feel that each person produces their own knowledge about their subjective experience in a unique way (namely, the individuals' feelings, thoughts and perceptions).

It is often difficult for the qualitative researcher to identify and clarify their own assumptions within the range of epistemological positions that are available. This is often a task that is taken for granted, as fundamental assumptions about the world are in many cases implicit (Willig, 2012). To help me become more aware of and prepared to acknowledge my own epistemological stance, it is important that I set to answer the following questions outlined by Willig (2012): What kind of knowledge do I aim to produce? What are the assumptions I make about the world? What is the relationship between myself and the knowledge that I aim to generate?

To explore the subjective experience of the participant and understand their unique world, it was essential to capture the participants' thoughts, feelings and perceptions without judging whether the account of their experiences was an accurate reflection of 'reality'. My task was to step into the shoes of the participant and produce knowledge that is concerned with the texture and quality of their experiences. In other words, I was interested in the experiential world of the participants and to create knowledge that explores what it is really like for the participants, in order to get close to their experiences of their unique world, and see how their experience differs from that of another participant (even if they experienced the same events). Therefore, this qualitative research aimed to generate 'phenomenological knowledge'. As Willig (2012) states, this aligns naturally with the person-centred counsellor who uses their skills and core conditions to direct their interests and understanding to the phenomenological world of the client.

In addressing what kind of knowledge this study will produce (i.e. epistemology), the next question was to think about the kind of assumptions this methodology and I make (i.e. the ontology). The focus of this research was to be interested in the participants' subjective experiences of their world rather than the objective truth. I found myself agreeing with Willig's (2012) comment in that phenomenological knowledge assumes peoples' experiences are mediated by their thoughts, beliefs, expectation and judgements, and therefore that each individual can experience the same 'objective' conditions (e.g. an individual's experience of a particular disease) in different ways. Therefore, this study emphasised the diversity of interpretations that can be applied to such knowledge, as opposed to obtaining 'factual' information. For this reason, the knowledge was not

considered purely realist, and nor was it considered fundamentally relativist as only an insight into the subjective experiences of reality was presented (Forrester, 2010).

Although the participants' experiences can be captured and therefore confirm the existence of some form of 'reality', I realised that the participants' psychological world could only be better understood through the researcher's engagement with and interpretation of their individual accounts. Therefore, their accounts could only come to life by the researcher adopting a reflexive attitude, whereby my own conceptions and perspective are implicated to access the participants' meanings and experiences (through a sense of discovery as opposed to the 'construction' of the findings). This resonated with my own practice, whereby great differences occur between the clients' narrative and my observations with the transference and countertransference. Therefore, the assumptions that one makes of the world (i.e. ontology), according to this perspective, would be a critical-realist position (Willig, 2012).

The phenomenological knowledge that is generated from qualitative approaches can differ due to the researcher's interpretation of the participants' experience. Phenomenological knowledge ranges from 'descriptive' to 'interpretative'. Descriptive phenomenological knowledge would stay close to the participants' account as it is believed that meaning cannot be found outside the actual experience. This research intended to move beyond the experience at 'face value' and to step outside the account to reflect on the wider meanings. The knowledge produced would therefore involve a process of interpretation of the participants' experiences of their child being diagnosed with cancer.

I intend to produce 'interpretative phenomenological' knowledge, as this approach believes that an understanding of the phenomena can only be made when we allow our own conceptions and standpoints to inform our analysis of the data. This enabled me to move beyond the 'descriptive' data and reflect on wider social, cultural and psychological meanings that underpin the participants' subjective accounts (Willig, 2012). It is necessary to adopt a reflexive attitude as my experiences, expectations and assumptions become the bases of how I interpret and give meaning to each account to understand it. Therefore, according to interpretative phenomenologists, it is not in fact possible to produce pure

descriptions to capture and comprehend the experience as it is inevitable that a certain amount of interpretation will have to be applied (Willig, 2012). I will later discuss how I aimed to make my own impact (e.g. experiences, attitudes, beliefs, culture, etc.) more transparent in the research.

Given the important role that parents play in the management of their child's condition, it seems critical that I provided these individuals with the platform to be heard and talk openly about their experiences. I acknowledge that my vested interest in achieving this helped my journey in establishing my own epistemological stance.

Given the vast array of epistemological labels available and the possibility of overly ascribing to a particular label, I attempted to describe how my choice of research methodology was compatible with my assumptions about the world (ontology) and what can be known about it (epistemology). Willig (2012) argues that one's affiliations towards their epistemological stance are mere angles in which different positions can be given different meanings by different writers and readers. In the context of my research question, I would locate the position associated with those assumptions within the interpretative phenomenological stance.

### **Choosing the Most Appropriate Methodology**

As with all research endeavours, choosing the qualitative methodology that was best suited to the line of inquiry was vital to obtain the desired results. Four approaches were considered to see which one was the most appropriate: Discourse Analysis, Narrative Analysis, Grounded Theory and IPA.

Discourse analysis evolved from exploring how individuals accomplish personal, social and political undertakings through their subjective use of language (Starks & Trinidad, 2007). It focuses on *how* the stories are told through the practice of language to help mediate and construct the individual's understanding of reality (Georgaca & Avdi, 2012). IPA, on the other hand, is concerned with cognition in the sense that cognition is a complex, nuanced process of sense- and meaning-making of the lived experiences. For this reason, it felt that

discourse analysis could not address the question of what it is like to live through and make sense of the experience of being a parent to a child who has a health-related illness. Furthermore, Chapman and Smith (2002) outline that discourse analysis questions the link between the individual's narrative and their underlying cognitions, which contrasts with the perspective of IPA. According to IPA, cognitions are not isolated functions, but are instead one aspect of being-in-the-world which can be indirectly retrieved through language, persons' experiences and their stories. Therefore, IPA seems more applicable to access the interpretation of the meaning for a particular person in a particular context through what they discuss.

There are various forms of narrative analysis that connect to the central focus of making meaning. A narrative approach that focuses on the *content* of peoples' stories to understand life experiences clearly resonates with the interpretative meaning-making endeavour to IPA. However, there are other forms within narrative analysis that are more interested in the *structure* of peoples' stories (Smith, Flowers, & Larkin, 2009) and how these structures function on the development of experiential accounts. I was concerned that the latter form would not address the research question alongside the strong focus on the social aspects of the narratives which may limit the data (Griffin & May, 2012). Furthermore, caution should be exercised in collecting narrative accounts of crises as the interviewee may need time and possible repeated meetings to develop their narratives (Murray & Sargeant, 2012). Due to the sensitive nature of this research topic, it was important to be aware that narrative research can evoke recollection of more traumatic events which may prompt unnecessary distress in participants of the study.

The other alternative method that was considered for my research study was Grounded Theory. Smith et al. (2009) outline that there is a considerable overlap between IPA and Grounded Theory: both aspire to an inductive model of knowledge generation that is directly grounded within the data and involve the attempt to bracket out the researcher's theoretical assumptions to study individual processes or experiences (Charmaz, 2006). Furthermore, both aim to obtain a rich and detailed view of the group's or person's world. However, on the whole, IPA was designed to gain a detailed insight into a small number of participants with emphasis on their psychological world, which is appropriate to the current

research question, whereas Grounded Theory posits that meaning is understood through interactions with others in social processes – therefore it addresses more sociological research questions than psychological (Starks & Trinidad, 2007). The goal of Grounded Theory is to employ a larger sample of participants with the aim of developing an explanatory theory of the social processes where they naturally occur (Glaser & Strauss, 1967). More importantly, IPA closely analyses the lived experiences to understand more deeply how meaning is created by exposing the taken-for-granted assumptions about our world. This cannot be granted by Grounded Theory and for this reason, IPA seemed a more complimentary approach to add value to the micro-analyses of individual experiences, which in turn may enrich the development of more macro-accounts.

### **Interpretative Phenomenological Analysis**

IPA is a qualitative research approach that was developed in the mid-1990s by Jonathan Smith and which paid particular focus to how people make sense of their experiences (Smith, 1996). An important role for Smith was to develop a research method which was qualitative in approach and that would revive a more pluralistic route in psychology. Much of the early work of IPA originated in Health Psychology but it is increasingly being picked up by those working in Clinical, Counselling, Social and Educational Psychology.

IPA provides an established, phenomenological, focused approach to exploring the subjective experiences to capture and reflect upon the claims and concerns of the research participant. However, it also includes elements of '*making sense*' by offering an interpretation that is grounded in the accounts to understand their experience (Smith et al., 2009). These are key conceptual touchstones that have informed IPA and are underpinned in phenomenology hermeneutics and idiography.

Phenomenology is a philosophical approach that provides a rich source of ideas about the study of 'Being' (i.e. how to examine and comprehend experience). It was the major work of Husserl (1927) who was particularly interested in identifying the essential core structures that give the phenomena their unique character. Husserl proposed that in order to get at the universal essence of a given phenomenon, it is essential to put aside our *natural*

*attitude*, which involves identifying and suspending our assumptions to adopt a *phenomenological attitude*. This allows us to describe the phenomenon as it presents itself to our consciousness. Husserl proposed that we need to 'bracket' the taken-for-granted world so we can *transcend* beyond our everyday assumptions to concentrate on the properties of an experience. It was these aspects of Husserl's work that helped IPA researchers to centrally focus on the process of reflection to examine our lived experiences within a particular context (Smith et al., 2009).

IPA does not aim for transcendent knowledge and instead it draws upon later developments of phenomenology by Husserl's successors: Heidegger (1962), Merleau-Ponty (1962) and Sartre (1956). Heidegger questioned whether knowledge can be attained without an interpretative stance within a lived world with people, relationships and language. He suggested that our observations are always made from *somewhere* and therefore can never apply Husserl's 'reduction' to abstract concepts. He proposed that we cannot detach the person's inner involvement with the world and their relationships with others, and instead our *relatedness-to-the-world* is a fundamental part of our constitution (Harper & Thompson, 2011). Heidegger proposed the strong emphasis of *worldliness* of our existence, whereas Merleau-Ponty described the *embodied* nature of the person's existence to the world. However, both suggested that phenomenological inquiry is a situated enterprise, which formed the basis of hermeneutic phenomenology. Sartre extended the *worldiness* of our experience from Heidegger, by developing that we are able to conceive our experiences in the presence and absence of our relationships to other people. The primary contribution of Heidegger, Merleau-Ponty and Sartre is the idea that people are immersed and embedded within a world of objects, relationships, language and culture. Such developments in phenomenology move us away from the descriptive commitments of Husserl to the interpretative implementation of our involvement in the lived world. We have to appreciate that perspectives and meanings are something personal to each of us and the way in which we relate to the world (Smith et al., 2009). IPA research encourages us to focus on the *meanings* of peoples' experiences and understand the other person's relationship with the world through necessary interpretation.

Following on from Heidegger's (1962) influential development of phenomenological thought, IPA embraces a hermeneutic theoretical underpinning of phenomenology. According to hermeneutic phenomenology, the interpretation and the awareness of what the researcher brings to the text can constitute an insightful understanding for a lived experience. Schleiermacher (1998) claims that if one engages in a detailed and holistic analysis of the individual's account, then one can understand the individual better than they understand themselves. Smith et al. (2009) notice that this contrasts with the IPA perspective, and correctly so in my mind, as this does not permit our analyses to be more 'true' than the claims from the research participant. Instead, interpretation can offer a meaningful perspective on the text which the author may not have themselves. To better our understanding of the individual's account, Schleiermacher (1998) outlined that the process of meaning-making cannot take place without some preliminary assumptions of our interpretation of what is trying to be understood. This refers to the 'hermeneutic circle' in that we cannot make sense of the whole until we have made sense of the parts, and vice versa. For the interpretative phenomenological researcher to understand the meaning behind the phenomenon, they work with and use their own pre-conceptions and assumptions about the world to advance the understanding.

Heidegger (1962) formulates phenomenology as an explicitly interpretative endeavour. He argues that we cannot ignore our prior experiences or pre-conceptions, as they often precede our encounters and can become an obstacle to interpretation of the new object (Smith et al., 2009). Therefore, priority should be given to the new object as Heidegger believes that our understanding of the new phenomenon can help us become aware of our pre-conceptions once the interpretation is underway. Gadamer (1990), who is in line with the readings of Heidegger, summarises that the phenomenon itself can influence the interpretation, which in turn can influence our preconceptions, and this influences the interpretation of the thing itself. This cyclic notion of the sense-making process refers back to the hermeneutic circle which helps us see a more enlivened form of reflexive practices (like bracketing) which can only be partially achieved in qualitative psychology as the researcher's perspective and position will inevitably shape the research.

In IPA research, the focus on hermeneutics provides a useful way to understand the process of analysis. It enlists the role of the researcher to move back and forth through the data to help think about their relationship to the data in accordance to the hermeneutic circle. This iterative process of analysis is a key tenet of IPA as different meanings can be extracted at different levels, rather than through a step-by-step fashion. In the attempt to make interpretations that are close to the participants' reflections, the researcher is engaged in a double hermeneutic, whereby they are trying to make sense of the participant who is trying to make sense of the activities that are occurring within themselves (Smith, 2011).

IPA's third major influence is idiography, which focuses on understanding the particularity of an individual case and produces insight as a result of an intensive and detailed engagement with the text generated by participants. This contrasts with the popular and dominant notion of the nomothetic approach within current psychology which is concerned with making claims at a universal level and establishing laws of human behaviours. The prior task for the IPA researcher is to remain within the detailed analysis of each case to understand the actual life and lived experiences for that particular person within a particular context. With a larger body of cases, IPA may lead to establishing the core characteristics of a particular phenomenon and how these can shed light on existing nomothetic research.

The commitment to understanding how a particular phenomenon is experienced from the perspective of a particular population is often time-consuming and requires a small, purposely selected sample. IPA has been criticised for utilising small samples as the empirical findings generated by such research cannot allow the results to be generalised (Smith, 2009). However, qualitative researchers go on to show that it is often difficult to capture the rich complexities of life into predefined categorical systems and therefore these cannot be truly representative of the individuals who provided the data in the first place. Alternatively, Smith et al. (2009) stress that a detailed examination of each case can help us move towards more general claims and can produce insightful findings within psychological research that do justice to the complexity of human psychology itself. They support the use of smaller samples within IPA research to produce a rich and detailed account of individual experience and have increasingly advocated the use of case studies in IPA research (Smith, 2004).

The analytical process of IPA can make an important and powerful contribution to understanding the lived experience by examining each case in detail, before analysing the patterns across participants that reflect a shared experience. Through connecting the findings across the cases, IPA can offer an avenue to see how each case can illuminate the existing nomothetic research (Smith et al., 2009).

Further criticism was launched at IPA by Giorgi (2010), who claimed that IPA did not endeavour to be scientific due to its lack of prescriptive nature and its inability to replicate findings. He further went to argue that IPA is not centred within the philosophy of phenomenology and hermeneutics. However, Smith (2010) highlighted a number of shortcomings in Giorgi's selective and incomplete assessment of IPA. He countered each accusation to conclude that Giorgi lacked sufficient evidence and rigour to support his critique and that both differed in their understanding of what was regarded as "science".

As with all qualitative research, a good IPA study requires the researcher to be proficient in a range of complex personal and professional skills (e.g. interviewing, writing, analysis, interpretation). Therefore, the processes involved in qualitative research are not prescriptive in nature, nor are they equivalent to the systematic processes involved in quantitative research. Furthermore, the criteria for evaluating the validity of qualitative research are often in accordance with the quantitative criteria (e.g. replicability), and therefore alternative criteria need to be established to assess its quality (see the section 'Validity' as part of this chapter). IPA is a well-established qualitative methodology in psychology that has substantial precedents for use in physical and mental health research and is increasingly growing in other areas too, e.g. sports and music (Smith, 2010).

### **Rationale for Adopting IPA**

It is important to evaluate IPA's position in relation to my own epistemological stance. As I have explored above, my phenomenological research question can be best answered by a phenomenological method. Among the array of qualitative methodologies available, IPA accepts the impossibility of gaining direct access to the participants' life and recognises that

the phenomenological knowledge it produces is always an interpretation of the participants' experience.

To evaluate the research in a meaningful way, we need a clear understanding of IPA's epistemological basis. To do this, we should return to Willig's (2013) three questions: What kind of knowledge does IPA aim to produce? What assumptions does IPA make about the world? What is the relationship between myself and the knowledge that I aim to generate?

The objective of IPA is to produce knowledge that captures the quality and texture of individual experiences through engaging with their thoughts and feelings. This encouragement to engage with the participants' inner perspective allows us to understand *what* and *how* people think of the phenomena under investigation. This could be perceived as adopting a *realist* approach, but IPA recognises that the experience is never directly accessible to the researcher as there is an interpretative engagement within the researcher-participant dialogue (Willig, 2008). This could adhere to the epistemological stance of 'constructivism-interpretivism', which holds that there are equally valid, multiple realities that are created through the mind of the individual (Ponterotto, 2005), whilst maintaining that the meaning can be hidden and be understood through deep reflection (Sciarra, 1999). IPA recognises that the researcher's own way of thinking and assumptions should not be eliminated; instead, they are embraced through a *reflexive* attitude to make them explicit (Willig, 2013).

IPA is interested in understanding the participants' lived, subjective experience and assumes that people attribute their unique meanings to events to shape them as their own. This is perceived as an alternative to the positivist paradigm (where there is a single objective external reality), as IPA is not concerned with whether the accounts correspond to a 'true or false' reality. On the contrary, IPA subscribes itself to a relativist ontology to see how people *experience* the event, which is in line with my aspiration to produce phenomenological knowledge. However, people's interpretation between themselves and their social world are not free-floating, as they are shaped by social interactions and processes (Willig, 2013). Therefore, IPA grounds itself in a 'symbolic interactionist' perspective.

IPA maintains that the researcher's values, assumptions and lived experience cannot be divorced from the process and that an exploration of the participants' psychological world must necessarily implicate the researcher's own view of the world. It conceptualises the role of the researcher as a vital component that works hand-in-hand to acknowledge, describe and "bracket" his or her values. However, Willig (2013) highlights that IPA does not inform us on how to incorporate the researchers' own reflexivity and how this may affect the analysis.

Another rationale for using IPA as my analytical procedure is its close relation to Counselling Psychology which espouses a phenomenological approach as the field maintains to explore the subjectivity and idiosyncratic nature of individual accounts. In addition to drawing on a scientific approach, Counselling Psychology aims to jointly create findings between the clinician and patient from their interactive dialogue and interpretation. It does not assume there is a 'correct' or 'true' way of experiencing a phenomenon, all of which resonate within IPA and my natural way of thinking and working.

On a final note, the open-ended, inductive research methodology of IPA aims to 'give voice' to those accounts that tend to be from marginalised individuals or communities (Larkin, Watts, & Clifton, 2006). There are substantial precedents for using IPA in social and health research and it is an increasingly popular approach to qualitative inquiry. This bottom-up approach can yield valuable research and an opportunity for those to be heard and talk openly about their experiences regarding a topic that needs to be understood.

## **Reflexivity**

Qualitative research has argued that it is impossible for a researcher to position themselves 'outside of' the subject matter as the researcher inevitably influences and shapes the research process (Willig, 2013). This notion of reflexivity is highly important in qualitative research because it encourages us to move away from the limitations that are dominant in positivism/empiricism, which focuses on developing techniques to detach the researcher from 'contaminating' the data collection. Instead, reflexivity invites us to think about how our own reaction to the data can contribute to gain a better understanding of the person. I

am aware that my motivation to study this topic was of a personal interest, which could potentially impact the construction of meaning of being a parent to a child who has cancer.

The interpretation that one takes on the participants' account will depend on the theoretical framework from which the text is approached. As Willig (2013) states, we can generate a number of differing interpretations of the same data depending upon the researcher's own epistemological position. Reflexive insights made by an interpretative phenomenological researcher will allow for a better understanding of the quality and meaning of the particular individual's experience of the phenomenon, while acknowledging the researcher's own personal 'biases'.

Willig (2013) outlines two types of reflexivity: personal reflexivity and epistemological reflexivity. Personal reflexivity focuses on how we think about our traits as a researcher (e.g. personal beliefs, social identity, etc.) and acknowledges how this shapes the research and how we are as people and as researchers. Epistemological reflexivity involves questioning the assumptions we make throughout the course of the research process and thinking about the implications this may have on the findings and our role as theorists/thinkers. Please refer to my epistemological reflexivity outlined earlier in this chapter under 'Epistemological Position' and my 'Personal Reflexivity' below.

Willig (2001) argues that being reflexive about our investments and motivations does not constitute 'biases' which need to be removed but are 'necessary preconditions' that help us make our own impact on the research more transparent.

As reflexivity is an integral part of the IPA approach, I attempted to reflect on my own position by keeping a reflective diary to help document my thoughts, assumptions, beliefs and my position throughout the research. At the end of this chapter, I provide a summary of the relevant points from this diary to show how the research has changed me and my way of thinking in relation to that particular context. I felt it was important to include reflections on my experiences of working with individuals who have cancer, and this initiated my curiosity of studying this subject matter. I hope it has provided a different perspective on my role in the research and my beliefs in a way that is clear, honest and informative.

## **Personal Reflexivity**

Prior to investigating the current research question, I had a placement working for a psychological and welfare service to support staff with their mental health needs. This was an eye-opening experience during which I came across a handful of patients who were affected by cancer. Over time, I developed a strong and rewarding relationship with these patients who often shared with me how challenging it was for them to look to work as a way to keep their lives as normal as possible, whilst battling with their sense of helplessness or hopelessness when stress became overwhelming. I noticed how a number of individuals just wanted to share their story with me which in turn helped me decide to focus on a qualitative design for the current study, to give a voice to them and others in a similar situation.

My interests in oncology grew further at the time when I came across an inspiring young adolescent, Stephen Sutton, who had been battling with cancer since the age of 15 and had raised a remarkable five million pounds for charity. I came across news articles highlighting how his father was concerned that his son might have the disease after noticing symptoms early on but was struggling to be listened to by the doctors (Weathers, 2014). I soon found myself asking more about what it may have been like being a parent to child with a life-threatening illness.

The prevailing impression that I gathered from my experience was that cancer is highly distressing and the lack of control that one has over the illness could highlight potential assumptions that might shape my opinion of parents' experiences of their child's illness. I acknowledge that my attempts to "bracket off" my assumptions (Husserl, 1927) may not be completely achievable but are necessary to focus on the data with an open mind.

In thinking about my motivation behind the research, I reflected on my own experience of witnessing my sister trying to cope with her child's illness. I was frequently met with feelings of helplessness, frustration and the need to be resilient, a feeling which if I were to be completely honest, echoed my own feelings. Although I am not a parent, I am aware of the

impact this had on me and this will hopefully help the reader to become aware of the vantage point from which the study findings were presented. This transparency in turn will enhance the validity of the study (Yardley, 2000). I gained a greater level of understanding of the experiences of parents and would like to use this to help enrich our understanding as Counselling Psychologists.

## **Validity**

Although qualitative research has had an enormous contribution to the field of psychology and health research, there has been little progress in assessing the quality and validity of its research findings (Meyrick, 2006). The barriers to establishing a simple guide to evaluate qualitative research, it has been argued, is that it is difficult to formulate an effective approach due the vast range of epistemological and methodological standpoints in this type of research (Smith et al., 2009). Understandably, there has been a growing dissatisfaction in applying the criteria that assess the validity and reliability of quantitative research to qualitative research (Smith et al., 2009). The little understanding there is of how to judge its quality has created scepticism around qualitative research and therefore alternative methods are long overdue to maintain the credibility it deserves.

Out of the number of guidelines produced to assess the quality or validity in qualitative research, two approaches have stood as being accessible and sophisticated: these are Elliot et al. (1999) and Yardley (2000). Their suggested criteria offer an alternative approach to the 'checklist' style assessment procedures which can be too simplistic and prescriptive and can be applied regardless of the particular epistemological orientation adopted.

Yardley's framework was used to explicate the validity for the current IPA study. However, Yardley (2000) stresses that this does not simply involve following procedures in a uniform way to assure strong validity, which is why I have flexibly applied these principles throughout my methodology. There are four broad principles involved: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

The first principle, sensitivity to context, was demonstrated by the study's sensitivity to sociocultural context, the relevance to the existing literature and to the participant. After an extensive review of the existing literature, the current study was developed to add depth in our knowledge. Also, the very choice of IPA offered a close engagement with the idiographic nature of the study, which demonstrated a way in which sensitivity could be established.

The current study used a purposive sampling strategy which made it difficult to recruit participants because of the lack of interest and difficulty in engaging with key gatekeepers such as charities. Despite the struggles, I was able to work closely with the NHS to generate referrals which demonstrated skill and dedication in my commitment to the sensitivity to the topic.

According to Yardley (2000), a good IPA analysis is only as good as the data it is derived from. Therefore, it was important for me to create conditions to produce a good interview, in order to show sensitivity to context e.g. showing empathy, creating a safe environment at a time that was convenient to the participants and with the opportunity to conduct the interviews at their home to make them feel at ease whilst discussing their lived experiences.

This principle continues through the analysis process and has explicitly manifested itself through the written report of the study. Much care was taken when collecting data from participants and ensuring that analytical claims were supported by verbatim extracts from the interview transcripts. The reader was able to check interpretations being made, and this ultimately gave participants a voice in the study to strengthen the sensitivity to the data. Furthermore, the findings were related back to the relevant literature in the Discussion Chapter to show awareness of and sensitivity to existing research.

Yardley's second broad principle, commitment and rigour, can be demonstrated by becoming aware of the complex skills that are required to attend to the participants during their interviews, with the hope of eliciting a deeper understanding of their lived experience. Smith et al. (2009) stress that it is vital for the IPA researcher to become aware of and practise those skills, which is why I took the opportunity to attend a workshop organised by

the British Psychological Society at their office in London on how to carry out an in-depth IPA study.

A good IPA study will demonstrate rigour by carefully selecting the participants (Smith et al., 2009) – this was displayed through my rationale for choosing a purposive sample that was fairly homogenous. This offered the research project insight into the participants' particular experience and nurtured good-quality interviews. Again, I hope to convey rigour by careful consideration of the idiographic engagement throughout the analysis and for it to be sufficiently interpretative to move beyond simple descriptive data.

Yardley's third principle is transparency and coherence. Transparency refers to how the writer can demonstrate clearly to the reader the rationale behind the stages of the research process, whereas coherence refers to the consistency of the study to its underlying theoretical principles and how it makes sense overall (Yardley, 2000). Evidence of carefully describing and explaining my research design, procedures and analysis within the write-up will act as a testament to this principle. In addition, the theoretical underpinnings of IPA (e.g. phenomenology and hermeneutics) and my epistemological standpoint have been apparent throughout my write-up to demonstrate my commitment to attend closely to the experiential domain for the participant.

Smith et al. (2009) suggest that a powerful way to illustrate rigour and transparency is by having a clear stream of evidence so one can make sense of the research from the initial conception to the final written report. Parts of my report were reviewed by my research supervisor to check that I had a plausible and coherent chain of arguments, thus developing my own skills as a novice qualitative researcher and representing an independent auditor to demonstrate validity.

Yardley's (2000) final principle, impact and importance, states that the true testament to validity is how well the research informs the audience of something useful or important. My hope was to conduct an in-depth IPA study to improve our understanding of parents' experiences of their child being diagnosed with cancer. The results will help strengthen the existing body of research and may inform the development of future treatments and clinical

practice. Also, participants may appreciate having the opportunity to talk openly about their experiences and de-centre themselves from the possible stigma associated with critical health conditions.

## **Recruitment**

My original method to support the recruitment process for this study was to approach children cancer charities across the UK, as they were widely accessible and actively involved in supporting children with cancer and their families. I contacted five charities in total: Children with Cancer UK, Kid's Cancer Charity, CLIC Sargent, Leukaemia Care and the Rainbow Trust, through telephone conversations, emails and face-to-face meetings. Only the first two charities were interested in the study, whereas CLIC Sargent, Leukaemia Care and Rainbow Trust declined their support due to the potential distress it may have caused to the parents. Although I provided these charities with a detailed set of procedures that were in place to manage these issues, they declined to take part as they were concerned that participants might experience acute distress as a result of participating in this research.

Discussing my research topic in detail with the supportive charities helped to keep potential risks and burdens incurred by research participants to a minimum. Children with Cancer UK and Kids Cancer Charity spoke from a position of knowledge and expertise on behalf of this client group, which brought a valuable insight into my research topic.

Actively involving these services in the design aspect of the research process was particularly helpful in reviewing my research topic and having open discussions about my inclusion criteria (Appendix A) and interview questions (Appendix B).

The interview schedule was developed with a view to facilitating a comfortable environment for the participants. The questions were open-ended and were driven by the research question in order encourage the participant to talk openly about their experiences related to the phenomenon under investigation. The interview schedule began with a question that helped the participants talk at length about what motivated them to take part in the study, as I felt this would allow participants to talk about something more descriptive and help

them feel comfortable in talking. With the assistance of my research supervisor, I aimed to design questions that were open-ended, not leading and not making too many assumptions about their experiences, in line with the guidelines proposed by Smith et al. (2009). Unfortunately, I did not carry out a pilot study due to the difficulty in recruiting participants, but I felt that having an open discussion with the charities (who spoke from a position of knowledge and expertise on behalf of the participant population) helped me to reflect on potential concerns and my role as a neutral, non-judgemental researcher in the process. After conducting and transcribing my first interview, I reflected on the questions and responses with my research supervisor, which helped me develop and change the way I responded to the participant. Producing an interview schedule is seen as an iterative process (Smith et al., 2009), therefore, for the subsequent interviews the questions (and my responses) were adapted in light of the participant's responses. Prompts were also prepared if participants found it difficult to respond for those more complex questions. They too were open-ended (Smith et al., 2009).

The charities struggled to recruit parents in line with the original inclusion criteria: parents were required to have a child who had been diagnosed with cancer for between 6 and 12 months to help maintain a homogenous sample. Due to the time constraints to complete the doctorate, it was necessary to be pragmatic and review recruitment as it was occurring. The charities suggested I expand my inclusion criteria by including parents whose child had been diagnosed for a minimum of 4 months and with no upper limit. As the charities were a representation of this client population, my supervisor and I agreed that it was sensible to expand my inclusion criteria to facilitate recruitment and help me answer my research question.

Unfortunately, the charities had to decline their support as they found it difficult to recruit participants, which resulted in recruiting participants from the NHS. I overcame this obstacle by getting in contact with The Macmillan Information and Support Centre at Chelsea and Westminster Hospital. During this time, I was employed at this hospital within the eating disorders service and had no conflict with my role as a researcher and the participants that were recruited. The Chelsea and Westminster Hospital Children's Cancer Services were interested in the research and were happy to help locate participants after I received the approval from NHS ethics. I found this client group difficult to reach and in need of various

health provisions, so to have support already involved in the families' care plan seemed necessary.

The recruitment material and research protocol were approved by the NHS Ethics Committee/Health Research Authority (HRA) and by City, University of London's Ethics Committee (Appendix C for ethical approval letters from both organisations).

After receiving approval from the NHS Ethics Committee and the letter of approval from the Health Research Authority, the first stage to recruitment was to engage with the Macmillan Oncology Clinical Nurse Specialist (CNS) in the service, who was responsible for supporting families after the initial diagnosis of their child and throughout their child's cancer trajectory. Following consent, I visited the CNS to go through the aims of the study and discuss what was required from the clinician and participants. Copies of the recruitment material were emailed to the CNS, so they could identify eligible participants from their caseload that adhered to the study's criteria. The CNS conducted the initial screening (via face-to-face interviews and telephone calls) and gave interested participants the Information Sheet (Appendix D) and a Consent Form (Appendix E). If the participant was interested and appeared to be appropriate to the study, their details were passed to me via a secure, safe and confidential NHS email system (as I was employed in the same hospital trust) with their consent. I contacted the participant a week later to ensure they had had an opportunity to read and clarify any questions/concerns and to ensure that they did not feel pressurised to take part in the study. If they agreed to take part, an interview date and location (at their home or at the hospital) was arranged.

One parent that I contacted asked whether their partner could also participate in the research. Both parents felt they wanted to share their different experiences and this was permitted in accordance with the inclusion criteria. Both individuals were interviewed separately. Another participant expressed that because of her religious beliefs, her husband needed to be present during our interview as her culture did not allow a female to be in the same room as a male (other than her husband). During this interview, only the participant spoke to give their account.

The demographical information (such as the child's diagnosis, date of treatment, contact

details) was given to me by the CNS and I did not use a formal demographic collection method as I felt this would be more appropriate for research adopting a positivist stance. Also, obtaining this highly identifiable information in the interview might have affected the power dynamics between me and the participant, and I did not feel it was relevant to the study or to help answer the research question.

The study was conducted using a small sample in order to produce a detailed case-by-case analysis and therefore be in line with IPA's orientation to the idiographic approach. Smith et al. (2009) highlight that anything between four and ten participants are manageable for a professional doctorate and are sufficient to allow meaningful conclusions to be drawn. Participants were selected using purposive sampling and were fairly homogenous to facilitate a detailed understanding of the parent's perspective of their child being diagnosed with cancer.

### **Inclusion/Exclusion Criteria**

To create this purposive homogenous sample, all participants were selected in accordance with the following criteria: all participants were 18 years or older due to issues of informed consent; all parents, including single parents, mixed-sex or same-sex couples, were invited to participate; if the child had two parents, the parents could decide which parent(s) would take part in the study; the child had to be 15 years old or younger and to have been diagnosed with a form of cancer; all participants had to be English speaking; and the child must have had a diagnosis of cancer within a minimum of 4 months.

The exclusion criteria were as follows: anyone with special communication needs; anyone experiencing a thought disorder or acute psychosis; anyone unable to or without the capacity to give informed consent. This just implied that I only excluded those with mental health issues if they were too serious for the person to give informed consent. However, this issue did not arise during the recruitment of participants. The clinical nurse specialist used her clinical judgement to establish whether potential participants could take part in the study in relation to their emotional stability. As a result, the group was made as uniform as possible to ensure a homogenous sample was sought. It was important to ensure that

this study did not ignore those parents who were single or same sex, as I wanted to demonstrate equality for all.

The child diagnosed with cancer had to be 15 years or younger. It is clear from the preceding chapter (see 'Terminology' in the 'Introduction Chapter') that what constitutes 'a child' is not clear-cut and different studies have recognised children as having varying age ranges. I chose 15 years or younger as I believe anyone older will draw on characteristics that define them as adolescent or *becoming* adults. I acknowledge that treating 'children' on specific characteristics such as age can be flawed and problematic as it negates other traits that can define this term. Although I have employed 'age' as my personal heuristic device to define 'children' in the present study, I believe that this will not have any impact when comparing the current findings with other studies as the primary focus is on the parents' experiences.

There were various challenges that were encountered during the recruitment process (please refer to the 'Recruitment' section for further details), so it was necessary to review the practicalities of sampling whilst trying to obtain a group that was relatively homogenous. This called for the study to expand its inclusion criteria by eliminating the upper time limit since the child was first diagnosed with cancer. Not only did this facilitate recruitment, but the minimum of 4 months gave participants enough time to work through the acute stages of diagnosis and avoid generating unnecessary distress during their participation in the study.

## **Sampling**

Eight participants were recruited: six mothers and two fathers, with their age ranging between 22 and 55. Five children were diagnosed with Acute Lymphoblastic leukaemia, one with Burkitt's Lymphoma and another child with T-Cell Non-Hodgkin's Lymphoma. Five children were diagnosed in 2016 and another child in 2015 and were actively receiving treatment. One child had finished their active treatment in 2013. I was informed by the CNS that all children received the same cancer treatment (called UKALL 2011). The diagnosed children were aged between 1.8 and 12 years with a mean age of 7.69.

## **Interview Procedure**

Three participants were interviewed at their home and the remaining five interviews were conducted at the hospital, at a time that was most convenient for the parents. Each interview took approximately one hour and was audio-recorded.

On the day of the interview, participants again had the purpose of the study explained to them, via the participant information sheet. Before requesting their informed consent, I explained that all identifiable information would be anonymised (by changing their names to a pseudonym) and they were given the opportunity to ask any questions.

Semi-structured interviews have been the preferred means for collecting data within IPA studies as they elicit detailed stories, thoughts and feelings from the participant (Reid, Flowers, & Larkin, 2005). The interview schedule was developed so as to start with questions that were fairly descriptive to facilitate a rapport with the participant and help them feel comfortable as they began to ease into the interview.

When the interview ended, participants were given a debrief sheet to inform them of the full aims of the research and contact details of the research team should they require further support. Each participant was given the opportunity to talk about how they found the interview and whether they had any questions or concerns about their participation.

The recorded interview was transferred to a password-protected computer through an encrypted USB stick that was provided by City, University of London Information Compliance Team. The research data was then deleted from the Dictaphone.

Participants who were interested in receiving a brief overview of the literature, results and discussion were asked to sign a statement at the bottom of the debrief sheet (Appendix F) which asked for their email address. The summary did not focus on individual responses in order to avoid unnecessary distress that might come from seeing their potentially emotive accounts in writing. Participants may see receiving this overview as an opportunity to feel involved and this may help normalise their experiences.

## **Ethical Considerations**

The research protocol received approval by City, University of London Research Ethics Committee. Further ethical approval was sought from the NHS and HRA ethics committee and followed the BPS Code of Ethics and Conduct (2009) and the HCPC Guidance on Conduct and Ethics for Students (2010).

All participants received an introduction about the study from the Paediatric Oncology CNS, who had a close and professional relationship with the families. This avoided any intrusion to the families and respected their space before they were approached by me.

All participants were provided with a participant information sheet and consent form that explained the true nature of the study, the data collection procedure, how data would be disseminated, confidentiality and the use of an audio recorder. At the interview, participants were asked if they had read and understood the information provided and were required to give their written informed consent. To maintain confidentiality, all consent forms were kept in a secure, locked drawer at the Paediatric Cancer Unit at Chelsea and Westminster Hospital, and attached to the family's clinical notes (separate from the data). Any identifiable information was anonymised to protect the confidentiality of the participants; their names were removed from the data and replaced by a pseudonym, with no record retained of how the pseudonym related to the identifier.

It was not anticipated that participants would be exposed to any risks or dangers during their participation in the study. However, most of the participants did show signs of distress due to the sensitivity of the topic and were asked if they were happy to continue with the interview. To adhere to the ethical obligations of the study, if the participants experienced any distress due to the sensitivity of the topic, they were offered an opportunity to take a break, to reschedule the interview for a different time or to end the interview if they felt unable to continue. None of the participants expressed that they wanted to reschedule or felt as though they were unable to continue. Also, they had contact details of their care team should they require further support. To safeguard this, participants were informed that they were allowed to withdraw from the study and have their data destroyed up until one week after interview. By this time, all identifiable data would have been completely

anonymised and the write up would have begun.

The original data is stored securely and retained for 5 years post-publication in accordance with the recommendations of the British Psychological Society (BPS) to answer the research question. Hard copies of the original transcript were stored in a locked filing cabinet.

## **Data Analysis**

There is no prescribed method to analyse the data within IPA. However, I followed the common processes that were outlined by Smith et al. (2009). The process is a close, reflective engagement with each participant's account before subsequently moving across cases in line with the ideographic nature of IPA (Smith et al., 2009).

Each audio recording was transcribed verbatim. Smith et al. (2009) highlight that it is acceptable to remove any prosodic aspects of the recordings and therefore only significant non-verbal utterances (e.g. "hmm"), pauses (e.g. illustrated by '...') and gestures were identified by using square brackets were included to preserve the original dialogue of each participant. Any identifiable information (e.g. names, places, services) was removed from the transcript and replaced with a pseudonym to protect the individual's identity. Any significant explanatory material that I added to aid clarity was inserted in square brackets (i.e. [...]).

To help immerse myself in the data and produce an account that was faithful to the participants' experiences, I listened back over the recording whilst reading the transcript. The process of engaging with the data was achieved by repeated readings of the transcript before writing the exploratory comments in the right margin. To provide a comprehensive set of notes and engage in an analytical dialogue, I followed Smith et al.'s (2009) suggested areas of focus: description, linguistics, and interpretative commenting. I conducted this process on the computer, as I found highlighting and inserting comments on Microsoft Word more legible than my handwritten notes and close to my normal working practices.

By now, I had a detailed set of exploratory notes that remained close to the text and the next stage was to reduce the volume of detail into emergent themes. Initially I felt

uncomfortable breaking up the narrative flow of the participants' experiences by re-organising the data, but then felt comfortable as I gained familiarity with the whole text through repeated readings (Smith et al., 2009). The themes were expressed using a more psychological language, which was grounded close to the text to reflect an understanding of the participants' account, but also to capture my interpretation. Any themes that were similar were given the same name to ensure the labelling was consistent. An extract from Holly's transcript in Appendix G illustrates this process. To maintain the ideographic nature of the participants' accounts, I created a table that showed the emergent themes, the line number and a few key words/quotes from the transcript (see Table 1, in Appendix H for an example).

The next step was to look for patterns and connections between the emergent themes (Smith et al., 2009). The themes were listed in chronological order (as they appeared on the transcript) and moved around to form clusters using 'abstraction', 'subsumption', 'polarisation' and 'numeration'. Abstraction is grouping similar themes together to develop a new theme to describe the cluster, whereas subsumption is when a theme itself becomes the superordinate theme that holds together other related themes. Polarisation focuses on the differences between the themes that cluster together, and numeration reflects the frequency of the themes that appeared in the transcript. Smith et al. (2009) highlighted the importance of using more than two strategies to help push the analysis to a higher level. The emergent themes that clustered together were given a new label which became the superordinate theme (Smith et al., 2009). This was done for each participant and placed in a table outlining the superordinate theme, subthemes and line number (see Table 2 in Appendix I).

The final step involved looking for patterns across cases by laying the tables on the floor to explore the spatial representations of how the themes compared to each case. It was interesting to see how some themes that seemed unique to an individual's case had shared high-order characteristics. A final table was created to show the connections for the group as a whole and how each subtheme was composed within the superordinate theme (see Table 3 in Appendix J).

## **Analytic Reflexivity**

The analysis process took a considerable amount of time to complete, more than I originally anticipated. After I immersed myself into the participants' accounts and used various devices along the way to make sense of their lived experience, I found myself feeling overwhelmed and anxious when trying to reduce the large volume of data I had collected. I was afraid of losing information that I thought was vital to the participants' account. Due to the large number of participants, I had to be more selective in choosing my extracts whilst maintaining the richness that was present within my data. One technique that I found helpful was to return to the transcripts to check the links between the quotes and themes and so ensure I was providing a meaningful account of my understanding about the participants' world. I built in sufficient time in my plan to cross-reference between the material and I consulted with my supervisor before finalising my themes, which helped to ease my anxieties. My active engagement within and between each transcript supports the iterative process of IPA (Smith et al., 2009).

Keeping up with IPA's ideographic commitment (Smith et al., 2009), I focused on each participant's narrative individually to draw together the themes that were most interesting to their account and which helped answer the research question. Before I repeated this process with the next participant, I worked hard to bracket my ideas that emerged from the previous cases. At times, I found this process difficult as I noticed recurring themes appearing, which made me worry that I was not doing justice to each case. One approach that helped me was to not look back at the previous case and try to think of a new label that captured the complexity of the participant's account. I found following the rigorous steps, as outlined in Smith et al.'s (2009) book, helped new themes to emerge, while consulting with my supervisor and peers helped to validate my findings.

I noticed that my interpretation of the data continued throughout the writing-up phase of the analysis, as one would expect according to Smith and Osborne (2008). As I began to write, I thought about some of the subthemes that overlapped and questioned whether they should be separate or belong under another theme. This process felt daunting as it brought about a constant shift in the analytic processes. However, the use of supervision

and following the set of steps presented by Smith et al. (2009) gave me a sense of confidence and competence to 'fix-in' the results through writing. I hope my desire and care in this process has given justice to the participants' accounts and interpreted their stories in the way they wanted them to be understood. To demonstrate this, the sequence in which the superordinate themes were written up was intentional, to share my understanding of the participants' experiences in the way they came up in the interviews and analysis. Hopefully, this will help the voices of my participants to come through and ensure the research question is answered.

I learnt that the analytic process is one that is fluid and multidirectional, as we constantly move between the part and the whole within the hermeneutic circle. The long, yet enjoyable process has helped me work on my own qualities such as open-mindedness, patience, persistence, flexibility and empathy, all which are important qualities required of an IPA researcher according to Smith et al. (2009). This dynamic notion that is at the heart of IPA, as with other qualitative research, has made me aware of the importance of having flexible thinking. I have often struggled with 'letting go' (especially when summarising and condensing what I thought to be the main themes) and I am constantly reminding myself that there is no such thing as 'perfect' data. Upon reflection, I have realised this process has helped me plan for and engage with the chaos and unpredictability of the lived world. Having embarked on an IPA analysis for the first time, I feel I am continuously learning and the help that I have received from my supervisor and peers has enabled me to feel contained during this process.

One of the central dimensions of the therapeutic relationship within Counselling Psychology is empathy towards the client's state of being. At times, the majority of participants visibly showed signs of distress and I felt quite emotional in places when analysing the transcript. The flexibility of coverage permitted by the semi-structured interviews facilitated empathy and enabled me to be effective and sensitive to the clients' negative emotions. Throughout the interview, I was struck by their gratitude and willingness to engage in some sensitive questioning as I felt, from my perspective, that they wanted to contribute to what the study might go on to change.

## Results and Analysis

### Overview

As discussed in the Methodology chapter, IPA was employed to explore what it is like to be a parent to a child with cancer. This chapter aims to produce a detailed analysis of each case and assesses the key emergent themes across cases. Due to the large corpus of material collected, the emphasis of this chapter is to capture the themes that are most pertinent across the whole group and that help answer the research question. Therefore, not all aspects of the participants' narrative accounts could be presented. To stay in line with IPA's ideographic approach, I will take particular examples from participants to give voice to their unique and individual experiences of being a parent, as well as also seeking to draw out themes that are common to the sample. This chapter is intentionally written in the present tense to illustrate how the themes came to materialise during the analytic process.

As themes emerge from the individual cases, the analytic process reveals patterns and similarities in participants' experiences across all cases. The themes that share higher-order qualities form superordinate themes. The process of analysis found all participants offered a similar account of their experiences that gave rise to four superordinate themes: "Sense-Making", "Powerless", "Relationship with Others", "A Process of Transformation". Each superordinate theme contains between two to four subthemes to capture the most meaningful excerpts that help answer the research question. There was some overlap between the themes, which is inevitable in the IPA analytical process as one is expected to examine the similarities and differences across cases (Smith & Osborn, 2008). Therefore, some themes shed light on others to help understand the individual phenomena better. After close examination and re-examination of the overlapping themes and their location, I felt each subtheme deserved a distinctively unique category that was most appropriate to the superordinate theme. Therefore, one should note that the themes do not inhabit disparate worlds as the themes represent fine-grained accounts of patterns of meaning for participants who are making sense of their shared experience. The final result of themes is presented in Figure 1 below.

The first superordinate theme, **“Sense-Making”**, describes how participants attempt to make sense of their experience of being a parent to a child with cancer. This theme explores the reasons they provided to help them make sense of their child’s illness and the meaning behind their experiences. It also covers how they made sense of their shock and disbelief of receiving the diagnosis as a surreal experience.

The second superordinate theme, **“Powerless”**, explores the participants’ experience of feeling a loss of control and helpless for their child’s condition. It looks into the impact this has on their life and how participants voice their difficulty in dealing with other issues beyond their child’s illness. This superordinate theme also reflects the participants’ experience of the need to appear strong and resilient to facilitate their child’s coping.

The third superordinate theme is **“Relationship with Others”**, which looks at how the participants perceive their relationships with the health professionals involved in their child’s care. It also explores the support participants received from their social relationships.

The final superordinate theme, **“A Process of Transformation”**, describes how having a child diagnosed with cancer led participants to re-evaluate their values in life and reconsider future relationships. It also presents an account of the significant changes that participants observed to their child during their treatment.

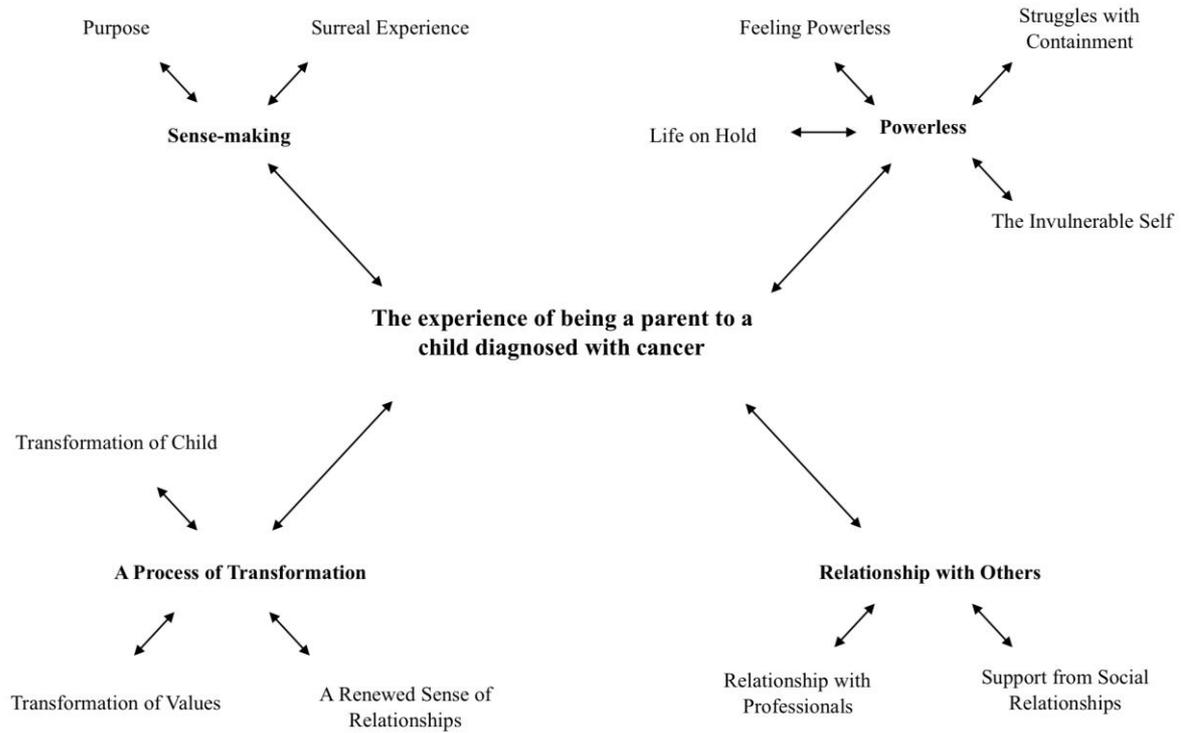


Figure 1: Map of themes<sup>1</sup>

### Superordinate theme one: Sense-Making

The first superordinate theme captures the attempts made by participants to make sense of their experience of their child being diagnosed with cancer. It encompasses participants' desire to understand their experiences and how they go about doing this. Within this superordinate theme, two subthemes were identified. The first theme explores the reasoning provided by each participant to make sense of the diagnosis. The second subtheme focuses on how parents described their experience of shock when they find out their child's diagnosis as being through a surreal viewpoint.

<sup>1</sup> This map of themes illustrates the development of superordinate themes (in bold font) and subthemes (in regular font) that have emerged from the analysis. Each arrow is bidirectional to show the reciprocal connections between the themes which influence each other to help understand the phenomena.

### **Subtheme one: Purpose**

Over half of participants provided an interesting insight into their attempts to make sense of the diagnosis through exploring the meaning behind their experience. The life-threatening illness gave two participants who followed the same religion, Islam, greater meaning and purpose through God's intentions. What was noticeable amongst all participants was their sense of fulfilment, of bettering oneself or others, as a result of their child having a life-threatening illness, thus helping them understand *why* their child received the illness.

Dara expresses her strong conviction in her belief behind the purpose of her child's diagnosis:

*We do see in my religion [Islam] always something bad always happen for good. He [God] gives you a test for you to get closer to him so you get elevated higher, because heaven has got 7 levels we call that, so you get elevated higher and that in my religion we believe that people are tested are the ones chosen by God because he wants to give them...make them more stronger, test your patience, testing your believe in him and that the more they pass that test, they get higher blessing (Dara, p.4)*

Dara's Islamic reference implies that her child's diagnosis, like other negative experiences, was sent to test her and that passing this test would strengthen her and her connection with God. This highlights that although Dara perceives this to be a challenging experience, she considers herself to be chosen by God who has desired intentions to empower and transform his followers to transcend beyond death and into "heaven". Dara makes several references to her faith throughout her account which signifies the important role her beliefs play in her ability to make sense of her experiences.

Mohammed, too, gives reference to his belief in God having purpose as to why his child suffered from cancer:

*I do believe is that we go through a test and we get a test in the most beloved things to us. I got a strong belief, I believe in God strongly and that kind of made things*

*easier in a way. I believe whatever happens to you, happens for a reason...and I should expect it happens for the better (Mohammed, p.5)*

Like Dara, Mohammed believes his child's cancer diagnosis was sent by God to test him. He found that his strong faith in God offered a very supportive experience and facilitated his coping. Although he seems to believe there to be an underlying purpose for every experience in life, he appears to view his child's illness as though he "should" feel hopeful that a desired outcome will occur, almost implying that he sometimes casts doubt on an optimistic outcome in God's intervention. His strong reference to faith throughout his narrative suggests that his understanding of his experience and beliefs reflects his sense-making activity.

Sally, on the other hand, provides a strong conviction in her belief that her child was destined to receive a diagnosis for greater purposes:

*The amount of change that she's created because of this, I can completely believe that she was meant to get this, for bigger purposes you know...from what I've seen from other people, children, school, teachers, what she's taught people is incredible, including us...so many people are touched and moved and it creates such a force of love, that I think if it didn't happen no one would learn these from what we're all learning from this little girl and from other people's children (Sally, p.2)*

Sally conveys a belief that it was inevitable for her daughter to get this illness as it provided a powerful learning opportunity to a broad range of people. Sally uses the word "created" which gives further weight to the notion of the transformation that she's observed in people, and that would not have happened otherwise. It seems that Sally discovered the purpose of her child's diagnosis through the way people were "touched" and "moved", suggesting the illness was so influential that it created warmth, gratitude and helped others to develop an awareness which involved a deep valuing of life. She later says, "I think if it didn't happen no one would learn", which emphasises the enormity and significance this diagnosis has had and how her "little girl" has exceeded her expectations to deliver this

“bigger purpose” to everyone. Her use of present tense in “*what we’re learning*” implies the diagnosis serves an ongoing purpose in Sally’s life.

Maya shares her search to understand why her child received the diagnosis:

*So pretty quickly I tried to work out why this was happening? Pretty quickly within a week, I was kind of thinking what’s, what’s the use of this? What is it? To everyone who touches his life, what is his use? (Maya, p.7)*

The many questions that Maya asks illustrate her curiosity in trying to understand why her son received this diagnosis. Like Sally, Maya tries to relate the “use” her child had on other people’s lives to help create an association between the diagnosis and purpose. Maya appears to feel somewhat impatient with her desire to understand, illustrated through her repetition of “*pretty quickly*”, almost implying that she was struggling to get past the magnitude of uncertainty.

Earlier in her narrative, Maya provides a sense of clarity in her search for a purpose:

*He raised you know around four thousand pounds for charity, and that made him! That helped him! That usefulness and gratitude. It helps your sense of happiness in the world, and they’re hard to find on this programme. So things that you can make happen, him [Son] I’m talking about now, that wouldn’t happen otherwise, it gives you a better sense of life (Maya, p.4)*

Maya uses the success of the charitable event that her son participated in to reflect on the purpose of this diagnosis as something positive, one that has helped shape her son’s identity (as illustrated through her words, “*that made him!*”). It seems important for her son and herself to seek recognition for feeling useful and find appreciation in the unpleasant nature of the diagnosis, as “*they’re hard to find*”. It seems she has found some of the answers to the questions that she was asking above. Her use of a second person narrative in this extract, e.g. “*you*” or “*your*”, suggests that the purpose is not limited to her son, and offers a broad, positive application to the audience (as well as herself) that resonates in her

feeling useful and thankful that her son has experienced this journey. What the last two cases share, i.e. Sally and Maya, is the desirable meaning this diagnosis instils in people's lives, which would not have happened in the absence of their child's illness.

### **Subtheme two: Surreal Experience**

When asked to describe what it is like to find out about their child's diagnosis, the majority of the participants describe their experience of shock and disbelief in terms of a surreal experience. The way they describe their experience is idiosyncratic as each participant demonstrates their own take on the way they make sense of a phenomenon that they find to be strange and difficult to understand. This subtheme carefully focuses on the 'phenomenological core' of their descriptions that can provide a valuable and revealing sense to their experience.

Abi describes how she is trying to make sense of her child's diagnosis:

*I just think it's the unfairness of it. It's just that why and how could it possibly happen to us? But there isn't anything that we could have done to prevent it, I think you just can't quite believe it's happened. I mean it really just feels like it's all been a bit surreal, like I've lived this life but I sort of feel removed from it too...It's like you're living another bad dream but there are happy times in that bad dream, like you're just living a bit of a dream (Abi, p.8)*

Abi's reference to a dreamlike experience, together with her difficulty in understanding the reason behind the diagnosis, excellently demonstrates the subtheme. Her repetition of "just" throughout her narrative emphasises her struggle to reach an explanation in a situation that she feels is unjust. Abi appears to acknowledge the lack of control she has over the situation and her inability to "prevent it", portraying a sense of helplessness and passivity to the situation. It seems that Abi feels overwhelmed by the magnitude of her surreal experience, illustrated by her use of the past tense, "it's all been a bit surreal, I've lived this life", almost implying that she's recalling her life as if it were a dream. It seems she feels "removed from" her present life and placed into a surreal world, creating a sense of

uncertainty between her reality and fantasy. Her experience of “*living another bad dream*” poignantly captures her frightening experience of re-living a nightmare that she cannot wake up from, suggesting she is feeling trapped in her current situation. However, her ability to recognise “*happy times in that bad dream*” could communicate her attempts to search for happy moments to help her appreciate and avert the bleak image created by this illness.

Lucy tries to make sense of when she found out about her child’s diagnosis:

*It was horrendous and you’re thrown into this sort of parallel world which you’re almost looking in on yourself? That you’re looking down at yourself and thinking this can’t be happening, more to Leah [child] than to you really...But you’re sort of living, it’s a weird feeling that you just can’t. You don’t really have time to think at the time of the diagnosis too much about it (Lucy, p.3)*

Lucy provides a moving account of her out-of-body experience when she learns her child is diagnosed. She vividly describes her experience as being “*thrown into*” a hypothetical world that is co-existing with her reality, as if she had no choice but was forced to examine herself introspectively. Her questioning suggests she may not believe in this experience herself and gives the impression that she could not possibly be believed by others. She describes it as though “*you’re looking down at yourself*”, suggesting a vivid sensation where she moves outside her physical body and feels disconnected with herself. Like Abi, Lucy shares her difficulty in making sense of her experiences through her comment “*you just can’t*”. Furthermore, the phrases she uses such as “*weird*” suggest she thinks her feelings are unbelievable, which adds a layer of meaning to her surreal experience. Her reference to not having enough time to comprehend the quick succession of events suggests the difficulty she experienced in processing her feelings and the magnitude of the shock of diagnosis.

Dara provides a moving account of how she made sense of her child’s diagnosis:

*So it’s a feeling when I was told my son has got cancer, I thought about death and I was like part of me is going to die, it’s going to go under the ground so my womb was*

*so sad, it reacted to that so we feel pain, I felt, for me I felt an explosion, you know there's a bomb exploding inside my tummy. When that happened, oh my God I was like shaking. I cannot explain what was it but that's how I felt. And that's connected to the bonding to the mother to the child, it happens to the whole of nature, it could happen to animals, they are the instinct (Dara, p.3)*

For Dara, hearing her child's diagnosis evokes a significant terrifying sensation within her body, illustrated through her vivid descriptions of an explosion. It seems the only way she can explain the dramatic, negative and deep psychological impact of shock, loss and grief is by connecting to and making sense of her psychosomatic response. Hearing the diagnosis was not just distressing, it was almost catastrophic whereby the effects of diagnosis were so broad they were felt inside her womb as a bomb exploding. One could interpret that Dara's inability to "explain what it is" emphasises her psychological shock as she loses her ability to explain her overwhelming experience. When Dara found out about her child's life-threatening illness, she was haunted by thoughts of mortality and felt a part of her was going to die. It's as though she was going to lose the parent in the child, as her son represented a part of her identity, which highlights a strong and inseparable attachment. She discusses further how her distress is symbiotically related across the "whole of nature" as a maternal instinct, whereby the mother's womb has an important and protective bond which warns of danger if her child is hurt or distressed. One could interpret Dara's vivid explicit descriptions, alongside her difficulty in sharing her experiences, as a meaningful response to her shock and paint an overall impression of a surreal experience.

Maya shares how she makes sense of receiving her child's diagnosis:

*I think it's because you can't believe...It's too big to believe...or I...I don't really know. I'm trying to remember times when I've been shocked more physically and what causes it? I suppose it's the...I suppose it's like being hit by a bus isn't it, so I suppose it's the weight of the diagnosis, yeah, you just...What is shock? Maybe it's the information that comes faster than you are moving to the body. So, faster than the speed of light but emotionally. Maybe it's information that happens and it's too quick to process (Maya, p.2)*

Maya describes the shock using metaphors to communicate the unexpectedness and great burden of receiving the diagnosis. The enormity of receiving the diagnosis feels so overwhelming that she struggles to comprehend her experience, as highlighted through her lack of conviction and her repeated questioning. It seems this sense of uncertainty can only be tangible for Maya by associating the shock and its importance to *“being hit by a bus”*. Her shock feels so surreal and uncontrollable; she uses the bus metaphor to help make sense of her shock as it helps her contain her emotional trauma and turn it into something *“more physical”*. In addition, her sense-making captures how surreal it feels for Maya to process what has happened to her. She describes receiving the diagnosis as though it happened at the *“speed of light”*, emphasising that the emotional impact feels so rapid that it’s virtually impossible for her to contain and keep up with.

### **Superordinate theme two: Powerless**

Participants express caring for a child with cancer as closely linked to feeling powerless. This superordinate theme attempts to capture this experience and is presented across four subthemes. The first explores the participants’ experience of feeling powerless which stems from not being in control and feeling helpless about their child’s condition. The second subtheme explores the impact of their experiences on their life and the third attempts to capture how participants struggle with holding onto other issues whilst they are trying to cope with their own. The final subtheme examines how participants feel they need to cope with feeling powerless by appearing to be strong and invulnerable for their sick child.

### **Subtheme one: Feeling Powerless**

This theme explores how participants realise how much control they hold in relation to their child’s illness. All parents reported the lack of control over their child’s condition left them feeling restricted and helpless. Parents have little choice but to accept that they are no longer in control, both of their child’s condition and more broadly speaking of their life. Holly provides a moving account of her feeling restricted and powerless when she has no control in handing over the care of her son to the healthcare professionals:

*He [son] couldn't explain how he was feeling...with all these people prodding and poking him so he was just, it was really strange so you can't explain so you feel a bit powerless in that sense to, even though I'm telling him "it's okay, it's okay", he doesn't understand, he was ten months old [Holly laughs whilst tearful]. He's just thinking why is my mum letting these people do this to me, especially trying to get, find a vein, get an cannula, that was ha-...one of the hardest things I found umm...having to help doctors or umm nurses anyone, to pin him down to get blood. You just want to say leave him alone, he's had enough but you can't because what I knew they needed it but oh it was heartbreaking especially with him just making eye contact with me and that was it, I can't do anything, I can't pick him up and say it's okay, I had to help holding him and things like that but umm yeah you do, you just feel powerless (Holly, p.5-6)*

What emerges from Holly's narrative is the powerful way in which her child's illness and the treatment can be seen as undermining her sense of power. The descriptions suggest a raw quality, the realness of someone getting tortured and consumed by pain that one cannot prevent or control. Holly felt restricted and helpless whilst watching her child suffer from a treatment that is unrelenting and intrusive. Her feeling of "powerless" is so profound and broad that it arises not only from her inability to protect and alleviate her son's pain, but through her child's inability to convey his emotions. The repetition of the word "powerless" emphasises how she is left feeling weak and defeated, as she battles to resist her loss of control. She makes it clear that she has very little choice but to accept and surrender to treatment as "they [medical professionals] needed it". Holly is explicit in pointing out how she thinks her son is perceiving this torture, as though she is failing as a mum to meet her expectations to rescue him and take control of his pain. It can also be hypothesised that Holly perceives herself as becoming another medical professional who intrudes on her son when she's "having to help doctors", reinforcing her loss of control as she has no other option but to help them. Her use of the word "heartbreaking" emphasises the enormity of her helplessness in letting go and watching her child suffer in pain through his sorrowful eyes. This notion is supported by the statement "I can't do anything", which demonstrates the complete removal of power and control.

Mohammed conveys his lack of control by describing his relationship with God:

*I have no control over it [cancer]. As a human, I have no control over it...you have to accept it's not from you. It's nothing that you've done bad because it happened, but it happened. God has created it for you and you're going through that experience. You have to take it the way it is (Mohammed, p.6)*

Mohammed recognises that his child's illness is beyond the control of human beings and attributes his child's illness to being part of God's divine plan. He conveys that the cause of the disease did not stem from his actions but from God himself, emphasising his perception of God's omnipotence. This perception is enhanced by his statement "you have to accept", which explains the complete removal of choice for him, other than to surrender to his destiny. The fact that his experience is induced emphasises him feeling completely powerless and results in self-reinforced passivity.

The idea of accepting a loss of control is well demonstrated in Sally:

*...accepting that I'm not in control. In a way, I kind of just went...you know we all think we're in control in life, but actually none of it is given what we're given. You just got to go with it (Sally, p.2)*

Like Mohammed, Sally accepts that she has no control over the situation. It seems that she has an emerging sense of certainty (through her process of acceptance) of the uncertainty in one's perceived level of control. The effects of her loss of control are global as she draws attention to how "we all" experience a cyclic notion of perceived sense of power but in reality, we fail to retain it. However, by stating that none of the control is "given", she implies that one has to learn to gain a sense of control, and she has struggled to accept this. The net result appears to be her sense of passivity or helplessness with the situation, which is demonstrated by her statement "you just got to go with it".

The worry of having no control for Abi appears as if it will continue throughout her life:

*The relapse thing niggles away like a worry but again, you just have to know that that's always going to be a worry, that's always going to be a worry for the rest of my life that something will come back but you have to park that worry because there's nothing that you can do about it, it's out of your control. All of this is out of our control (Abi, p.5)*

It seems Abi's danger of relapse is so consuming and powerful that her ability to control her catastrophic thoughts are underestimated, as she is certain that she will always be worried that "something will come back". Abi gives the impression that there's a sense of inevitability of cancer going hand-in-hand with the fear of relapse, as illustrated in her phrase "you just have to know", which infers that she accepts her inability to no longer feel in control. The gravity of this powerless position is more evident as she has no choice but to adjust her mind-set, so she can occupy space for her worries in order to cope. Her description of not being able to escape from the confinement of her ruminative thoughts, as well as her admitting more broadly "all of this if out of our control", highlights the extent to which she feels powerless.

### **Subtheme two: Life on Hold – 'My hands are tied'**

Another factor contributing to why the experience of having a child with cancer evokes feelings of powerlessness is because parents experience a significant change to their daily routine and lifestyle. The child diagnosed often spends much of their time in hospital receiving treatment, accompanied by their parent. As a result, participants have no choice but to focus their time and attention on their sick child, which impacts on their life. All participants express that their life feels on hold, which means a reduced ability to engage in the things that are important in their lives. Maya describes how her child's diagnosis restricted her life:

*I feel like I've got my life on hold. I kind of. How does it feel? With my kind of parenting, he was 7 and I was about to go to work after my two kids, to really go back to really focus on myself and then he was 8 and then he got the diagnosed. So,*

*I've had to go back in time, totally going back to having a baby or a toddler so my life's on hold (Maya, p.6)*

Maya describes how her child's diagnosis affected her perceived capacity to return to work and concentrate on her personal development. Her questioning of herself can be interpreted as though she is trying to get past the magnitude of her feelings that impact her life. She gives an example of how these hinder her personal aspirations that she had after having children, highlighting the sense of chaos and unpredictability associated with illness. It seems as though she is yearning to return to her former self, as emphasised through her comment *"to really go back to really focus"*, which gives a sense of what has been lost. Furthermore, her description of her life being *"on hold"* conveys a sense of feeling trapped in her current situation, as though life is stagnated. This adds to her notion of time passing and life stages – she is explicit in pointing out how she has regressed to a more primitive stage to meet the needs of her sick child.

Like Maya, Sally describes the significant impact her daughter's illness has on her work life:

*...so anger hmm...and you know I've had to stop work and not earn money and you know resentment about that but luckily I've got someone that can support me, but still I like, I don't, I feel like my hands are tied. I just feel like my hands are tied. I know when you have a child, that's your job but it's tough when you don't have a choice you know (Sally, p.5)*

Sally highlights how she stopped engaging in employment to care for her child and how this experience has caused her to feel resentful. This anger draws on a sense of disappointment as a result of her not earning money, which suggests a loss of empowerment and independence as she becomes more dependent on her husband for support. The repetition of *"I feel like my hands are tied"* emphasises her struggle to live a life that she would like without feeling trapped, but also mirrors her loss of control in her current situation that she refers to in the theme *"Powerless"*.

Michael also shares the negative impact of child's illness on his work and goes further to describe the effects on his social life:

*So although, I was focused on getting Sophie right, which is the right thing to do over 3 to 6 months, you start to see the other two, work life and social life, starting to suffer...you know, your friends don't see you, you don't get an invite. They're always there when you pick up the phone but you do start noticing you haven't done stuff with them, so it becomes a bit more difficult. It's like if you were posted overseas for 6 months (Michael, p.5)*

The impact of cancer for Michael appears to be mediated by the demands of the illness (during the initial stages) that force him to adapt his lifestyle and in turn prevent him from engaging in work and having a social life. Throughout his account, Michael highlights the importance of his work as a source of support and refuge from his child's illness, but by losing this framework and focusing entirely on his daughter and her needs, it seems he has noticed an increased sense of isolation and separation from the community. By relating this journey as though he was "*posted overseas for 6 months*", Michael portrays his isolation from a community structure that gave him a sense of cohesion a sense of normal activities, as he demonstrates in his comment "*you do start noticing you haven't done stuff with them*".

Holly provides a perspective on the impact her experience has on her quality of life when her child finished treatment:

*...it was the end of everything but I think it was because I've had someone dictate what's happening for so long, like we had dates, we're doing this, we're doing this, this is what's happening and now it's down to me, and I felt bit like "oooo what do I do?"...I didn't know what to get on with [Holly laughs] cuz everything has been so structured...hmm...and restricted...he was so poorly after every round of chemo... he was in for his first birthday, he was in for Christmas, he was in for my birthday, he was in for my other son's birthday...we spent so many of the big milestones in one room (Holly, p.11)*

The regularity of the cancer treatment is so consuming and controlling that it causes Holly to undermine her role and disrupts her sense of time. The hospital regime is unrelenting and restricting, allowing very little movement for her to take control which in turn causes her to question her own role after her son is discharged from hospital. Her questioning emphasises the extent of her dependency on an authoritative figure who *“dictates what’s happening for so long”* that she feels redundant in her role and adds to the broader sense of feeling powerless with her child’s illness. Her comment *“it was the end of everything”* provides an overall feeling of temporal and spatial entrapment that has the greatest impact on her sense of agency and time. The recognition of the number of milestones that were experienced in one room illustrates the perceived detachment and alienation Holly feels.

### **Subtheme three: Struggles with Containment –**

#### ***“I’ve got this to deal with and I can’t deal with you”***

A theme common across all cases is the participants’ struggle with tolerating issues outside their own, as they express their desire to withdraw from such issues that are potentially distressing in order to facilitate their coping. Having a child with cancer evokes difficult emotions and feelings within participants (in particular feeling powerless, as outlined in the previous subthemes), which is why participants feel it is important to feel safe and contained whilst they prioritise and care for their sick child. Holly’s quote below perfectly illustrates how difficult it was for her to manage others’ distress:

*I have become very hard as well...like emotionless...hmm and I felt bit, I didn’t want to hear anyone else’s problems, I didn’t want to see other people’s children, which is really a bizarre feeling but with my family, if they had children, I wouldn’t want them to come and visit because why is your child ok and mine isn’t...I felt terrible feeling that way and even saying it because I love these children in my family but I couldn’t bear to see them or to hear anybody’s stories “oh this happened”, I don’t care! I just felt like I was in a bubble, wouldn’t want to hear about anything else, couldn’t watch T.V., I couldn’t watch the news (Holly, p.8)*

It seems that Holly was overwhelmed and frustrated with minor issues that she was presented with, that she refused to worry about upon realisation of her own misfortune and tragedy of her child's illness. She describes feeling like she was in a "bubble", which gives an impression of the extent to which she was immersed in her own feelings – as though she was at a tipping point of easily bursting with her uncontained feelings or implying a desire to float away and become de-attached from *"anything else"* that would make her feel more vulnerable. Her refusal to worry about petty issues from others illustrates how her anger appears to feel so uncontrollable that she isolates herself further by avoiding contact with the outside world (by avoiding news and T.V.). Her sense of guilt from her inability to tolerate seeing healthy children signifies the sacrifices that she's had to make to protect herself, and ultimately her sick child. One might assume that Holly is referring to herself in the past, as most of her narrative is expressed in past tense, but she starts in the present tense: *"I have become very hard"*. It seems her psychological distress is so enduring and uncontained that she's observed a transformation in herself, to one who is now tough and more able to cope but is numb and no longer affected by distress, *"like emotionless"*.

Abi experiences similar feelings to Holly as she refuses to hold worries of other people in order to facilitate her coping:

*Also, I can't cope with other things to worry about as well. I think I'm full of the worry anyway and anything that's trivial that comes in I literally cannot cope with it. It's a coping thing I'm sure because otherwise I just won't cope (Abi, p.10)*

Abi's preoccupation with her own worrisome feelings makes it very challenging for her to attend and cope with other people's issues, on top of her own. The threat that she faces from small and insignificant issues can contaminate her ability to cope, implied by her phrase *"trivial that comes in"*, demonstrating how delicate her containment process is. Her phrase *"I literally cannot cope"* suggests that she acknowledges she can no longer bear the experience of worrying about petty issues and suggests these sacrifices must be made to prioritise her sick child and help her cope. Sally, similarly to Abi, found it unhelpful when others shared their distress as it impacted her ability to cope:

*I know what I found really hard, is seeing how upset people get. I find that hard. You know when my family might ring me and go “oh my gosh she’s got no hair, I saw that photo and I just... [Sally grasps with shock]” and I can really break something, because I’m like, “so what she’s got no hair!? Why!?” That’s not helping me, it makes me upset, because you can’t deal with a lot of people’s emotions. I fear on their end and actually that is the hardest bit, keeping your own strength while other people are breaking down (Sally, p.4)*

Sally describes how coping with the emotional distress of others can be very challenging and overwhelming. Her phrase “*you can’t deal with a lot of people’s emotions*” fits perfectly with this subtheme, suggesting how she struggles to hold different emotions and feelings from others. She provides an example whereby her parents’ shock in her child’s hair loss feels unconstructive and, in some way, damaging to her ability to remain strong as a parent for herself and her child. It can also be interpreted that through highlighting the stark changes in her child’s appearance, her parents indirectly remind Sally of the loss of control that she has over the changes that occur during the illness, and in turn force her to acknowledge her pain that she is desperately trying to suppress. In turn, such unexpected emotions of shock create anger in Sally, and the profound sadness she observes in others reinforces the perception that the cancer is having a negative impact upon everyone’s emotional well-being. She illustrates this further through her phrase: “*I fear on their end*”, demonstrating the dread she experiences in people’s inability to process their grief and despair whilst she struggles with her own. It potentially creates a vicious cycle, in which it reinforces her need to cope by maintaining her “*own strength*” to help her create a holding environment in which she and her child feel safe and contained.

Michael provides an interesting account where he overtly expresses his struggles to contain his mother’s grief:

*I’ve said to my mother that “I’ve got this to deal with and I can’t deal with you, so you need to sort yourself out, last thing I need is for you to become a liability because*

*I've got enough to deal with...look mum, it's not for you to deal with. I need to deal with Sophie [child] not you, so sort yourself out" (Michael, p.9).*

It is clear that Michael avoids processing his mother's grief, and assertively expresses that he already has "enough to deal with", illustrating his difficulty in managing additional emotions. It seems that his mother is offering some space to share this grieving process, as he states, "it's not for you to deal with", suggesting he feels she is not emotionally prepared and is making the situation worse. As his anger fails to subside, he threatens her with "last thing I need is for you to become a liability", which suggests his mother's emotions are likely to put him at a disadvantage and divert his focus away from his child. His fear of feeling vulnerable and overwhelmed with another's emotions forces him to deal with the situation by gaining a sense of control and disconnecting from those who hinder his ability to cope. The participants all feel the need to move away from the unproductive, emotional weight of others to help them cope and overcome feelings of powerlessness; thus, strengthening the link between this subtheme and the overall powerless theme.

#### **Subtheme four: The Invulnerable Self**

This subtheme explores how the participants feel uncomfortable in showing their emotional distress to their child diagnosed with cancer and instead wish to appear strong and robust. Due to feeling powerless in not being able to control their child's illness, parents feel susceptible to upsetting feelings and thoughts. This theme examines how participants express an element of responsibility towards protecting their child, as they feel sharing emotions that are upsetting will expose their vulnerability and might impact their child's well-being during their recovery. Participants comment on the importance of appearing to be strong (by suppressing their feelings) as they consider that a parent's emotional state can affect their child's capacity for effectively regulating his or her emotions. Abi's excerpt highlights how she believes it is important for her to convey a strong sense of self in her child's presence:

*I think you can't go into pieces in front of your child, you got to pull yourself together and seem strong, and be there, you're their life line and that's what I mean, you have*

*to think “right ok, this is horrendous and there’s tears” but then you can’t let Alice see that we’re obviously really upset about something that is told to us, so you go on autopilot...I have tried not to show my emotions in front of her (Abi, p.3)*

Abi seems confident in her pursuit to “*seem strong*” for her child who, she believes, is relying on her for a sense of security and safety. Her phrase “*you’re their life line*” highlights the significance of her role as a parent to protect and motivate her child’s emotional well-being and she believes her child is reliant on her mother’s robustness and resilience. It seems that Abi recognises this journey as evoking feelings of grief, as illustrated in her use of words such as “*horrendous*” and “*tears*”; however, her capacity to recover quickly from such difficulties and not display her emotions seems to hold paramount importance and serves to position Abi with an obligation to look after her child. Her repetition of the word “*can’t*”, alongside phrases like “*got to pull yourself together*”, emphasise her need to become calm and remain in control by pushing away her emotions. Abi’s tendency to hide her true emotions from her child and stay in control suggests that the fear in exposing them would make her look weak and powerless, which resonates with the subtheme of ‘Feeling Powerless’. However, the word “*tried*” suggests this tendency to conceal is not always possible and instead of feeling susceptible to them, she forfeits her personal power by going on “*autopilot*”.

Mohammed also shows a strong obligation in his need to show a strong sense of self:

*I’ve learnt that you need to be strong, and you need to stay positive, you need to think positively for your child, because your child basically will see your reaction and he will basically get his strength from you, so if you’re weak, he will get weaker...the more you’re strong for him and for yourself, the more you’ll come out of this stronger together (Mohammed, p.18)*

Like Abi, Mohammed believes it is essential for him to be perceived as a strong parental figure who fosters emotional stability for his child. He has “*learnt*” that strength and an optimistic mind-set are key ingredients for a parent to provide for their child. Similar to Abi’s

narrative, Mohammed suggests children are weak, inexperienced and dependant as demonstrated through his use of phrases such as “*you need to*” or “*for your child*”. It seems children rely on their parents to provide strength and security by instinctively patterning themselves on them. He provides a strong conviction in how children acquire their strength of character, and their ability to cope, through observing their parents. One can infer that Mohammed avoids sharing his vulnerability (emotions that are particularly upsetting) as he explicitly associates a parent’s emotional strength as having a significant influence in the development of a child’s well-being, and their own. Providing assurance and being responsible for his child’s emotional robustness seems crucial if they are to have an optimistic outlook in their journey, as illustrated through his words “*you’ll come out of this stronger together*”. This helps him to avoid sharing his feelings of powerlessness to his child, thus facilitating his child’s coping as well as his own.

Lucy conveys how she avoids sharing her emotional vulnerability with her child to facilitate coping:

*I cry a lot. So, but, at the same time you can’t be too emotional or too pathetic, because you know you have to look after Leah and she’s the priority. So, you know it actually all stems, I realised for me, that I struggle the most when Leah is struggling...I think a child feeds off your, you know, it can feed off your emotions and can see if you’re worried, especially an older child. So it is important that you are strong for them and that you...I suppose it’s a balance isn’t it between showing them emotions. So a child doesn’t want to see a parent crying because that’s not going to make them feel better, so you then think “get a grip” and then you know, I’m not the person going through this and you have to be strong for them (Lucy, p.12)*

Lucy disapproves of sharing her sadness with her child in order to appear brave and provide protection, perfectly demonstrating this subtheme. She describes her struggle with sharing her vulnerability with uncompassionate, self-critical expressions like “*pathetic*”, which emphasise Lucy’s robust attitude by suppressing her emotions in order to prioritise her child’s care and well-being. Like Mohammed, Lucy recognises how children can learn and “*feed off*” their parents’ emotions, which seems to reinforce her sense of responsibility to

provide a safe, containing and a more resilient environment for her child. Having an “*older child*” adds to this notion of how she needs to be more careful in how she appears emotionally, as she implies that her child is more able to understand, use, regulate and manage her emotions than a younger child would be. Lucy’s need to maintain a strong sense of self may stem from her belief that failing to do so might hinder her child’s ability to cope, which in turn would make Lucy more vulnerable as she stresses how she struggles to cope when her daughter is struggling. This reciprocal mirroring of emotions in a parent-child relationship seems to reinforce the need to sustain stability to prevent affecting the other, which is further strengthened in Lucy’s phrase “*get a grip*”, and echoes Abi’s notion to stay in control of one’s emotions. Lucy’s dismissal of her own emotions, as she is “*not the person going through this*”, is also shared by Michael:

*..there were moments when I look back and think “gosh this is crap” but then I thought I have no right to feel sorry for myself because it’s not impacting me, it’s Sophie’s the one who needs the support so any moment of that mind-set I will just dismiss it and kind of go “that’s not right, you need to be strong for her” (Michael, p.3)*

Here Michael focuses his tendencies to conceal his emotional fragility away from his child during times when he feels overwhelmed with his daughter’s illness. It appears that Michael experiences a sense of emotional pain, as illustrated through his phrase “*gosh this is crap*”, but is quick to deny, invalidate and withdraw himself from potentially feeling distressed and appear helpless when protecting his child. His endeavour to suppress the emotional pain seems to come in the wake of his belief that he “*needs to be strong for her*”, as otherwise being vulnerable may reveal his susceptibility to his feelings, thus exposing him as a weak and powerless parental figure.

### **Superordinate theme three: Relationship with Others**

This superordinate theme seeks to explore the relationships between the parents and other people during the journey of their child’s cancer. The first subtheme explores the relationships participants formed with professionals who provided care and treatment for

their child. It also examines participants' experience of support received from their relationships with others in their social network. On the whole, it aims to address the positive and negative impact that such relationships have had on the parents during their child's cancer journey.

### **Subtheme one: Relationship with Professionals**

All of the participants have experience of receiving care from NHS medical professionals, which forms an essential part of their child's care and treatment. An interesting finding that emerged from the data was the participants' satisfaction and dissatisfaction with their relationships with hospital staff. This subtheme examines how parents relate to these professionals, which in turn can inform us about their perception of service provisions.

Dara shares her satisfaction in the service she received:

*They did not really pressurise me on anything and they were, they seemed to be easy when I was doing so with the juicing everything was all ok, when they came to me about flu jab...I had a choice to say yes or no and I was not criticised for it, so I felt like I was given my parenthood power and no one snatched it from me because it's like parent have a power and the doctors have their job to do so I didn't feel like I was, pushed into something. I was respected, my views were respected as a parent...so they didn't make me feel like stupid or something (Dara, p.13)*

Being flexible, understood and respected seem to be important aspects in the care Dara received. She conveys contentment with professionals who do not reduce her agency as she gives examples of when her interventions were respected alongside medical treatment (e.g. refusing the flu jab or creating vegetable juices to promote her child's health during chemotherapy). Her statement; *"I was given my parenthood power"* illustrates how doctors listened to, and responded to, her concerns and preferences which created a power balance between her (as a parent) and the doctors to reach decisions about her child's treatment and care. It seems Dara was afraid of her decisions being *"snatched"* away, but she was not undermined and was given the opportunity to practice what she knew was best for her

child. In Dara's statement *"I had a choice to say yes or no and I was not criticised for it"* she emphasises that the care she received was relational, demonstrating that she was not insulted or judged negatively.

Sally describes a satisfying and unique relationship that she had with a professional:

*CNS [clinical nurse specialist]'s very spiritual and weirdly we are as well, and Katy [child] has these hmm crystals and Ganesh, CNS gave these gorgeous like rose crystals that talked about how it helps about healing and love and I think, we go in there and talk about those things with CNS and it just, it just changes everything and it just shifts it all you know...I feel very fatalistic about having her in our life and having her help us (Sally, p.12)*

Sally's *"very spiritual"* relationship with her CNS illustrates the deep and sacred bond that they have created. The word *"weirdly"* illustrates a unique connection and implies how Sally may not have expected to form such a personal and compassionate relationship with a medical professional. The receiving of spiritual gifts from the CNS appears to show how she felt comfortable and grateful to be receiving affectionate care from someone who has gone beyond what was expected of them. In her statement *"it just shifts it all"*, Sally appears to feel somewhat overwhelmed by the enormity of change these heartfelt gestures create. All of this provides a strong conviction that her relationship with the CNS is *"very fatalistic"*, which relates back to the subtheme of *"Purpose"* where she emphasises that her child's diagnosis is part of a *"bigger purpose"*.

In contrast, Mohammed conveys his dissatisfaction about the care he received:

*It was stressful, I was not able to see the doctor the first, second, or third time and then after all that to get this kind of treatment, I felt really angry and I was really furious because you know your child better than anyone else and you would know basically if something was going on wrong. I know even if it was a cold or flu...then to be treated in this manner and to be told basically "you don't know anything, we*

*know better”, I got really angry so I was really in a state that I could have just burst into the air (Mohammed, p.5).*

Mohammed shares his frustration and discontentment with the service he received from his doctor. He gives the impression that not only did the failure in securing an appointment mean his needs were not being met or recognised, but “*then after all that*” to feel disregarded by his doctor in his ability to make a decision humiliated and enraged him. Mohammed’s repetition of “*angry*”, along with his description that he could have “*burst into the air*”, emphasises the intensity of his anger that is building up as a result of neglect from the doctor. In contrast to Dara’s account, Mohammed felt his parental concerns were not understood nor respected by the professional, and instead his knowledge was insulted and undermined by the doctor who explicitly highlighted a hierarchical power imbalance in their relationship. Mohammed’s remark “*you don’t know anything, we know better*” exemplifies this power difference and the lack of autonomy in his ability to influence the doctor-patient relationship.

Holly also shares her frustration with professionals involved in her child’s care:

*At least just do a blood test, just listen to parents more...and know that you’re not going crazy. As a parent, when you really know something is really wrong. You can’t switch off from it. You really push for medical professionals to just go that little bit further to check...I literally had to take back-up and say “don’t let me leave”. You have a right, I have an instinct as a parent so I think they should go with it, don’t leave it (Holly, p.23)*

Like Mohammed, Holly feels dissatisfied that her concerns and requests were not taken seriously by medical professionals, as one could potentially interpret through the way Holly begins her narrative with “*at least just do*”. She gives the impression that health professionals failed to meet her expectations of basic care or attention that her child deserved, which created a sense of frustration. It seems she is desperately seeking validation in her concerns as she wants to know she is not going “*crazy*”. This word also gives insight into her enhanced sense of urgency as she is conflicted with her innate

parental “*instinct*” to be listened to and not dismissed or discounted by the doctors. The fact that Holly had to take her sister as “*back up*” illustrates how lacking in confidence she feels, as a parent, to attend to her child’s suffering and assertively protest against the medical advice. This is further exemplified by her words “*you have the right*”, as though she is encouraging other parents to follow their gut feeling and demand the basic human rights she expects to receive from healthcare professionals. Holly, and indeed other participants like Mohammed and Dara, express their innate parental instinct which drives them to know when their child is unwell and demand their dignity is respected when seeking appropriate healthcare from their professionals.

### **Subtheme two: Support from Social Relationships**

All participants comment on the support they have received from their social relationships since their child was diagnosed with cancer, which for most was a salient part of their experience. Most participants express such support as being positive and helpful, which appears to stem from feeling accepted, understood and validated by others. However, some participants describe the occasional difficulties they encountered within social relationships.

Sally discusses the helpful support she received from her social relationships:

*The mums, especially the mums really, I don't have to explain anything, I can go and go “I’ve had a shit day” and they’re like [Sally sighs] “we get it”, I can cry and say I don't want to talk about it, you know, they just, I don't have to explain anything...I get that from my friends and normality you know, just normality, it feels normal. Because you walk down the street with a child with cancer and you’re like “why is everyone staring?” and then you’re like “oh my God, that’s right, of course I forget Katy’s got cancer” because around our friends it’s so normal, you’re in your little world (Sally, p.8)*

Central to Sally’s account is the tremendous sense of collectiveness and acceptance she experiences amongst other mums, which seems to be different from other relationships. She very effectively communicates the unconditional acceptance and validation whenever

she conveys her distress. Her repetition of “*I don’t have to explain anything*”, along with their response “*we get it*”, further exemplifies this point and again suggests her friendship alliance provides compassion for her to explore and attend to her pain by taking away the pressure of feeling excluded. Sally’s haunting observation of the public gazing at her child’s appearance really stresses how this illness creates a sense of being different from others, making it more difficult for her to relate to others for fear of being stigmatised. However, her interpersonal relationships strengthen her sense of belonging and seem instrumental in helping her cope by providing containment for her issues. This is noticeably different from the difficulty she faced from containing others’ distress under the theme “struggling to contain”.

Holly also describes her relationship with another parent as beneficial:

*She hasn’t spoken to anybody, so it’s different with parents talking to parents, it is different talking to a professional because even though they’re professionals, they deal with it day-in day-out, they don’t have the emotion that a parent has, and yeah, that was really really helpful and again we got quite close (Holly, p.19)*

Like Sally, Holly describes her relationship with another parent as distinctly special, one that creates a feeling of acceptance and ability to engage through empathy that stems from a shared experience. Communicating with and relating to the other parent seems to be a valuable component for Holly, as she feels that parents have significantly greater knowledge of and emotional attunement to her experience than professionals. Another feature illuminated in this account is the importance of validation amongst parents, which allows one to disclose vulnerable parts of oneself that can be very difficult. During her interview, Holly also expressed her avoidance of sharing her distress and her withdrawal from society during the initial stages, and this highlights the progress and value both parents found in subsequently supporting one another.

Lucy conveys how she and her child have found benefit from adult relationships:

*Adults throughout this whole time have been a very important part of Leah's well-being...and it's been really helpful to her and there's an old lady who is an old brown owl who has gone through cancer herself and has been incredibly kind where she has offered to take the children to brownies and now she's taking them to [Name of Garden] tomorrow because I think she just wants to help. So again, it brings out the best in most people (Lucy, p.22)*

Lucy provides an example of how she is grateful for the generosity, kindness and support adult relationships provide throughout her child's journey. She draws on how this lady, who also suffered from cancer, has provided a support network for her child, helping one another to make sense of their shared experience, which in turn provides comfort and supports the child's "well-being". It seems this lady has extended her support for Lucy, too, by offering support with child-care, as she highlights in her interview how she has continued to work throughout her child's treatment. The theme of receiving positive support from others appears to serve a function for individuals, as according to Lucy adversities like cancer "brings out" positive attributes in others or makes them easier to notice.

Conversely, some participants draw on the exceptions to this positive and supportive experience from their social relationships. This appears to be evident in Michael's extract:

*All your friends want to help but they don't know how to or they don't quite know what to say, like "be strong for your child" is probably the worst thing that you can say to someone. Like if someone else tells me to be strong, then I'm just going to lose it. Because that's the natural response to someone who is going through a difficult time and what I've realised is actually that's not necessarily needed (Michael, p.8)*

Michael relates his dissatisfaction with the support he receives from his friends. He believes his friends have good intentions in wanting to help him, but do not fulfil the intended purpose as they lack the ability to convey their support. Michael appears to be experiencing a sense of frustration and bitter disappointment when he is overwhelmed with comments pressurising him to "be strong". It could be argued that Michael is reminded that he can't or shouldn't show any vulnerability, and the term "I'm going to lose it" could be interpreted as

an act of aggression when someone stops him from being open to express his difficult emotions. It seems their offering of help is interpreted as extremely emasculating and useless, which highlights the gravity of his disappointment in others' support.

### **Superordinate theme four: A Process of Transformation**

Within all the interviews, the experience of having a child with cancer is profound in terms of the deep impact it has on parents' personal lives. Participants reflect on the significance of the event in shaping their subsequent experiences. This superordinate theme explores what changes have occurred within the participants as a result of their child's illness and how they re-evaluated their interpersonal relationships with others and themselves. It also investigates the transformation that parents observed to their child during chemotherapy.

#### **Subtheme one: Transformation of Values**

Throughout the participants' accounts, it appears that the experience of having a child with a life-threatening illness has led them to re-evaluate what is important in their life. Particular areas of self-reflection revolve around changing their perspective on values that they once believed to be important in their lives, a new awareness of health, and an appreciation of valuing life after realising how fragile it is. This subtheme also discusses how their perspectives have changed after having a child diagnosed with cancer, suggesting a temporal element to the subtheme.

Abi shares her how her daughter's illness has modified her beliefs around not letting minor issues bother her:

*It's like silly things, like "have you been invited for a coffee with a friend?" It's the things really that you would get yourself worked up about that, like "are they [friends] going out for drinks and they haven't asked you?". It's all totally rubbish...those are the things that used to worry me. I used to be quite insecure about things (Abi, p.6)*

Abi reflects on the change that occurred in her attitude towards not being invited to events by her friends. It appears being involved or being a part of friendship gathering were once important to Abi's self-worth, as she uses past tense to stress how this "used to" evoke anxiety for her. She reflects on how this worry would pre-occupy her thoughts and impact her perception of herself but are now meaningless and are not worth worrying about. This can be seen in her comment "it's all totally rubbish", which illustrates how the effects of her daughter's illness are very broad on what she values. Abi is able to reflect on the change that has occurred to her personality, as her phrase "I used to be quite insecure" implies a change to the way she judges herself on values that threatened her self-image around her social network.

Michael also presents how his values have been changed by his experiences:

*It's helped me review where I am as a person. I actually think it's positive because I am questioning things that I do, from my work and my pleasure and if it's not important, I think, well why bother? It's reset what we want, what should we be doing (Michael, p.5).*

Michael describes how his daughter's illness has given him the opportunity to make sense of his life through questioning his actions, with the intention of instituting change in his work or social life if necessary. It appears he uses his perception of what he values to be important as a barometer to measure whether he should engage in a particular activity. His use of the word "reset" implies that his experience has caused a process of change in the things he desires (i.e. "want") and obligations (i.e. "should"). Although Michael does not bring to light what these are, there is an overall sense that this process of re-evaluation feels quite liberating for him.

This notion that the child's illness has created a positive change in one's values is also expressed by Dara:

*I think my child's illness has opened my eyes to health, how to live healthy. It's changed me into a more sophisticated lifestyle, rather than junk lifestyle [Dara*

*laughs]. So that is what is needed in my religion, don't spend too much money on unnecessary, don't do this, don't eat too much, don't drink too much, watch your health (Dara, p.6)*

Dara highlights how her experience of her child's illness has made her more aware and knowledgeable about health. She reflects on the change that has occurred to her lifestyle, implying that she has moved away from things that she considers as useless or of low quality to one that is "more sophisticated", suggesting a higher degree of knowledge of her values that promote better health. The term "lifestyle" also gives an overall sense of permanence to the changes that she has made her priorities. Her realisation of the importance of health seems to provide a reaffirmation of her religious values that impose numerous limits on her behaviours.

Sally describes how her perspective on life has changed:

*I'm just a lot more appreciative of life really. Of love. It's all just love...I also think you never know what's in store with life and you can never be too, you know when things are good they're great, you can't hang on for too much, everything's impermanent (Sally, p.8)*

Sally's excerpt demonstrates an interesting experience where she has developed a renewed appreciation of life and a deep valuing of love. It is clear that Sally acknowledges how one's life can change unexpectedly, which not only emphasises the fragility of life but the importance of making the most of opportunities. Her phrase "you can't hang on for too much" highlights the temporal aspect and how one has to let go of feelings as they do not last and can change unexpectedly. Sally sees everything as "impermanent", which emphasises the undeniable and inescapable fact of human existence within which nothing is static and provides more of a reason why she has developed a new awareness of the importance of life.

## **Subtheme two: A Renewed Sense of Relationships**

As participants go through this process of re-evaluation and reconsider the implications of their values to their lives, their accounts suggest that their perception of their relationships are altered as a result. Having a child diagnosed with a potentially life-threatening illness, participants begin to re-evaluate their priorities and their resources to focus their care on themselves and their child. This theme has some degree of overlap with the subtheme “struggles with containment”. However, this subtheme emphasises the change that has occurred in their relationships, which was a dominant finding throughout the narratives. I feel it belongs under this superordinate theme because participants face their future relationships with a renewed focus around what is important to themselves and to their family, highlighting a process of transformation. Mohammed shares his experience of how his son’s illness has re-emphasised the importance of the family unit:

*...you start appreciating what you have around you more, you want to start spending more time with the family...everything will go and things could go within a second so, you make the most of what you have with each other as much as you can (Mohammed, p.8).*

Mohammed comes to realise how fragile life is and so recognises the importance of valuing his time with others. His increased sense of appreciation and engagement with his family is stressed through his use of a comparative like “more”, suggesting a process of change as a result of his child’s illness. His phrase “everything will go” suggests a deterministic belief that life is impermanent, which is later characterised through his reference to time, emphasising how fragile life is. As a result, it leads him to make the most of his opportunities by maintaining what is important to him – his connection with family.

Maya discusses the changes she’s had to make to her social relationships:

*So I’ve unstuck myself from pretty needy relationships and my friendship circle is smaller. I am now looking and thinking “I need to start building things again bit” but maybe more mindfully. But it’s definitely changed it...I’m uncomfortable with that*

*though, it's not my nature so I'm still uncomfortable about some of the relationships that I've needed to let go of (Maya, p.9)*

Maya's comment to have "unstuck myself" really stresses how trapped she felt with unsatisfied relationships whose apparent needs were too consuming, so much so that she decided to separate from some of her friends. The fact that she "needed to let go" emphasises how vital it was for her to disconnect. The reduction in her social network suggests that she now maintains relationships that are good quality, rather than focusing on the quantity. Although Maya does not explain why she feels the "need" to rebuild her relationships, she stresses that it has "definitely changed" since her daughter's diagnosis and that she would like to re-build her relationships "more mindfully". This suggests that she wants to renew her relationships with careful consideration to her own needs, as the difficulties that she's encountered with separating from certain relationships are inconsistent with her identity, as she highlights that "it's not my nature". This process of change in social relationships is further discussed by Abi:

*The people who came forward might not be close friends but they become closer friends when you're going through these times and other friends who were there at the beginning are not there. So you get the feeling who are your strong friends during these times and you keep it small...the friends that matter are the ones that are helping you (Abi, p.6)*

Abi's excerpt illustrates how she's seen her friendships to change over the course of her child's illness and that this has challenged her expectation of relationships. It appears Abi's deep sense of connection is actually built around those that take the initiative to offer their support and show their presence, as this demonstrates to her that they are "strong friends". Such qualities seem important to Abi's sense of self as she highlights her need to be strong as a parent in "the invulnerable self" theme. Therefore, one can interpret that Abi seeks to maintain relationships with those that reciprocate this ability to endure through difficult times, possibly to maintain her strength. She stresses a change in her relationship through the use of a comparative like "closer", suggesting they are not static as they have become more intimate over time. Like Maya, it seems Abi has had to let go some of her friendships

to “keep it small”, emphasising how the quality of relationships is perceived. It seems she evaluates the importance of maintaining a relationship based on the person’s ability to provide what is necessary to satisfy her needs and contribute strength.

Lucy provides an interesting account in the change that has occurred to her relationship with her husband:

*...my relationship with my husband...it’s definitely cemented our relationship in many ways. It does put a strain in many ways on your relationship because obviously if you’re spending alternate evenings away when you don’t see each other as much, but it’s definitely not made us drift apart from each other if anything, it’s definitely I think brought us probably together as a family as well (Lucy, p.20)*

Here Lucy discusses how her experience of her child’s cancer has strengthened her relationship with her husband and family members, as she notices a renewed sense of togetherness. Her assessment of how her relationship has developed into something that is stronger and more long-lasting is emphasised through the use of the word “cemented”. This is a recurrent notion that Lucy refers throughout her excerpt, which addresses the perceived positive contributions that could come to one’s relationships from a potentially life-threatening illness. None of the participants expressed challenges to or conflicts within their relationship with their partner as a result of having a child with cancer.

### **Subtheme three: Transformation of Child**

An interesting finding to emerge within the data concerns the changes that participants observe to their child during chemotherapy. Their concerns coalesce around the superordinate theme of transformation as most participants experience a change so profound from the effects of steroids that this impacts their child’s sense of self and has a negative impact on their mood and physical ability. No participant reports any positive changes to their child during their treatment. One of the most poignant accounts of observing change in their child is conveyed by Sally:

*I think the worst bit was hands down the steroids because you lose your daughter, your child's personality and they become someone else, and they become...my daughter Katy is a very up little girl and to see her depressed broke our heart...when you lose their personality, and they look at you, and then they look at you and she say's "I don't feel myself", you know, "why does this keep happening to me?", and I feel so angry and I feel so weird...they're just the demons to me the steroids...it was just hell (Sally, p.6)*

Sally describes the devastating impact of steroidal use on her child's identity and psychological well-being. She explicitly alludes to the magnitude of change that she notices in her child, which seems so catastrophic that her child "becomes someone else". Sally sees her child as having lost her identity – an extremely happy girl who has been replaced by an enfeebled and "depressed" self, which causes Sally to feel great sadness and anger. This anger also appears to feel uncontrollable for Sally as she notices her child voicing her struggles with the changes she experiences, which may elicit Sally's loss of control as she cannot help her child's feelings of despair. Sally uses the word "weird" to convey her difficulty in understanding the substantial changes to her child's sense of self. Surviving this ordeal for Sally appears to be highly traumatic and one that is full of suffering, as she makes theological references to it feeling like "hell". Furthermore, she refers to the steroids as "demons", which one could interpret as referring to the supernatural powers these steroids have to possess and threaten her child's identity.

Maya shares the changes she observed in her son by trying to make sense of them using a powerful metaphor:

*He is very gentle, very beautiful spirit and it was too much for him. You know he was on heavy steroids which turn him into like the Hulk so for someone who is incredibly gentle to ever feel angry there...umm...and upsetting someone else's life, a nurse or a doctor being slightly intolerable for him...he looks at me...the easiest way to describe is the look in the Hulk's eye when he's looking at Scarlett Johansson, that is how Ben [sick child] looks at me. It's only with me that he would do it, and deep in his eyes are*

*“I can’t help it and I’m sorry” and he makes everyone else leave and it’s just agony*  
(Maya, p. 3)

As a result of the steroids used to treat Ben’s cancer, Maya notices a significant transformation in her son’s personality and compares him to *Hulk* to exaggerate this transition. The Incredible Hulk is part of the Marvel Comics character where a scientist, Dr Bruce Banner, becomes exposed to ‘gamma radiation’ during an experiment. He transforms into an incredibly powerful superhuman called the Hulk whenever he experiences anger or pain. This transformation into the Hulk metaphor captures Maya’s own problematic experiences of her son’s aggression due to the side effects of the steroids which “*makes everyone else leave*”, illustrating how distressing this must be for both Maya and Ben. Another aspect of the Hulk’s character is that he is an outcast because his actions are often misunderstood by others, which is similar to Maya’s experiences of what happens with the doctors and nurses who struggle to endure and understand the changes occurring in her son. Maya portrays her son’s eyes as resigned in order to demonstrate his sense of helplessness and despair, making this change even more agonising for her to observe. The Hulk’s behaviour is the personification of righteous rage but is often misunderstood, just as Maya portrays Ben’s actions as a meaningful response to his transformation during treatment.

The transformative capacity of the child does not only impact their emotional state, but is also noticed in terms of their physical ability, as illustrated by Michael:

*She’s [sick child] not the same and also, she’s tired physically, she’s not the person she was a year ago but she’s started to push her stamina up as well a bit* (Michael, p.4)

Michael describes the changes he’s observed in his daughter both at a holistic and surface level. He communicates an overall change in his daughter’s identity by comparing her to what she was “*a year ago*”, emphasising a temporal element to his account through his past and present tense (e.g. “*she’s not the same*”). In addition to his daughter’s change at a macro level, he draws attention to her physical performance where he notices an increase

in her stamina. However, it appears his daughter's fatigue is not a static quality as it seems to alter over time and it can be hypothesised that this can help Michael better understand the transition between the different states of his daughter before, during and after treatment.

## Discussion

### Overview

Following on from the interpretative accounts provided in the Analysis chapter, the discussion chapter will place the findings from the current study into the wider context (i.e. the existing literature). I will attempt to engage in a dialogue between the existing research findings and the themes that emerged within the broader superordinate themes, which were “Sense-making”, “Powerless”, “Relationship with Others”, and “A Process of Transformation”. This chapter will discuss the findings which support or differ from the existing literature that explore parental experiences of their child’s cancer diagnosis. Some of the literature discussed will stem from the Introduction chapter but I will also look at new research that was not previously discussed, as some themes emerged during the process that were not anticipated by the interview schedule. Introducing new literature in the discussion is common for IPA studies (Smith et al. 2009). The chapter will then go on to discuss the clinical implications of the findings to the field of healthcare and in particular counselling psychology. I will conclude by offering an evaluation of my methodology and offer suggestions for future research.

### Sense-making

The present study provides a crucial insight into how participants frame their experiences of their child’s illness, as they seek to understand the purpose of the illness and attribute their own definitions as to why their child suffered from cancer. Participants from the Islamic faith believed their child’s cancer was a trial sent by God and that passing this test of adversity would bring about rewards (e.g. personal strength, spiritual growth, optimism, hope). Parents attributing their child’s cancer diagnosis to God’s will (as a trial sent by God) have been widely reported in previous studies (Jadidi et al., 2014; Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2017; Yeh, 2003). More specifically within the Islamic literature, a child’s illness is mentioned as an atonement of parents’ sins and happen for a reason, such as God testing the patience of his followers, testing things that are most beloved to them, for rewards, etc. (Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2017). In the current study, participants conveyed similar reasons in relation to their belief in God which enabled them

to make sense of their child's illness and feel hopeful. Similarly, Schweitzer, Griffiths and Yates (2012) found that families (parents and children) who demonstrated their strong belief in God felt hopeful that their child would get better and their trust in God provided them with the ability to make sense of their experience.

It has been proposed that spirituality ideology and the search for meaning in cancer is a common phenomenon that helps parents to let go of what they cannot control and instill hope in parents who feel unable to protect their child (Nicholas et al., 2017; Meireles et al., 2015). Some studies (e.g. Rassouli & Sajjadi, 2016; John et al., 2009) have found that spirituality facilitates the parents' coping as it enables them to feel relaxed and offers support for adapting after the initial shock and trauma of their child's diagnosis. Interestingly, in the current study none of the participants reported feeling disconnected with God as a result of their child's illness, as was found in the mothers studied by Reisi-Dehkordi et al. (2014). Instead, participants who expressed their belief in God felt their child's cancer had renewed their faith as they drew support from their religion and were hopeful when enduring the threats of cancer.

The present study provides a new insight into how participants construe the meaning of their child's illness, as most participants described it to have a positive purpose in terms of fulfilling and improving people's lives. Previous research has found that parents construct narratives when they question why their child has suffered from cancer (such as "why me?" or "why now?") and depict their negative feelings around unfairness (Pill & Stott, 1982). Other studies have focused on the psychological resilience outcomes that parents report having experienced after their child's illness (Phipps et al., 2015; Rosenberg, Strakes & Jones, 2014) such as positive life changes (e.g. greater closeness with others, taking more care of oneself). However, childhood cancer studies have not reported or focused on the positive meaning-making aspects in the way parents attribute a purpose to their child's illness and which provide us with a rich insight into their experience. For example, in the current study participants reported finding a positive meaning in their child's cancer diagnosis, one that was influential and significant as it served a useful purpose in people's lives that would not have been there in the absence of the illness. It is entirely possible, for

example, that parents engage in this positive meaning-making activity as a way of rationalisation or of coping with the horror of their child's diagnosis.

Overall, this searching for a purpose in their child's illness was a significant theme among participants as it helped them understand why their child received the illness. Researchers have also stressed that finding meaning in adversity, such as in childhood cancer, is a key characteristic that should be incorporated when defining and facilitating resilience in parents (Rosenberg et al., 2013; Rolland & Walsh, 2006).

In this study, participants shared their experience of shock and disbelief on receiving their child's diagnosis by describing it as a surreal experience. The confirmation of a diagnosis can be deeply shocking and difficult for parents to comprehend, and this is well documented within the current literature (Binger et al., 1969), with parents expressing their disbelief, anger, shock and denial. Similar themes were also found in an earlier study by Eden, Balck, MacKinlay and Emery (1994) where all parents reported feelings of shock, anger, numbness and devastation when they were informed of their child's diagnosis. In one study exploring the families' lived experience when their child is diagnosed with cancer, it was discovered that parents felt their experience was unreal (Bjork, Wiebe, & Hallstrom, 2005). However, previous research has not reported on a detailed examination of how parents make sense of their shock. The present study provides new insight into participants' attempt to conceptualise their child's diagnosis from the perspective of their own experiential knowledge base.

Some participants shared a detailed picture of how they perceived their shock – one participant described their experience as if they were in a trapped in reoccurring bad dream that they could not wake up from. However, as this parent conveys there to be "*happy times in that bad dream*", one is reminded of Yalom's attitudes towards death, where it is suggested that we cannot tolerate our own death, so we flit in and out of awareness about it (Yalom, 2008). He suggests that death is often inferred by disguised manifestations such as dreams that could be interpreted as one's underlying anxiety and defence towards death. Another participant spoke about feeling '*thrown*' into a parallel world, which echoes the existential idea of "*thrown-ness*", a concept introduced by Heidegger who uses the

expression of *Dasein* ('being there') to describe how humans' individual existences are *thrown* into this pre-existing world of people, frustrations, sufferings, language and culture that one cannot choose (Smith, Flowers, & Larkin, 2009). Participants were increasingly existential in focus, as some engaged in explaining the impact of shock to their thoughts about their own mortality, as though part of them were going to die upon realising their child's diagnosis. Bronstein (2002) addresses how individuals find it impossible to bear the mental pain of death, as it epitomises the ultimate manifestation of human vulnerability and loss. It is possible that when parents become aware and acknowledge the severity of their child's illness, it can force individuals on their relentless pursuit of searching immortality (Bjork, et al., 2005). Participants expressing the thought that a part of them was going to die could suggest that they were expressing a fantasy of removing the self from the grief and fear that results from being alive.

Although each participant described their experience in their unique way, they all gave focus to the 'phenomenological core' of their descriptions and this can be very valuable and revealing. It allows us to understand the way the disclosure of the diagnosis impacted on them existentially, as it is the very detail of their sense-making activity (i.e. their surreal descriptions) which allows for this potential for understanding their shared distress. The creative and interpretative focus on the participants' metaphorical descriptions provides us with powerful insights into the parents' world at the time of diagnosis and how their metaphorical descriptions work as a *meaningful, sense-making response* to their experience of shock and disbelief. Paying attention to the participants' use of metaphors and similes is an important aspect of phenomenology. Ludwig Binswanger (best known for his existential analysis, *Daseinsanalyse*) stresses how metaphors and similes are the foundations to human existence and help us shape and inhabit our world (Lanzoni, 2005).

## **Powerless**

A dominant theme that emerged from the current study was the participants' experience of feeling powerless, which appeared to be determined by their lack of control over their child's condition, a finding that has also been mentioned in previous studies (Bjork et al., 2005; Griffiths, 2009). Participants conveyed feeling powerless, restricted and helpless

because they could not protect their child. One participant, for example, expressed her feelings of powerlessness when she had to assist healthcare professionals in submitting her child to the painful and distressing treatment procedures. Young et al.'s (2002) work provides an important context for the existing study. They suggest that when it comes to a life-threatening illness like cancer, parents accommodate to the demands of the illness (such as treatment procedures), otherwise they risk compromising their child's survival. Meeting these demands can destabilise their usual manner of parenting, but Young et al. (2002) suggest that parents achieve this in a reflexive process by weighing up the pros and cons, and more importantly, they engage in a relationship between medicine and clinicians that is underpinned by belief, trust and faith. The current study complements the work by Young and colleagues by providing a detailed picture of how a perceived sense of powerlessness does not mean they are abdicating their authority as they continue to cooperate with the treatment procedures and convey their trust and faith in the medical programme.

Out of eight participants interviewed, only two parents conveyed their belief in God and described this to have facilitated their acceptance of their inability to control their child's illness or protect their child from it. Similar findings have been widely reported in existing literature whereby parents' belief in God functions to instil hope for their child's survival and helps create a positive focus for the parents (Bjork et al., 2005; Jadidi et al., 2014; Nikfarid et al., 2017; Reisi-Dehkordi et al., 2014). A recent study examining the role of spirituality among parents of children undergoing cancer treatment with a poor prognosis (e.g.  $\leq 10\%$  survival chance) described that spirituality helped them to mitigate their worries as it helped them cope with their experiences, accept their lack of control they had over their child's illness, and offered hope for the future (Nicholas et al., 2017). A similar experience was echoed by participants in this study who made reference to their religion (i.e. Islam) as a way to facilitate their coping and instil hope. Milberg and Strang (2011), who conducted a study in an advanced palliative care setting, found useful coping strategies described by caregivers protected them against feelings of powerlessness and helplessness and contributed to feelings of meaningfulness, acceptance, hope, and security. These included trying to accept their situation; searching for meaning and hope; believing in God. All these themes were observed in the current participant group and the findings can be

extended to make them applicable to parents of children with cancer who have a better prognosis.

Specific beliefs about the illness, such as the threat of relapse, have been widely reported in both qualitative and quantitative evidence where some parents experience fear of their child's illness returning (Grootenhuis & Last, 1997; Klassen et al., 2007; Ljugman et al., 2014; Woodgate, 2006). Such difficulties can become a potent feature of the parents' lives as the ever-present fear of relapse can have far-reaching consequences in terms of changing their self-identities (Dixon-Woods et al., 2003). Parents contrast their sense of control and certainty of their pre-diagnosis lives with their post-diagnosis lives (Young et al., 2002), and the threat of their child's cancer can remove parents' sense of invulnerability about their own lives (Van Dongen-Melman et al., 1998). Parents undergo a process of constructing their new identity (by adopting new roles and responsibilities) that is not tainted by the uncertainty of their child's illness returning in the future (Van Dongen-Melman et al., 1998; Young et al., 2002). Participants in the current study did highlight their feelings of uncertainty and inability to control the risk of relapse. While participants learnt how their experience of parenting a child with cancer removed their sense of control, their accounts suggest that this experience encouraged them to re-evaluate and transform their lives, values and relationships with others. Their identities were not exclusively defined by the worries about the illness, as participants' self-identities were continuously reflected upon and iterated as the illness progressed (see 'A Process of Transformation' below).

Linked to their lack of control over their child's cancer, all of the participants appeared to feel restricted by their lives revolving around their child's cancer treatment, causing disruptions to their daily routines and prior commitments. Participants spoke about how they had to relinquish their commitments, such as in employment, socialising, and personal development, to help manage the day-to-day routines and practical requirements of their child's illness. This idea of parents' lives being on hold and suspended in time has been widely documented in childhood cancer literature (Schweitzer et al., 2012; Bjork et al., 2005, 2009; Woodgate, 2006) and is likely to lead to distress and poor quality of life. Participants experienced that their life had been put on hold as they had no choice but to compromise their role to look after their child and prioritise their recovery. The significant

costs involved in staying close to their child have been reported by mothers as they try to manage the practical requirements of their child's treatment (Young et al., 2002). Young et al. (2002) explain that mothers maintain this physical 'proximity' because they feel obliged to comfort their sick child and convince themselves that they are still effective and adequate parents when they have little control over their child's recovery. Interestingly, the current study extends these findings on proximity as other parents (i.e. fathers) also demonstrated an obligation to remain close to their sick child and prioritise their lives around their child's illness. Fathers also highlighted the sacrifices they experienced with their own needs and other roles. This contradicts the common misconception in research that mothers remain responsible for childcare in Western societies (Young et al., 2002).

During the child's course of treatment, parents reported to have struggled with managing the constant demands placed on them such as work, school, other children, attending hospital, etc., all of which can contribute to them feeling tired, stretched and under pressure (Bjork et al., 2009; Patterson, Holm & Gurney, 2004). A dominant theme to have emerged from the current study was the participants' struggle to contain issues outside their own, such as those that were potentially distressing. There appears to be no reference in the current literature to parents conveying their sensitivity and overwhelming vulnerability to the emotional distress of others. Previous research, however, has examined the coping strategies that parents adopt to help them regulate the amount of stress they can tolerate and in turn reduce the emotional impact of the stressor (Van Dongen-Melman & Verhulst, 1998; Patterson et al., 2004). In a study exploring how parents of childhood cancer survivors cope with late consequences (after treatment had finished), coping strategies were identified including avoidance strategies (e.g. distancing oneself to not think about the disease) and confrontational strategies (e.g. talking with other parents or medical staff; Van Dongen-Melman & Verhulst, 1998). One can suggest that such confrontation-avoidance strategies were employed by participants in the current study as a means to help them contain their own struggles and feel safe whilst they prioritised and cared for their sick child. For instance, some participants (like Holly) coped by withdrawing themselves from others to establish some control over the challenges posed by their surrounding environment. This coping behaviour perhaps shares characteristics of avoidance strategies. On the other hand, participants like Michael confronted the stressor as he assertively

expressed that he could not deal with his mum's issues as this would divert his focus away from his child. One can interpret such coping behaviour as sharing characteristics with confrontation strategies as described by Van Dongen-Melman & Verhulst (1998). The findings from the present study suggests that parents take on these self-protective strategies during treatment (as well as those who completed treatment) to overcome new and complex challenges posed to parents during their child's illness, thus widening the range of stressors reported in existing literature that are inherent in the disease and reported by parents.

Interestingly, it appeared that having a child made vulnerable by cancer increased parents' sense of duty to protect their sick child by not sharing their emotional distress or difficulties with them. Instead, parents felt the need to maintain a 'strong' disposition by suppressing their emotions in the presence of their child. This is congruent with the findings of Young et al. (2002) who found that mothers felt compelled to identify themselves as hopeful, optimistic and strong in order to promote their child's psychological well-being. Participants in the current study stressed the importance of nurturing a version of themselves which was invulnerable, strong and brave, so their child could be shielded from their vulnerable emotions and they could facilitate their child's coping. Participants undertook this emotional work to protect their child as they perceived that their children might mirror their distress and that in turn this would impact their psychological health and recovery. Participants described a reciprocal mirroring of emotions between the parent and the child, as they took on this dual role to manage their own emotional well-being as well as their child's. This feature of emotional work has been observed in mothers (Young et al., 2002), where their emotional interdependence is intertwined with that of their children, as mothers feel obliged to relieve their child's burden and contain their distress.

Interestingly, the current study also identified this theme as running through fathers, suggesting this emotional response is an important aspect that is common among both fathers and mothers dealing with childhood cancer. Studies have suggested that cultural expectations demand that men present themselves as 'strong' and inclined to provide emotional support to others (Reay et al., 1998). However, fathers have reported that their child's cancer can threaten their self-concept as a 'provider and protector' (Jones & Neil-

Urban, 2003; Chesler & Parry, 2001), making it difficult for fathers to acknowledge their vulnerabilities and constraining their own needs of emotional expressiveness (Chesler & Parry, 2001; Reay et al., 1998). On a broader level, the invulnerable exterior (as detailed in the current study) communicates a great deal about parents' experiences of childhood cancer and the personal meaning they attribute to it. In terms of what it claims (about their need to provide emotional strength, resilience, protection and perseverance), it tells us a great deal about the way the illness represents their inability to protect the child and about the qualities they draw upon to cope with feelings of powerlessness and helplessness in their situation.

### **Relationship with Others**

A large body of literature has highlighted the importance of adequate support for parents from healthcare services throughout their child's cancer care pathway and how this plays a key role in mediating the parents' experiences. In the present study, parents reported on their satisfaction and dissatisfaction in the relationships they formed with healthcare professionals. Sadly, most of the literature has highlighted the negative impact parents experience with doctors and reported very little on the more satisfactory relationships that parents form with professionals in their journey. Indeed, it is possible that participants experienced some positive experiences in these studies, but the authors make little reference to them.

Participants who expressed their satisfaction emphasised the qualities professionals possess (e.g. empathy, spirituality, compassion) that helped them feel understood and respected. The finding may be compared to a quantitative, longitudinal study by Poder and Von Essen (2009) who found parents were most satisfied with nurses' interpersonal skills perceptions, slightly less with doctors' interpersonal skills. The authors suggested that nurses tend to spend more time with parent and are more focused on the psychological well-being of parents than doctors. However, participants in the current study also emphasised their satisfaction with doctors. One participant, for example, conveyed how doctors respected her interventions and personal preferences in her child's treatment procedures, highlighting the power equality between her and the doctors. This finding contrasts with the widely

reported power imbalances that unfortunately exist among doctors and patients (Holm et al., 2003; Dixon-Woods et al., 2001) and illustrates the potential benefits in managing parental anxiety by trusting them to act as effective advocates on behalf of their children.

Another participant described her immense gratitude to be able to share a unique, close and spiritual connection with a clinical nurse specialist. Studies have addressed that healthcare professionals should embrace the spiritual needs of the patient (i.e. their individual personal beliefs and principles) whilst attending to their physical and psychological needs as this gives hope, reduces suffering and enhances their quality of life (Champion, 2011; Petersen et al., 2017). Studies in promoting resilience in parents of children with cancer have found that spirituality and facilitating a supportive relationship with healthcare professionals are two of many evolving constructs that can enable positive adaptation for parents following the shock and trauma of a cancer diagnosis (McCubbin et al., 2002; Rosenberg et al., 2013; Rosenberg et al., 2014).

On the other hand, participants in the current study also shared their anger, frustration and dissatisfaction as their general practitioner (G.P.) failed to realise their child's symptoms were serious. Participants who expressed their distress described how they perceived the response from their G.P. to be inadequate as they had to insist on action being taken, causing delays in their child receiving a diagnosis. This is congruent with the findings of Dixon-Woods et al.'s (2001) study, who found over half of the parents experienced some delays in obtaining a diagnosis, despite having made repeated visits in a desperate attempt to reach a conclusion. In the present study, participants conveyed their distress when their concerns were not taken seriously and talked about how the G.P.'s undermined their parental '*instincts*' – their intuitive insight that told them something was wrong with their child. Interestingly, these themes were also found in studies by Dixon-Woods et al. (2001) and Holm et al. (2003), thus highlighting the importance of attending to the needs of the parent and valuing their contributions. Participants in the current study demonstrated their parental persistence and advocacy by insisting that they be seen or returning repeatedly to ensure the child's investigation was carried out. In one qualitative study exploring the pervasive difficulties that parents described in their relationship with clinicians (such as clinicians making mistakes or showing disinterest in the parents' concerns), it was

discovered that participants who were unable to 'contain' the problems (i.e. continue to maintain trust with the doctor despite the problems) lacked confidence and profoundly distrusted all their clinicians involved in their child's care (Davies, et al., 2017). The authors also found that these parents suffered considerably as their perceptions pervaded throughout their relationship with the clinician and endured over time, a concerning finding given its applicability to the current client population.

In addition to their relationship with healthcare professionals, all participants spoke about the support they received from their social relationships during their child's care. A large portion of the existing literature places an importance on the perceived support from social relationships to help parents manage the demands of the illness (Poder & Von Essen, 2009; Bjork, et al., 2009) and improve their own well-being as well their child's (Von Essen, Enskar & Skolin, 2001). Participants felt supported by their friends, other parents and the wider community which helped them in many different ways, such as with childcare, providing respite, facilitating a sense of normalcy in their lives, or feel connected with one another. Some participants commented on the support they received from talking to other parents, which helped them feel understood, validated and accepted when sharing their painful experiences. Similarly, Reay, Bignold, Ball and Cribb (1998) reported that mothers received comfort and support when talking about their feelings (with regards to their child's cancer) to other mothers in hospital. For parents who spoke highly of their social support, it seemed to alleviate their anxieties and provided the necessary reassurance by assisting them on an emotional and practical level when caring for a child with a life-threatening illness.

McCubbin et al. (2002) found that parents who reported receiving support from their healthcare team, extended family, community and workplace saw these all as key resilience factors that played a unique role in helping them to adapt, manage, and recover from their child's cancer diagnosis and treatment. Interestingly, all participants in the present study spoke about these sources of support to help make their experience more manageable and meaningful, thereby adding support to the studies of resilience in parents. McCubbin et al. (2002) propose that parents to children with cancer are likely to receive support from the community because the negative side effects of treatment and the sad images of childhood

cancer are likely to evoke empathic and sympathetic responses from the community, and they may reach out with assistance (McCubbin et al., 2002).

Sadly, participants also expressed their disappointment with the support they received within their social network. One participant highlighted his frustration and disappointment at his friends making unhelpful comments by persuading him to 'be strong'. Young et al.'s (2002) study identified that parents do create an obligation for themselves to appear strong, but the findings from this participant suggests that being told to 'be strong' is not always helpful or sustainable. Within the current qualitative literature, however, there appears to be little reference to the lack of support parents receive from their friends and family, although Bjork, Wiebe and Hallstrom (2009) do highlight how parents experience frustration and sadness when the people they expected to receive help from did not contact them or when family members, employers and teachers did not understand the seriousness of the situation. It is important that parents feel supported as a number of quantitative studies have indicated that a perceived lack of support for parents (both during and after their child's treatment) is significantly associated with an increase of emotional distress among parents and children after treatment (Dockerty, Williams, McGee, & Skegg, 2000; Han, 2003; Norberg, Lindbald, & Boman, 2006; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2005).

### **A Process of Transformation**

The experience of parenting a child with cancer led participants to re-evaluate what was important to them and change their perspective on life. Participants took a humbler outlook and appreciated the things that they once took for granted. They reassessed how they would want to spend their time, as they became aware of the fragility of life and of how things can change unexpectedly. Participants' experience of their child's cancer had provided the impetus to re-evaluate their lives across multiple domains and the way they valued things in relation to what they felt was important to them, such as their social network, their workplace, reaffirming their religious beliefs, or their health. Schweitzer, Griffiths and Yates (2012) found similar themes, as parents expressed their new realisation that they no longer worried about minor issues that they once thought important.

Participants in the current study, for example, discussed how they once used to worry about work pressures or about not being invited to events by their friends, but in their renewed awareness since their child's cancer diagnosis, they refused to let such small issues worry them and impact their well-being. Participants held the overall belief that this was a positive learning experience as the cancer reframed their attitude to life and they approached it from a positive perspective. Similar results have been found in families who have dealt with their child's cancer and have 'strived to survive' by setting out new priorities, feeling hopeful and thinking positively to help them mitigate their feelings of powerlessness (Bjork et al., 2005; Bjork et al., 2009; Woodgate, 2006).

Having a child diagnosed with a life-threatening illness like cancer led participants to face their relationships with a renewed perspective focused around what was important to them, their family and the sick child. Learning how fragile life could be, participants concentrated on their priorities and began strengthening their relationships with their friends, family and partners who mattered the most. This supports previous research that has identified that parents' relationships undergo a process of change as a result of their child's illness. Qualitative studies have revealed that the adversity of having a child with cancer fosters a strengthening of relationships for parents, as they come to realise the paramount importance of unity and spending time with friends and family (McCubbin et al., 2002; Woodgate, 2006; Schwietzer et al., 2012). In a recent qualitative study exploring the impact of the child's diagnosis on marital relationships, parents report that having a child with cancer strengthened parental unity and brought couples closer (Silva-Rodrigues et al., 2016). These findings were also observed by participants in the present study.

The superordinate theme 'A Process of Transformation' attempted to capture how participants strive to give meaning to the changes in their lives resulting from their child's cancer and how this leads them to re-evaluate their priorities and their inter-personal relationships. This finding supports the ever-growing evidence that suggests the adversity of the child's cancer may promote psychological growth in parents, as researchers describe this to be one of many factors that reveal resilience (Phipps et al., 2015; Rosenberg et al., 2014; Rosenberg et al., 2013). One could interpret the findings from the current participants as them demonstrating their resilience, as they express their ability to withstand and

bounce back from the adversity. Empirical studies have highlighted resilient properties in parents (such as optimism, meaning-making, accepting support from family and professional relationships, positive changes in their perspectives, strengthening relationships, etc.) that have helped them manage childhood cancer (McCubbin et al., 2002; Phipps et al., 2015; Rosenberg et al., 2014; Rosenberg et al., 2013), and which have been echoed throughout participants' accounts in the current study. As resilience factors and definitions are unique and personal to the individual (Rosenberg et al., 2013), one could suggest that participants in the current study demonstrated their own resilience factors which helped them recover and make their experience more meaningful and manageable.

As part of the transformation process, participants observed negative changes to their child resulting from the side effects of chemotherapy. Studies have documented how parents have had to submit their children to unpleasant treatment procedures (Young et al., 2002) and how this has been emotionally challenging for parents (Bjork et al., 2005; McGrath, 2001). However, there appears to be no reference within the past literature that captures how parents made sense of these changes they witnessed and their personal meaning of that experience. Within the present study, participants witnessed their child's loss of self, in that parents noticed a complete change in their child's identity. We can understand the participants' experience of their 'transformed child' through their vivid descriptions that very poignantly (and sometimes metaphorically) communicated the devastating and profound impact that the steroidal drugs had on transforming their child's mood, personality, physical ability, and ultimately their identity. This is important to highlight if we are to understand what it is like to be a parent to a child with cancer, as their description captures their meaningful responses to those experiences. Past research does, however, capture that parents felt powerless in not being able to protect their child from the painful medical experiences and how this felt as though it had destabilised their usual parenting style (Bjork et al., 2005; McGrath, 2001; Young et al., 2002). Considering that parents' diminished sense of control and feelings of powerlessness were a significantly dominant theme in the current study, the research findings can tell us about the magnitude of internal conflict and emotional work that parents experience when their child is made vulnerable by cancer. That is, they are accommodating demands of treatment for their child's survival such that their parenting is turned into a no-win situation. Their felt responsibilities to

protect their child whilst witnessing their child's suffering is a major source of distress for parents.

### **Clinical Implications**

From the participants interviewed, the study revealed that having a child diagnosed with cancer was deeply shocking, highly distressing, and uncertain. As demonstrated, similar experiences have been well documented in the existing literature and given that parents play a key role in managing their child's illness, it seems critical to ensure that healthcare professionals (e.g. Counselling Psychologists, nurses, doctors, etc.) can provide the appropriate emotional and informational support to assist parents through this difficult process. Helping clients to improve their quality of life is a key role for Counselling Psychologists and one that will be welcomed in their practice for this client group.

What is evident from the participants' accounts is that there are commonly occurring themes that may influence their adjustment to their child's cancer. Participants had to deal with managing the uncertainty of their child's illness, dealing with a loss of control, searching for meaning, making sense of their shock and distress, along with dealing with the emotional and medical support from others. Parents can, of course, experience problems with these factors at any time during their child's cancer trajectory. Therefore, it is important for Counselling Psychologists to take into account the unique aspects of the parents' experiences and develop an individual case formulation that focuses on helping clients understand the factors mediating their psychological distress. This should include the parents' pre- and post-life experiences in relation to their child's cancer (e.g. their experience of receiving a diagnosis, social support, past experience of illnesses, if there are any current problems with social isolation, etc.).

Focusing on the participant's description of their experience when obtaining a diagnosis would be worth attending to, as this study found that the parents' unique take on their child's cancer (i.e. via their use of strong metaphors) can be very valuable and revealing. A Counselling Psychologist who focuses on the parents' subjective accounts and their reactions to their shock/distress can add depth to their formulation, build empathy, and

attain a deeper understanding of how people respond to their experiences, which are important aspects of meaning-making. Boman, Viksten, Koger and Samuelsson (2004) found that parents are in need of psychosocial attention for a long time in order to process their initial experiences of shock, which highlights the importance of giving parents the space and focus at the time of the initial shock to help them process their grief. Furthermore, it is vital that healthcare professionals integrate and honour the parents' religious, spiritual and cultural orientations in their work, as for some participants in the current study this facilitated their meaning-making, appeared to offer great acceptance in the parents' inability to protect their child and their illness, and instilled hope amid uncertainty. Giving parents the opportunity to define their problems from their own perspective will be important when planning a holistic and family-based care.

Healthcare professionals meeting parents should bear in mind that being immersed in parents' distress and negative emotions during their child's cancer diagnosis can be at times overwhelming and elicit difficult emotions in the professional. The present study supports existing research in the call to attend to the psychological needs of parents following their child's cancer diagnosis. Given that Counselling Psychologists are expected to conduct comprehensive assessments and explore the individual meaning behind parental distress, they may find themselves overwhelmed by the content of the psychosocial experiences of parents. Therefore, it may be important for Counselling Psychologists to seek personal therapy to explore their struggles with their own beliefs about mortality and ideas such as 'justice' and 'fairness' in the world. Personal therapy could be an option to help clinicians manage their own thoughts, feelings, emotions and experiences towards cancer/other illnesses, especially when cancer has far-reaching effects and can threaten our own identity. As Counselling Psychologists are encouraged to reflect on their practice and are required to take responsibility for their own personal psychological counselling during their training, they will be able to draw on their personal experiences to help them gain confidence and form an empathic relationship with the client.

Helping parents to facilitate control will be an important consideration within the current therapeutic environment. Clinical support should attempt to minimise the impact of the disease and treatment on the parents' lives by involving them throughout the decision-

making process, providing them with a sense of agency as well as continuously updating them about treatment procedures, as participants highlighted their distress when observing their child's complex treatment. Although psychological treatment strategies have not yet been developed for parents, the experience of loss of control has been linked to psychological distress in adult patients suffering with cancer (White, 2001). As this was a significantly dominant theme in the current study, initial interventions could involve facilitating the parents' control through behavioural work (i.e. cognitive behavioural therapy). White (2001) suggests that techniques such as Weekly Activity Schedules can enable patients to pre-empt their problems and provide structure to buffer their feelings of distress and loss of control when exposed to difficult treatment procedures. Parents in the current study expressed feeling powerless in not being in control and helpless about their child's condition and so may benefit from interventions that encourage them to keep records of their child's treatment and their own activity. These behavioural interventions can be helpful for cancer patients to explore and manage their negative emotions to promote their sense of agency by reflecting on their daily activity levels (White, 2001). If this is the case, then therapy incorporating this may help parents to accept the need to factor in time for rest, or to reflect on thoughts/feelings that accompany their loss of powerlessness. However, these claims need to be validated by empirical evidence; therefore, any recommendations should be considered tentatively. In addition, it may be helpful for healthcare professionals to assess the emotional readiness and ability of parents before they are required to assist in submitting their child to the demands of the complex and potentially distressing treatment procedures.

As well as thinking about possible forms of effective interventions when working with parents, it is important to acknowledge the possible obstacles that could impact the parents' adjustment to their child's cancer. For example, all participants in the current study appeared to find it difficult to contain issues outside their own and found others' distress or concerns quite emotionally overwhelming as they tried to focus on their child's care. In addition, some participants found the support from their social relationships and relationships with health professionals dissatisfying. Healthcare professionals should acknowledge the importance of enabling parents to talk about their 'cancer story' in its entirety and help them feel contained. What may form an effective intervention here is to

consider some psychologically based therapies, such as CBT, that provide an opportunity for parents to talk about their experiences whilst picking up clues on thoughts, feelings, behaviours and coping strategies. This could help them feel contained whilst they prioritise and care for their sick child. As well as exploring the use of interventions, practical considerations within the service provision may help alleviate the feeling of being overwhelmed with distress and uncertainty, and instead help parents feel in control. These includes things such as reducing waiting times, helping them arrange appointment scheduling, adjustments in the way information is delivered (Kastel et al., 2011; White, 2001) or practical assistance (like travelling, finding accommodation, childminding).

Perhaps it will be beneficial for services to explore, understand, support, and seek feedback on the reasons the parent was not getting on with the healthcare professional. Given that some participants found it distressing when they were not taken seriously by professionals, together with previous research reporting on the potential problems that threatened parents' trust in clinicians (Davies et al., 2017; Dixon-Woods et al., 2001), it is important to consider the credibility of the parents' intimate knowledge (i.e. their 'instincts') that tell us something is wrong with their child and not discredit their concerns. This may help establish the power balance between the clinician and parents by introducing empathy and helping mitigate parental distress, given that these were issues presented by participants in the current study and reported in previous literature (Dixon-Woods et al., 2001; Holm et al., 2003). However, it is important to acknowledge that parents will come across challenges in their relationships, as no clinician, social relationship or system of care will be perfect. It is equally important for healthcare professionals to foster successful relationships with parents. Meeting socially competent staff who can understand individual needs and preferences, as well as assist them regarding treatment procedures and show compassion, are important for parents, as demonstrated in the current findings and previous literature (McCubbin et al., 2002; von-Essen et al., 2001). Therefore, it may be helpful for Counselling Psychologists to be aware of these potential difficulties and draw upon their large repertoire of skills to model a successful therapeutic relationship built around trust, empathy and acceptance.

Healthcare professionals can also play a key role in mitigating the parents' increased distress associated with their child's treatment, as participants in the current study found it highly distressing when observing the powerful changes to their child from the steroidal medication. Young et al. (2002) found that children were less likely to resist treatment and more likely to cooperate when professionals developed successful relationships with the sick child. In line with these findings, one of the implications would be for healthcare professionals (i.e. nurses) to support mothers and fathers and relieve them of their emotional distress/anxiety when seeing their child undergo complicated and painful treatments by establishing successful relationships with the sick child to gain their cooperation.

Another potential obstacle that would be helpful for Counselling Psychologists to be mindful of is the way parents guarded their own vulnerable emotions in order to appear 'strong'. The participants in the current study demonstrated how uncomfortable they felt showing their emotional distress to their child and may show a similar reluctance when voicing their own needs or distressed emotions in therapy. In considering the implications for practice, it is vital that we recognise how parenting a child with a life-threatening illness may shape the parents' coping mechanisms as they feel responsible to protect and care for their sick child. In addition, this may be a means of demonstrating their adequacy as parents, as found in mothers (Young et al., 2002). As participants in this study were so used to suppressing their emotions from their children and avoiding drawing attention to themselves, it's possible that they may reproduce this within the therapeutic relationship to protect their self-identity and maintain their inner strength. As a result, healthcare professionals may fail to recognise the parents' own needs and therefore it will be important for Counselling Psychologists to foster a warm, empathic, safe and supportive therapeutic environment to enable the parent to be expressive and open about their feelings. This may serve to help parents fulfil their roles and help normalise the idea that seeking support and being expressive is acceptable rather than interpreted as undermining the parents' role (i.e. the strong self) and responsibility.

It may be useful for trainees and professionals to reflect about their own experiences of being vulnerable and think about the defences that work to protect them from and diminish

whatever distressing factor is beyond their control. Counselling Psychologists, who are highly reflective, should be able and willing to explore their own struggles and evaluate how they use self-protective mechanisms to cope with their emotional vulnerabilities, while understanding that it is no means limited to this. Being encouraged to do work of our own will enable us to properly understand and make meaning of our participants' frame of reference.

Another implication that can be considered is for parents to talk to other parents who are in a similar situation if this is likely to facilitate the parent's well-being and the parent is willing for this to happen. The reason for involving those who are not healthcare professionals would be to help parents who have struggled with demands of the illness, as participants in the present study and existing literature have found this comforting and validating (Reay, Bignold, Ball, & Cribb, 1998). It is quite possible that different parents will perceive this parent-to-parent talking as beneficial. Although it is important to take heed of individuals' accounts when thinking about effective interventions, it is not argued that participants accounts in these studies are representative of others in a similar situation, and some parents may find sharing their 'stories' distressing. Other issues may arise, such as the risk of losing one's confidentiality, parents regretting having shared their experiences with other parents, or parents on the receiving end (i.e. the parent being 'talked to') finding this extremely uncomfortable. Therefore, it will be necessary for healthcare professionals to be mindful of this and for the Counselling Psychologist to use their therapeutic skills to help parents who convey that they are upset.

This study can prove to be beneficial for therapy courses and counselling/clinical psychology doctorates as there is limited information and training given on what it is like for parents (or carers) of a child suffering from a life-threatening illness. Likewise, there is limited awareness in the public regarding this client group, though recent fundraising campaigns such as the 'The Bradley Lowery Foundation' (n.d.) are a welcome addition to help fund medical treatment/equipment for children with cancer. With regard to how to work with clients from this population, training could involve experiential learning or encouraging students to take placements at one of the UK's 22 childhood cancer treatment centres. However, due to limited resources, it may not be feasible for the entire cohort of students

to undertake this kind of placement. Alternatively, training courses could invite parents who are willing to discuss and share their experiences of their child's cancer first-hand with other trainees. This type of training will improve awareness and confidence among trainees when working with this client population. Such initiatives may help Counselling Psychologists to feel at ease and focus on building an empathic rapport within a therapeutic environment, as working with this client group can seem to be a somewhat overwhelming and distressing task.

The current NICE guidelines recommend that all parents of a child with cancer should have access to expert psychological and social support (NICE, 2005). Although Counselling Psychologists are expected to assist in providing this support, along with assessing their needs and coping skills, the NICE guidelines are yet to recommend treatments for parents. The present study lends support to the need to recognise and advocate the significance of psychological support for parents across their child's illness trajectory. However, these recommendations should be considered tentatively and must be supported with empirical evidence that investigates the efficacy of therapeutic interventions on parents. Due to the idiosyncrasies of the parents' accounts and the subjective nature of being a parent to a sick child, it follows that how we help parents *feel* better through interventions will also be subjective (i.e. what may work for one individual may not work for the other). Therefore, it is vital as Counselling Psychologists that we utilise our skills and knowledge to effectively form and maintain a collaborative therapeutic relationship that works in accordance with the client's need.

### **Critique of Methodology and Future Research**

A number of strengths and limitations associated with this research study will now be discussed and suggestions for future research will be identified. As discussed in the Methodology chapter, purposive sampling was used to recruit a small sample of participants from a single paediatric oncology unit to grant us access to a particular perspective on the phenomenon of being a parent to a child with cancer. Although this achieved reasonable homogeneity and demonstrated rigour (through the appropriateness of the sample relating to the research question), it does however limit the conclusions, as they cannot be

representative of other parents. Furthermore, the majority of the participants in this study were mothers. Although consistent with most research that has focused on parents to children with cancer (both quantitative and qualitative), the notable lack of research on fathers' experiences still represents a gap in the literature. While two fathers participated in this study, more research needs to be done to understand the fathers' experiences. It is unclear whether this noticeable lack of a fathers' perspective reported in current research reflects the different roles that fathers may play in parenting a sick child, the research topic, or the way in which mothers naturally elect themselves as the family spokesperson who remains close to the child's side during treatment (Young et al., 2002; Schweitzer et al., 2012). Future research should include more studies on the fathers' experiences to gain a fuller and more balanced perspective as qualitative literature has documented some differences in fathers' responses to their child's cancer (Yeh, 2002; Jones & Neil-Urban, 2003).

Although this study included all parents (i.e. single, mixed-sex or same-sex were invited to participate), only one participant in the current study was a single parent and the rest were married respondents. Given that previous literature has highlighted that single parents report lower levels of support and have to take on all aspects of childcare (e.g. financial demands, managing other children), attention needs to be afforded to single parents (Long & Marsland, 2011). To my knowledge, research is yet to assess the experiences of parents who are of the same sex. Additionally, studies are yet to explore the experiences of parents who are unable or not willing to accept the role of taking care of their sick child.

Due to the challenges that I encountered during the recruitment phase (as discussed in the 'Recruitment' section of the Methodology chapter), the inclusion criteria were broadened which meant there was no cap on the amount of time elapsed since the child's diagnosis. Although this facilitated the recruitment, it is an important methodological consideration as the children varied in their condition and were at different stages in their illness (see 'Sampling' section in the Methodology chapter for different diagnoses and time of illness in children). This may lead to different experiences among the particular subset of illnesses (e.g. leukaemia, lymphoma, brain tumours, etc.) as the symptoms and prognosis differ. As

this could not be assessed in the current study it will be an important aspect for future research to take into consideration and explore further.

Future research will also need to consider investigating the influence of the child's age and gender on mediating the parents' experience. The age of children who were diagnosed in the present study ranged from 1.8 to 12 years and it is not known whether the child's developmental level influenced the parents' experiences. For example, parents to younger children who have not yet developed their language skills may struggle to understand what their child needs whereas parents to older children may find their child is more vocal about their experience. These developmental aspects of the child may have very different consequences for the ways in which the parents are involved in their child's care. Such methodological flaws outlined in this study also reflect the majority of current research in parental experiences of childhood cancer that present the combined findings across different subgroups, such as different illnesses, different stages of the illness and of children of different ages (Pai et al., 2007; Bjork et al., 2005, 2009; Jadidi et al., 2014; Young et al., 2002). To what extent these factors apply to the parents' experiences is relatively unknown and in need of empirical research.

In order to be inclusive and not discriminate against any potential participant in this research because of their culture, spiritual or religious beliefs/practices, one participant was allowed to have her husband in the same room whilst the interview was carried out. Undertaking an interview in the presence of another family member in this way might contribute to a potential bias in the response (i.e. the participant may answer the question less truthfully or more favourably in front of others). As this arrangement only took place in one case, the potential effect on the overall findings was controlled for and cannot be applied to the entire data set.

Another pertinent point is that this study focused on the parents' experiences within a Western society. Previous research reporting on findings from Eastern societies have highlighted the presence of sociocultural differences in parents and how their religious beliefs and cultural attribution to their child's illness may serve to influence the way they engage in treatment and make sense of their experiences (Jadidi et al., 2014; Reisi-Dehkordi

et al., 2014, Yeh et al., 1999). With the added support from participants in the current study who highlighted how their spiritual and religious beliefs played a key role in mediating their experiences of the child's cancer, a cross-cultural and cross-national research would be a welcome addition to strengthen the current literature and enhance our understanding of the phenomenological experiences of parents.

Research methods that are consistent with the interpretative designs are needed to build on the current research, as interpretative qualitative work in this area is still in its infancy. This study can offer value to the limited interpretative work that already exists as it provides emphasis on the individual making sense of their child's cancer diagnosis and points to the possibility of a rich interchange with quantitative methods. As IPA is positioned as an integrative approach (Smith et al., 2009), it enables the researcher to develop an intense interpretative engagement with the participants' verbal account that is grounded in the text and may also go beyond the individuals' own sense-making (Smith et al., 2004). As demonstrated in the previous chapters, the analysis was conducted thoroughly and produced sufficiently interpretative results to communicate something important about the individual participants' accounts as well as about the themes they shared. Sense-making is a crucial component to see how we frame the participants' experiences and there are substantial precedents for using IPA in health and social research. Therefore, a mixed method design that combines quantitative instruments like the Benefit Finding Scale (Antoni et al., 2001; Lindwall et al. 2014) with an in-depth experiential qualitative analysis like IPA could enhance our understanding of resilience theoretical frameworks related to parents in childhood cancer.

During the analysis, I noticed that the content of the participants' experiences was somewhat similar and that a pattern of key themes had emerged across the participants' accounts. When I first noticed the connections between the cases, I was struck with anxiety as I feared that I had led the participants in some way. However, I did not believe my interview questions were leading as the questions were prepared to be open and expansive. When constructing my interview schedule, I carefully reflected on my interview questions with the help of my research supervisor and peers, who independently offered their critique and helped address my sensitivity to the context. Likewise, my close engagement with and

high degree of attentiveness to the participants' transcripts and emergent themes were cross-referenced by my supervisor and peers who acted as independent auditors (Smith et al., 2009). They also shared similar themes after reading the transcripts which helped validate my observations on the original text. Given that my supervisor and peers acted as independent auditors to ensure the claims produced were credible, that the participants were recruited using a purposive sample, and that the current study findings were supported by existing literature, I feel confident that my study has demonstrated findings that could represent the sample population in relation to the phenomenon.

Having said this, another possible limitation could be that I have no personal experience of having a child, which may have impacted the construction of the interview schedule. Speaking from a position of limited knowledge and experience of this phenomenon, the interview questions were formed from my own assumptions rather than drawing from what was relevant to the participant. Although the schedule was refined and rehearsed with the collaboration of my supervisor and peers, it would have been helpful to have co-constructed the schedule with a parent whose child had a similar illness to see what they felt was important to focus on. Using a focus group or doing a pilot study with a member of this client population would have helped to achieve this. However, given the challenges that I encountered during the recruitment phase, this may have not have been a feasible solution within the timeframe of the current study.

Despite areas for development within the interview schedule, I did feel I attended closely to what the participant was saying, gave them time and space for reflection, and conducted in-depth interviews by picking up on important cues from the participant and exploring the phenomenon deeply to obtain rich data to address the research question.

As with all qualitative research, the relatively small sizes of this IPA study limit the generalisation of findings beyond the client group investigated. A common criticism with IPA is that it cannot explain the experience of participants, despite the richness of data that can be captured through this methodological approach (Willig, 2008).

It is hoped that readers will see the value in developing the interpretative approaches in the field of childhood cancer to help understand more about what it is like for parents to have this profound, personal experience. Several themes to have emerged from this study may be a starting point for further exploration and qualitative research. For instance, many participants referred to the struggle to contain others' distress during their child's cancer, and further exploration of this would be welcome. Similarly, some of the participants expressed the distressing changes they observed in their child during chemotherapy and the emotional work that parents carry out is poorly understood within the present literature. The participants in the current study discussed their relationships with medical professionals, in particular with doctors and nurses. Although these clinicians are at the forefront of their child's care, it will be interesting for future research to explore the relationship between the parent and the psychologist/therapist. In addition to this, exploring the parents' experiences of participating in childhood cancer research will be a fascinating addition to the current literature as it will help address important questions around the preferences of participants and assist in the development of methodologies. This would be particularly helpful for the Counselling Psychologist as it can provide them with an opportunity to evaluate their own services and how they can be organised to meet the needs and priorities of parents.

## **Conclusion**

Being a parent to a child diagnosed with a life-threatening illness like cancer can have a significant impact on the parent's life, as shown by the detailed and meaningful accounts of participants in the present study. The parents shared how they attempted to make sense of their experiences by engaging in the search to find a purpose for their child's illness and the meaning behind their experience. Another way in which parents conceptualised their experiences was by making sense of their shock and disbelief of receiving the diagnosis as a surreal experience. Participants expressed feeling powerless and helpless in not being able to protect their child, whilst conveying their struggles in managing additional issues. The findings in this study can provide a useful insight into the unique ways parents coped with feelings of powerlessness and how they aimed to facilitate their child's well-being by appearing to be strong and resilient. Participants also spoke about the ways in which their

relationships with others, both with the healthcare professional and their social network, affected their experiences of having a child with cancer. Finally, it was evident that having a child with cancer provided impetus for parents to re-evaluate their life and brought about a new perspective on how they considered future relationships. Some participants also shared the significant changes that they observed to their child during their treatment.

It is hoped that this study may provide healthcare professionals with a useful insight into understanding the unique experiences of being a parent of a vulnerable child who is diagnosed with cancer and inform future research to consider developing interventions for this clinical population. I believe this study can be a valuable contribution to illuminate the lived experience and meaning of this phenomenon for Counselling Psychologists, as it offers great insight for therapists working with this client group.

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## Appendix A

### Inclusion / Exclusion Criteria



Central and North West London   
NHS Foundation Trust

Information for clinicians

#### **Study Title: An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer**

**Principal Investigator: Rohit Dhillon**

**Contact details:** 

**IRAS Project ID: 222410**

The inclusion criteria are as follows:

- All participants will need to be over the legal age of 18 and above because of issues of informed consent.
- All parents, including single, mixed-sex or same-sex will be invited to participate. If there are two parents of a child, they can decide which parent(s) will take part in the study.
- The child of the parent must be 15 years old or younger and has been diagnosed with a form of cancer.
- Participants must be English speaking.
- The child must have a diagnosis of cancer with a minimum of 4 months.

The exclusion criteria are as follows:

- Anyone with special communication needs.
- Anyone experiencing a thought disorder or acute psychosis.
- Anyone who is unable to or does not have the capacity to give informed consent.

Clinicians will use their clinical judgement to establish whether potential participants are able to take part in the study in terms of emotional stability.

## Appendix B

### Interview Schedule

1. I am wondering what motivated you to take part in this study?

2. Can you tell me about the first time you found out about your child's diagnosis?

Prompts: What was that like for you? How did you feel? Tell me what you were thinking?

3. What was it like for you after you found out about your child's diagnosis?

Prompts: How did it feel? Please tell me what this diagnosis means to you?

4. Has your life changed since your child's diagnosis?

Prompts: can you tell me more about that? Did you learn anything from it? Did you make any changes? Focus: How did it make you feel?

5. How has the diagnosis changed your relationship with others?

Prompts: How has it changed your lifestyle? What was it like for you as a parent to see how this illness changed your relationship with other – partner/siblings/son?

6. How do you think this experience has changed the way you look at yourself, others and the world around you?

Prompts: Others? About the world? Some people refer to spiritual or religious values and beliefs. Does any of that relate to you? If so, how do you think of religion now? Since the diagnosis, has this changed your practice of religion?

7. What would you want someone else to know if they discovered their child was recently diagnosed?

Prompts: Anything helpful? Or useful? How do you think that would make others feel?

8. Before we bring our session to a close, is there anything that you would like to add?

General Prompts: Why? How? Can you tell me more about that? Tell me what you were thinking? How did you feel?

## Appendix C

### City, University of London and NHS Ethical Approval

Version 1 08.05.2017



Psychology Research Ethics Committee  
School of Arts and Social Sciences  
City University London  
London EC1R 0JD

8<sup>th</sup> December 2015

Dear Rohit Dhillon,

**Reference:** PSYCH (P/F) 14/15 253

**Project title:** An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Ethics Committee.

#### Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this [period](#) you will need to apply for an extension using the Amendments Form.

#### Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

#### Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee [REDACTED] in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and vulnerable adults
- (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford  
Student Administrator  
Email: [REDACTED]

Katy Tapper  
Chair  
Email: [REDACTED]

Mr Rohit Dhillon

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

26 June 2017

Dear Mr Dhillon

**Letter of HRA Approval**

**Study title:** An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer  
**IRAS project ID:** 222410  
**REC reference:** 17/LO/0877  
**Sponsor:** City, University of London

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

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procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

#### **HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **222410**. Please quote this on all correspondence.

Yours sincerely

Juliana Araujo

Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Sponsor Representative: Professor Emmanuel Pothos, City, University of London  
Lead NHS R&D Office Representative: Mr Damon Foster, Chelsea and Westminster  
Hospital NHS Foundation Trust  
Student Supervisor: Dr Jacqui Farrants, City, University of London*

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## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [University Ethics Approval]	Version 1	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Insurance]	Version 1	06 February 2017
Interview schedules or topic guides for participants [Research Interview Questions]	Version 1	24 April 2017
IRAS Application Form [IRAS_Form_19062017]		19 June 2017
Other [Data Protection Policy 2]	Version 1	16 June 2017
Other [Data Protection Policy 3]	Version 1	16 June 2017
Other [Data Protection Policy]		01 February 2017
Other [Data Security Guidance]	V.1.3	01 January 2016
Other [Debrief Sheet]	Version 2	06 June 2017
Other [HRA Schedule of Events (Dated)]	1.0	19 June 2017
Other [HRA Statement of Activities (Dated)]	1,0	19 June 2017
Other [Inclusion/Exclusion Criteria]	Version 1	23 March 2017
Other [Information Security Policy]		01 October 2016
Other [Lone Worker Policy]	Version 1	02 April 2015
Other [NHS Data Technical Security]		01 October 2016
Other [Sponsor Insurance Document]	Version 1	30 July 2016
Other [University Email Confirmation for PC Use]	Version 1	23 June 2017
Participant consent form [Consent Form]	Version 2	06 June 2017
Participant information sheet (PIS) [Participant Information Sheet]	Version 2	06 June 2017
Research protocol or project proposal [Research Proposal '17]	Version 1	23 April 2017
Summary CV for Chief Investigator (CI) [Chief Investigator (Rohit) C.V.]	Version 1	24 April 2017
Summary CV for supervisor (student research) [Research Supervisor C.V.]	Version 1	24 April 2017
2017-05-08 Application Valid does not require SSA 17-LO-0877.pdf		08 May 2017
2017-06-05 Favourable Opinion at First Review 17-LO-0877.pdf		05 June 2017
2017-06-22 Acknowledgement for Documentation Received Following a FO FIFO AC 17-LO-0877.pdf		22 June 2017

## Appendix D

### Information Sheet



Central and North West London   
NHS Foundation Trust

**Study Title: An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer**

**Principle Investigator: Rohit Dhillon, e-mail: [REDACTED]**  
**IRAS Project ID: 222410**

I would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the study?**

The aim of this research study is to understand the parents' experiences when their child has been diagnosed with cancer. Many parents have reported to have experienced a range of challenges that has affected their quality of life using methods like questionnaires. However, it is important to gain an in-depth understanding of the parents' experiences using methods like interviews, as this will give research a deeper understanding into this area. Furthermore, this study will provide parents with an opportunity to voice their experiences which can be comforting and could help improve existing psychological interventions for those parents who have been affected with childhood cancer.

The proposed duration of the above study is approximately 10 months. The study is undertaken as part of a completing the Professional Doctorate in Counselling Psychology.

#### **Why have I been invited?**

I am asking all parents who have had a child diagnosed with cancer to take part in this study.

#### **Do I have to take part?**

No. Participation in the project is voluntary and it is up to you to decide whether to take part. If you decide to take part, you are still free to withdraw at any time without any disadvantage to yourself and without any obligation to give a reason. If during the interview you feel the questions are too personal or intrusive, you can avoid answering them. This will not result in you being penalized if you choose not to answer. If you do decide to take part you will be asked to sign a consent form.

**The support and help you receive from your team will not be affected if you decide at any time you do not want to take part in this study.**

**What will happen if I take part?**

If you decide to participate in the above study, you will be asked to take part in a semi-structured interview that will last approximately one hour with the researcher. During your meeting with the researcher, you will be asked to talk about your experiences in mostly an open-ended way. Your interview will be audio recorded on a Dictaphone and transcribed (typed word by word into text) for analysis. The Dictaphone will be stored in a locked, secure cupboard at Chelsea and Westminster Hospital to protect your confidentiality. The interviews will be destroyed at the end of the study. The results will be analysed using Interpretative Phenomenological Analysis (IPA).

**Location of the study** - The interview can take place at your home or in a room at Chelsea and Westminster Hospital. If you do have to travel to the interview location, then you will receive travel reimbursements (maximum of £5) in appreciation of your time and participation in the study.

**Expenses**

- If the interview takes place at the hospital site, all participants will receive travel reimbursements (maximum of £5).

**What do I have to do?**

Participants will be asked to talk about their experiences of their child being diagnosed with cancer for about one hour.

**What are the possible disadvantages and risks of taking part?**

It is not anticipated that you will be exposed to any risks or dangers as part of the study. However, it is possible that you might get upset when talking about your experiences either during or following the interview. If you do get upset, you will be offered an opportunity to take a break, to reschedule the interview for a different time or to end the interview if you feel unable to continue. You can contact your care team should you wish to or require support. I will also give you a debrief sheet at the end of the interview.

**What are the possible benefits of taking part?**

It is hoped that information generated from this study will help improve understanding of the parents' experiences in relation to childhood cancer and contribute to the development of research and psychological treatment in the future. You may also appreciate having the opportunity to talk openly about your experiences.

**Confidentiality of the data**

- All information you provide will be kept confidential.
- All participants will be anonymized (whereby identifying material are removed from data and replaced by a code and there is no way of relating the code to the identifier).

- The signed consent forms will be kept with your clinical notes at Chelsea and Westminster Hospital. The anonymized data will be kept in a safe and secure place. This information will only be viewed by the researcher and the research supervisor who is overseeing the anonymized data.
- The interviews will be recorded on a digital voice recorder and transcribed (typed word by word into text) for analysis. Audio recordings will be encrypted and stored securely in a separate password protected files on both a password protected memory stick and password protected computer. All names and other identifiable information will be changed in the transcripts to ensure anonymity. The recordings will be destroyed at the end of the study.
- The transcripts may be read by my supervisor at City, University of London and the examiners who will assess my work when I submit the research. No one else will be able to read the transcripts.
- There may be certain instances in which I may need to break confidentiality, for example if you provide information where you threaten to harm yourself or to another person, or if we believe a child is at risk of harm or abuse. If confidentiality needs to be broken, I will make every effort to discuss this with you beforehand.

#### **What will happen to the results of the research study?**

The research findings will be written up as a doctorate thesis and may be submitted for publication in journals or at the library in City, University of London. You will not be identified in any publication. If this goes ahead, all personal or identifiable information will be confidential and protected. At the end of research, all anonymized transcripts will be stored securely and retained for 5 years in accordance with the recommendations of the British Psychological Society, (BPS) to answer the research question.

#### **How will the findings be disseminated at the end of the study?**

**If you wish to receive the findings, you will be given a small summary sheet of the overall research at the end of the study. This will include a brief overview of the literature, results and discussion. Please provide us with your email address at the bottom of the debrief sheet to receive the findings.**

#### **What will happen if I don't want to carry on with the study?**

You will be free to withdraw from the study without an explanation or penalty at any time. You will not be penalized in any way. If you decide to withdraw from the research, then any personal information you have provided will be deleted from the study. However, you may only withdraw your data from the study up to a 1 week after the interview. By this time, your data would have been completely anonymized and the write up would have begun.

#### **What if I like further support after the interview?**

If you would like further support after the interview has taken place, then please contact Rachael Welsby (Paediatric Oncology Clinical Nurse Specialist at Chelsea and Westminster). Please see details below.

**What if there is a problem?**

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer*.

You could also write to the Secretary at:

Anna Ramberg  
Secretary to Senate Research Ethics Committee

Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this [study](#) you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity.

Thank you very much for reading this information sheet and for thinking about the study. Please keep this information sheet for reference, and feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation.

**Further information and contact details:**

**Researcher:** Rohit Dhillon - [REDACTED] Telephone Number: [REDACTED]

**Supervisor of the Project:** Dr Jacqui Farrant - [REDACTED] Telephone Number: [REDACTED]

**Paediatric Oncology Clinical Nurse Specialist** – Rachael Welsby – [REDACTED]  
Telephone Number: [REDACTED]

Thank you for taking the time to read this information sheet.

## Appendix E

### Consent Form

Central and North West London   
NHS Foundation Trust



**Study Title: An Exploration into the Parents' Experiences of their Child being Diagnosed with Cancer**

**IRAS Project ID: 222410**

Please initial box

1.	<p>I agree to take part in the above City, University of London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand this will involve:</p> <ul style="list-style-type: none"><li>• being interviewed by the researcher</li><li>• allowing the interview to be audiotaped</li></ul>	
2.	<p>This information will be held and processed for the following purpose(s):</p> <p>For the data to be transcribed and be analysed into themes relevant to the research topic. If the research gets published, the British Psychological Society recommends retaining the data for 5 years in order to answer the research question.</p> <p>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p> <p>In order to protect your identity from being made public, all identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.</p> <p>There may be certain instances in which I may need to break confidentiality, for example if you provide information where you threat to harm yourself or to another person, or if we believe a child is at risk of harm or abuse.</p>	
3.	<p>I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.</p>	
4.	<p>I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.</p>	
5.	<p>I agree to take part in the above study.</p>	

Page | 1

Consent Form (Version 2, 06.06.2017)

\_\_\_\_\_  
Name of Participant                      Signature                      Date

\_\_\_\_\_  
Name of Researcher                      Signature                      Date

When completed, 1 copy for participant; 1 copy for researcher file.

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Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

## Appendix F

### Debrief

Central and North West London   
NHS Foundation Trust



#### **Study Title: An Exploration into the Parents Experiences of their Child being is Diagnosed with Cancer**

**IRAS Project ID: 222410**

The aim of this qualitative study was to gain a better understanding about what it is like for parents who have to experience their child being diagnosed with cancer. I am interested with the quality and texture of your experiences who often find this life circumstance stressful and highly emotional. It is only through this interview where I might get a faithful understanding of your experiences. This is why you were asked to come and meet with the researcher for approximately an hour.

Previous research suggests that good psychological and emotional support should be made available to parents during their child's diagnosis. This study will hopefully strengthen existing research and will grant us rich data to develop ways in which we can attend to the needs of the family members as well as the patient. It might also encourage other parents or other primary caregivers to normalise their experiences and seek appropriate help when coping with their child's diagnosis.

However, it is possible some emotional upset may come about during the course of the interview as this is a very sensitive topic. Therefore, I would recommend that have provided details of local counselling services and support for you to contact. This will be offered irrespective of whether one needs the support or not.

If you would like further support after the interview has taken place, then please contact Rachael [Welsby](#) (Paediatric Oncology Clinical Nurse Specialist at Chelsea and Westminster Hospital) -

[REDACTED]

I hope you found the study interesting. If you have any other [questions](#) please do not hesitate to contact me at the following:

Rohit Dhillon - [REDACTED] Telephone number: [REDACTED]

Dr Jacqui [Farrants](#) - [REDACTED] Telephone number: [REDACTED]

I would like to thank you very much for your valuable time and participating in the study.

#### **Dissemination of your results**

**If you wish to receive the findings, you will be given a small summary sheet of the overall research at the end of the write up. This will include a brief overview of the literature, results and discussion.**

*If you would like to be informed about the results from this research, then please provide your email address*

here:.....

# Appendix G

## Analysis of Transcript (Holly)

1 • All names in this transcript have been changed to a pseudonym  
2 to protect the patients' identity

3  
4 Me: Umm what actually has actually motivated you to participate  
5 in this study?

6  
7 Holly\*: Umm, For the reason of the study, there isn't really much  
8 literature or anything like that, that I found for parents. There was  
9 lots of things that I could give to my elder son, umm, once my  
10 youngest was diagnosed. Umm so no that's why I think it's a  
11 ...and anything I can do to help somebody else because it was  
12 obviously the hardest time of my life. If it can help then I'll continue  
13 to help any way I can [Holly laughs].

**Commented [DR1]:** Lack of literature for parents

14  
15 Me: When you were saying about the hardest time of your life, can  
16 you tell me a little more about that?

**Commented [DR2]:** Repetition of you 'just' highlights the expectation one makes to seek a "fix" when something is out of your control. Expectation of medicine.

17  
18 Holly: Yeah of course. Umm so obviously in terms of when he was  
19 poorly you just go to the doctors don't you and you just think  
20 there's a medicine and it just fixes your child and obviously that  
21 was all I was hoping for. Umm but then it didn't quite happen that  
22 way. Umm when he was, when you was told it was something

**Commented [DR3]:** Matter of fact. Routine procedure to seek professional advice. Expectation of doctors.

**Commented [DR4]:** Acknowledge changes to process of diagnosis

**Commented [DR5]:** Death sentence/ Feeling trapped/

**Commented [DR6]:** No sense of hope. Placed into darkness /the unknown/Anxiety/Fear/Helpless

**Commented [DR7]:** Powerless.

**Commented [DR8]:** Loss of parental power / Loss of control

**Commented [DR9]:** Expectation to fix the problem

**Commented [DR10]:** Repetition of "powerless" – emphasising feeling powerless

**Commented [DR11]:** Instant shock which blocked any sense of rationalising despite knowing high chance of survival.

**Commented [DR12]:** Difficulty in making sense of what happened. Feeling overwhelmed? Difficulty comprehending.

**Commented [DR13]:** Stage to experience

**Commented [DR14]:** Feeling no chance of survival. End of the road.

**Commented [DR15]:** Questioning son's mortality.

**Commented [DR16]:** Change in mind set / "mind frame"

*Expectations*

*Sense of Mortality*

*Powerless*

*Loss of control*

*Questioning child's sense of mortality/survival*

23 that, as soon as you hear that word you think that it's a death  
24 sentence and you don't obviously see any light at the end of the  
25 tunnel. Umm and you just feel powerless to help your child. There  
26 isn't anything you can do as a mum, umm to fix what's wrong with  
27 him, umm so that's, I just felt really powerless, umm and I just,  
28 yeh... couldn't see any good that was possibly there even though  
29 everybody said that there's percentages and things. I just ... I  
30 don't, I don't know. The very initial stages, I just felt that this is  
31 possibly it and that my son wasn't going to make it because he  
32 was so poorly. Umm so that's what I found the hardest thing and  
33 then soon after that, you have to, well I had to completely change  
34 your mind frame because I was just constantly crying and then he

Reciprocal mirroring of emotions  
Determination

Facilitating each other's coping

Sense of helplessness

-ve emotional impact

Convincing specialists (medical staff)

Diagnosis transforms child - personality

Excessive thinking

Helplessness  
Powerless

35 was constantly crying so he was feeding off of my energy and  
36 then I don't know what happened, it was just like a light bulb  
37 moment and that was it, we were going to fight this, he's fine, he's  
38 going to be ok and then he did, he started to pick up and his mood  
39 was picking up and we were just bouncing off of each-other then  
40 but umm initially it was, you know, you just think that's it - there's  
41 nothing. But obviously there was [Holly laughs]. So yeah it was  
42 umm.

44 Me: And how did that make you feel?

46 Holly: Umm... I felt dead inside completely umm... because he  
47 was at an age where he couldn't even explain whether he was in  
48 pain, whether umm... how he felt. I just had to go by what, he was  
49 ten months old so I was literally just going by his facial  
50 expressions or his movements. He would normally crawl across  
51 the front room... umm and he stopped he would crawl two spaces  
52 and then just lie still... so it was heartbreaking. It was really really,  
53 this was obviously before his diagnosis... umm so you just think oh  
54 I'll just pick him up and cuddle him and everything will be okay.  
55 You go to the doctor, the doctor told us, we went to the doctors  
56 four times and A and E twice and everybody just told me he has a  
57 virus and he'll be okay. Umm so obviously you believe people that  
58 know what they're dealing with. I have no idea. Umm but then he,  
59 I became quite angry when I could tell something more than just a  
60 virus was going on, because everything changed about him, his  
61 whole personality, he was really happy, he wouldn't smile, he  
62 wouldn't nothing and it was really really really sad for everybody.  
63 Nobody, even in my family were telling me that the doctors know  
64 what they're talking about, stop being silly because I was really, I  
65 was just obsessing over his mood because he couldn't tell me  
66 what was wrong, he would just sit on my lap and wouldn't move,  
67 just constantly. For hours I couldn't go to the bathroom, couldn't  
68 do anything. He would just sit, wouldn't cry... just sit, like lifeless,

**Commented [DR17]:** Child mirroring parent's emotions. Feeling guilty? Affecting others around her – negatively impacting child's emotions

**Commented [DR18]:** Felt overwhelmed. Difficult comprehending what happened.

**Commented [DR19]:** A new sense. A new discovery of overcoming the darkness. "Light" – symbolic of a new phenomenon

**Commented [DR20]:** Sense of optimism. A new sense of hope coming to reality.

**Commented [DR21]:** Reciprocal roles facilitating coping

**Commented [DR22]:** Stages to experience

**Commented [DR23]:** Sense of helplessness in beginning. "Obviously" – sense of certainty that things do get better.

**Commented [DR24]:** Entire loss of life. Feeling numb. "Dead Inside".

**Commented [DR25]:** Major struggle to respond or attend to child's pain. Working to manage her child's pain. Feeling helpless. Struggling to understand child's feeling due as child's language skills have not yet developed.

**Commented [DR26]:** Heart-breaking. Struggle to see child helpless. Both feeling helpless.

**Commented [DR27]:** Maternal role to comfort sick child. Providing reassurance.

**Commented [DR28]:** Uncertainty about child's symptoms and diagnosis.

**Commented [DR29]:** Trust in the medical professionals and accepts her own lack of knowledge in this area.

**Commented [DR30]:** Frustration and anger in being with the unknown. Internal instinct.

**Commented [DR31]:** Change in child / personality / mood

**Commented [DR32]:** Sense of despair, Sadness

**Commented [DR33]:** Sense of disbelief in doctors. Struggling to accept what doctors noticed

**Commented [DR34]:** Completely consumed/preoccupied with the change in child and not knowing how to fix the problem.

Not taken seriously by medical prof.

Parental comfort  
Internal conflict

Surreal, confusion

Withholding diagnosis

Instinct

-ve emotional impact

Struggling to accept diagnosis

Lonely

-ve exp with medical professionals

69 really just really really tired. Umm yeah so it took me to just get  
 70 really angry umm because I just felt I was being fobbed off... umm  
 71 then we went to, I had to go to A and E and refuse to leave until  
 72 somebody would even just do a blood test and just tell me what  
 73 was wrong. And then it just went to like a whirlwind within a few  
 74 days, we was at Great Ormond street and, everything so that  
 75 beginning part from being just so sad and feeling, wanting to  
 76 comfort him to just being really angry so then the beginning I can't  
 77 even remember too much about that, I just remember running  
 78 around the hospital to this scan, that scan, MRI and it was just,  
 79 very surreal, very bizarre and I don't remember exactly how I felt  
 80 at that moment. Umm but I do remember the night before we  
 81 received his diagnosis, I picked up on words and different things  
 82 that had been said. Even though they were obviously keeping it,  
 83 they hadn't even mentioned cancer... umm but they just said we  
 84 would be moved to a ward where there's lots of children that have  
 85 lost their hair so all the way that they were trying to sort of keep it  
 86 away from you isn't that, it wasn't that great, they should have said  
 87 what they had suspected because you're thinking it and you're  
 88 seeing it and you just, it was yeah, that was hard and then I  
 89 remember just constant, just being a Google doctor. So the night  
 90 before, I had, obviously knew he had cancer at that stage... umm  
 91 and I knew it was a form of Leukaemia and I obviously didn't know  
 92 what it was but obviously when, even though I cried myself to  
 93 sleep that night, the following day I felt I was okay, I know they're  
 94 going to tell me he has Leukaemia. When they tell you, sorry,  
 95 [Holly became tearful] when they actually say it, it just, it makes it  
 96 real. When you still hope that no, it's only the bloody internet is,  
 97 it's not going to be true but obviously it, it was. So yeah, that was  
 98 umm, that was really emotional, really sad and umm... its really  
 99 lonely, even though I had my family around, it's your child, it's  
 100 different than what everybody else can feel. Umm... and I felt a bit  
 101 relieved as well in a sense that I wasn't going crazy because I  
 102 kept... telling four times to a doctor. I called an ambulance at one

Commented [DR35]: Very symbolic. Sounds as though she was lifeless/helpless with not being able to fix the problem or meeting expectation of self.

Commented [DR36]: Had to get angry in order to be heard by doctors

Commented [DR37]: Not being listened to. Being deceived or misguided by doctors

Commented [DR38]: Protesting to be heard. Sense of desperation to cope with feeling helpless, being with the unknown and not taken seriously

Commented [DR39]: Internal conflict with role as parent

Commented [DR40]: Struggling to meet demands of treatment

Commented [DR41]: Surreal / Confusing experience

Commented [MOU42]: Confusion?

Commented [DR43]: Had to become her own doctor and trust herself

Commented [DR44]: Being deceived from doctors. Hidden truth. Frustration in the sheer confusion in not being told. Conflict with what she internally suspected and external reality.

Commented [DR45]: Sense of desperation. Trusting only what she suspected. Lack of disbelief in medicine.

Commented [DR46]: Feeling uninformed about the diagnosis  
Distressed with the knowing the unknown

Commented [DR47]: Sense of reality kicks in

Commented [DR48]: Struggling with the accepting diagnosis  
Wanting to disbelieve

Commented [DR49]: Lonely, negative emotions, sad

Commented [DR50]: Unique parental feeling of her child's in pain

Commented [DR51]: Sense of normality. Feeling grounded with her anxiety

Struggling to be heard

persistence

103 point and I walked into A and E as well and I just felt that... finally  
104 it's the worst thing you can hear but now I know what's wrong with  
105 my son, we need to try and fix him. Umm but it wasn't obviously  
106 that simple, there isn't just a, I was obviously just expecting oh

Adapt to expectation

107 here's some medicine, go home, he'll be okay in a week. It wasn't  
108 like that, it was being admitted, umm to hospital. Umm yeah so  
109 that, that early stage after that was just bit of a, bit of a blur

Struggling to cope with change

110 because he, he was diagnosed with one type of Leukaemia and  
111 then it was changed to a Burkitt's Lymphoma and then they, they  
112 said it's actually Burkitt's Leukaemia so he was on one protocol for

113 two weeks and you get your head around all of that and you know  
114 the ins and outs of it and what day and what to expect and stuff  
115 and then it all changed umm and when it... umm when they told us

116 he had ALL which was the first diagnosis, we was waiting for a  
117 result to come back to see whether it was like low, medium or  
118 high, I can't remember exactly but umm, we was told it was low

119 which was a really good prognosis of that being low, and it not  
120 returning, and then umm after that, two weeks later, three

Confusion over diagnosis

121 consultants come in and actually said we need to speak to you  
122 about Luke's\* diagnosis umm, and then it turns out it was stage  
123 four... umm Burkitt's Lymphoma and they seemed happy in the

Major difficulty to adapt to diagnosis

124 sense that it was a shorter, umm protocol and there was better  
125 prognosis, I couldn't get my head around that stage four but it was  
126 better than it being a low risk ALL so that was really really hard I

127 think, I, even though I felt really good, not really good but I felt  
128 stronger after those two weeks of starting that okay, it's okay, I've  
129 got my head around this, I understand everything and then it

130 changes... umm I found that very very hard, and that set me back  
131 a bit quite a bit, umm but then once I had obviously examined all  
132 the paperwork, the different types of Chemo and everything how,

Sense of clarity

133 and I felt like I got it into my head umm, then I did feel so much  
134 better umm again looking online, I was trying to look online to see  
135 if there's anything about Burkitt's Lymphoma umm in his age  
136 group and there's nothing to compare it to. There was children

**Commented [DR52]:** Desperate measures to be heard. Frustrations and worry of not taken seriously meant she had to physical protest.

**Commented [DR53]:** Accepting the condition

**Commented [DR54]:** Solution orientated approach.

**Commented [MOU55]:** Acknowledging the difficulty in diagnosing.

**Commented [DR56]:** Challenge to adapt with change to the norm/assumption with hospital.

**Commented [MOU57]:** Confusion.

**Commented [DR58]:** Struggling to adapt with the change. Did this make her distrust/doubt their (medical professionals) decision more?

**Commented [DR59]:** Confusion with medical doctors knowledge and diagnosis. Frequently changing conditions. Having to adapt to change.

**Commented [DR60]:** Confusion surrounding child's diagnosis

**Commented [DR61]:** Major difficulty in adapting and accepting to change. Internal frustration of change during a critical, life-threatening period.

**Commented [DR62]:** Transition from known to the unknown was weakening her. Signs of strength over time. Better clarity with diagnosis.

**Commented [DR63]:** Repetition of "very" emphasises how difficult it was shifting the self. Set backs.

**Commented [DR64]:** Discovery herself through her own work.

**Commented [DR65]:** Sense of desperation. Find answers herself by using the internet. Wanting to feel more grounded in sense of uncertainty/unknown.

## Appendix H

**Table 1: Emergent themes (Sally)**

Emergent Themes	Line Number	Quotes/Key Words
Negative emotional impact	30	I was just in shock
	88	I felt devastated. Sad. Angry
	116	it's really tough, its overwhelming
	142	the stress is far beyond what I've ever know right now
	433	emotionally exhausting, physically exhausting
Time	57	It took at least a month to sink in
	78	In the past
	120	It's made me very present
	406	everything's impermanent
Negative experience with medical professionals	67	She was awful!
	36	I think the problem is with [name of hospital]
	43-44	it was really not great, the way they dealt with us
	70	she was particularly emotionless
	68	I truly believe we weren't dealt with in a very good way
	71	it was terrible
Struggling to contain others	159	seeing how upset people get. I find that hard
	162-163	you can't deal with a lot of people's emotions
	219-221	I think there's gonna to be more anger to come out later because I think the anger is kind of, I've pushed it away a lot,
	213	I think I got really angry, just just anger and fear
Positive experience with medical professionals	75	One amazing NHS nurse that I didn't know her name, just hugged me and was just amazing
	78	we've met some incredible nurses
	555	One thing that I think has really helped us is CNS obviously
Positive support from others	407	I've met some incredible helpful parents who were really helpful
	409	it's so humbling, so humbling seeing these people
	343	you see these people pouring out, pouring with love
	366	it makes you feel so loved and so fortunate with the friend that we've got
Negative support from others	162	that's not helping me

Life on hold	240 -241	I've had to stop work and not earn money and you know resentment about that
	242	I feel like my hands are tied
	221-222	we can't plan, we can't go away
	223	its not fair
	451-452	I just think back to my life before you know being on my own and single
	248	I stopped working
Loss of control	88	Accepting that I'm not in control
	89 -90	We all think we're in control in life, but actually none of it is
	90	You just got to go with it
	136-137	they're actually they were inflicting pain on my daughter at times
Helplessness	332	helplessness, there's so much helplessness
Child reciprocates parents feelings	148	I really think the children pick up on what the parents are feeling
Strong self	146-147	I'm just trying to hold it together for her
	147	I fall into a heap then she's got no one
	238	keep like as strong as possible
	98	what she's taught people is incredible
	112	this is meant to be, what we're meant to go through it
	494	there's someone beyond our, something beyond our control doing all of this
	556	I feel very fatalistic about having her in our life
Coping as a process	116	I tried to compartmentalise
	106	I kind of don't want to know about the information
	114 - 115	I'm choosing to kind of be very positive about it
	116	I just do it day by day
	163 - 164	keeping your own strength
	206	I try and look at the good bits
	140	you get angry at the nurse
	144	I found it very hard actually to mediate since she's been diagnosed
	450	I just want to run away
	513	you kind of go on autopilot
Re-evaluation of values	411	I just all the superficial stuff tends to fall away
	413-414	it's actually it's made me much more focused with work and it's made me kind of realise to really do what I love now
	354	I don't invest in much that waste my time or people that would waste my time
	358	just cut out the bullshit, which is lovely
	492-493	I've probably got more spiritual, definitely

		got more spiritual
	402	I'm just a lot more appreciative of life really
	404	you never know what's in store with life
Negative impact of treatment	295	demons to me the steroids
	290	that was heart-breaking
	283	worst bit was hands down the steroids
	305	this poison in her body
	267	the steroids, so they're my worst enemy, that's the one thing I hate the most
Negative changes to child	284	you lose your daughter, your child's personality
	284	they become someone else
	285	see her depressed broke our heart
	301	mood swings'
	325	it was really hard
Diagnosis as transforming relationships	250	I'm super close to Katy, like much closer to I probably would be if she not had it
	338	our bond has really changed
	358	made me see who's strong and who's weak in in their ability to support
	356	made me close to certain people
Expectations of self	447	I guess there's a sense of responsibility when you have a child
	437	It's a lot of responsibility
	356-357	I've got to conserve my energy, I've got to save what I have
Diagnosis as transforming the self	252 - 253	I'm much more empathetic, I don't care as much about, I'm much more present
	254	I am a better person from it
	259	it's really taught them a lot
	254	we are better people from it

## Appendix I

**Table 2: Superordinate Table of Themes (Mohammed)**

<b>Superordinate Theme</b>	<b>Subtheme</b>	<b>Page Number</b>
Relationship with others	Questioning medical expertise	2, 3, 4, 5, 12, 13, 14, 15
	Sharing experience as problematic	3, 5, 10, 12
	Others as facilitating coping	6, 10, 11
	Dissatisfaction with medical professionals	2, 3, 5, 12, 13, 14, 15
	Satisfaction with medical professionals	1, 11, 12
Purpose	Test of God	2, 5, 6, 7, 8, 12, 13, 19
	Religious beliefs facilitating coping	2, 5, 8, 12, 13, 18, 19
Powerless	Loss of control	5, 6, 7, 8
	Helplessness	10, 13
The different selves	Loss of self	4, 7, 10, 11
	Parental expectations	1, 10, 11
	The strong self	5, 6, 12, 18
Sense-making	Prior family loss to illness	8, 10, 14, 15
	Difficulty describing experience	12, 13
	Religious attributions to illness	2, 5, 8, 12, 13, 18
	Parental Instincts	1, 2, 15
Re-evaluation of life	Renewed sense of relationships	8, 12, 13, 14
	Renewed life values	10, 13, 14

## Appendix J

**Table 3: Superordinate themes, subthemes, and quote locations**

Superordinate theme	Subtheme	Quote location (Participant initial Page number)
Sense-Making	Purpose	D4, D6, D12, Mo5, 12, Mo13, Mo19, S2, S10, Ma4, Ma7, L2, L15
	Surreal Experience	A2, A3, A8, L3, D1, D2, D3, D5, Ma1, Ma2, Mo2, Mo3, L3, L4, S2, S3, H3, H6, H18, Mi1, Mi2
Powerless	Feeling Powerless	H1, H5, H6, Mo6, Mo6, Mo7, S2, S3, S5, A5, A9, L11, L13, L14, D2, D3, D4, Mi7, Mi8, Ma5, Ma6
	Life on Hold	Ma4, Ma6, Ma8, S4, S5, Mi2, Mi4, Mi5, H11, Mo1, Mo10, Mo11, L23, L24, D6, D14, D20, H10, H11, H12, A4, A7
	Struggles with Containment	H8, H9, H12, A10, S4, S5, Mi8, Mi9, Mo6, L18, L19, D19, D22, Ma3, Ma5
	The Invulnerable Self	A3, Mo18, Mo7, Mo10, L12, L13, L15, Mi3, Mi6, Mi,7, D10, D11, S5, S8, H13, H14, H23, Ma2, Ma3, Ma4, Ma5
Relationship with Others	Relationship with Professionals	D9, D13, S12, Mo5, Mo12, Mo13, H3, H13, H23, L23, L24, L25, S6, S11, S12, A3, A7, A11, A12, Mi9, Mi10, Ma1, Ma3
	Support from Social Relationships	S4, S8, S12, H12, H19, H20, L9, L19, L22, Mi8, Mo6, Mo10, Mo11, L25, L28, L18, D14, D15, A6, Ma9, Ma3
A Process of Transformation	Transformation of Values	A5, A6, A8, Mi5, D4, D6, D11, S4, S8, S9, S10, Mo10, Mo13, Mo14, L13, L14, L18, H9, H10 H12, Ma4, Ma7, Ma9
	A Renewed Sense of Relationships	Mo8, Mo13, Mo14, Ma9, A6, A7, A10, L20, L22, D5, D6, D8, S6, S8, S11, H9, H12, H23, Mi4, Mi6, Mi8, Ma9, Ma10
	Transformation of Child	S6, S7, Ma3, Ma5, Mi2, Mi3, Mi4, Mo10, Mo11, L11, L12, L15, D9, D10, H7, H10, H11, A8, A11

## **Part B: Clinical Case Study**

**Collaboratively Uncovering Over-Valued Beliefs  
that Inhibit Change in Other Specified Feeding  
and Eating Disorder using Eating Disorder  
Focused Cognitive Behavioural Therapy**













































## **Part C: Publishable Article**

# **Feeling Powerless when Caring for a Child with Cancer: An Insight into the Parents' Experiences using An Interpretative Phenomenological Analysis**

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## Abstract

Although the survival rates for children with cancer have improved significantly due to biomedicine advancements, the illness nonetheless is devastating and presents significant challenges for parents. Given that parents have an important role in their child's well-being, it is necessary that we develop an understanding of their experiences to better support them. For this purpose, the aim of the current study was to explicate the parents' lived experiences of their child being diagnosed with cancer. Semi-structured interviews were conducted with eight parents attending a UK oncology unit within the National Health Service. The empirical data was analysed using Interpretative Phenomenological Analysis. Four superordinate themes emerged from the data: "Sense-making", "Powerless", "Relationship with Others", and "A Process of Transformation". The focus within this article will be on the "Powerless" theme as it reveals how participants face the reality that they no longer have complete control of their child's cancer. Nestled within this superordinate theme were subthemes that revealed parent's experience of feeling helpless and not in control over their child's condition. It explores the impact this had on their lives and their struggles in dealing with other issues beyond their child's illness. Despite finding their child's illness as feeling powerless, parents strove to cope by appearing to be strong and invulnerable for their sick child. The findings are considered in relation to existing literature and discuss implication for clinical practice, as well as the limitations and recommendations for future research.

Keywords: Children with Cancer, Parents, Lived Experience, Interpretative Phenomenology

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