Exploring the Experiences of Healthy Siblings and Parents When a Child is Diagnosed and Treated For Cancer

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Abstract

The diagnosis of childhood cancer is recognised as a significant stressor for families. There is a growing body of research exploring the experiences of parents and healthy siblings during the treatment of childhood cancer. The first paper is a systematic review of 28 qualitative studies that explored the experiences of mothers and fathers from different countries and cultures. Key findings included the desire to feel in control, the need to continuously adjust, various coping styles were adopted, emotional and practical support was valued, and gender and cultural differences were reported. Clinical implications include the need to provide clear information and aid the sense of control, care needs to be individualised, and fathers' needs should be acknowledged and met. The second paper aimed to address some of the gaps in the literature on healthy siblings, as few studies have explored the experiences of adolescent healthy siblings. A qualitative study was carried out using grounded theory to explore adolescent healthy siblings' experiences across the duration of treatment for childhood cancer. A semi-structured retrospective interview was completed with eight participants. A grounded theory model was developed, which illustrates how the healthy siblings' experience changed over time, with the most challenging period being the diagnosis and initial phase of treatment. Their experiences appeared to depend on a number of factors including: how they managed the stressors; temperament; family relationships; individual coping strategies; and support received. Developmental changes associated with adolescence appeared to further serve as a potential protective factor. Clinical implications include health care professionals needing to ensure healthy siblings have appropriate support in place and the required coping skills to reduce the chance of psychosocial problems developing. There is a particular need for early support, as healthy siblings are likely to particularly struggle between the diagnosis and initial treatment.

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PAPER A

A Systematic Review of Qualitative Studies Exploring the Experience of Parents Whose Child is Diagnosed and Treated for Cancer.

Jonathan Andrew Gibbins

A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology validated by the University of Oxford

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A Systematic Review of Qualitative Studies Exploring the Experience of Parents Whose Child is Diagnosed and Treated for Cancer.

Jonathan A. Gibbins, Harris Manchester College,
University of Oxford, Doctorate in Clinical Psychology,
Trinity Term, 2011

Abstract

A growing body of research has investigated the experiences of parents of children treated for cancer. Until recently, a qualitative review has not been possible due to the lack of qualitative studies in this area. However, this has changed in recent years. The purpose of this systematic review is to summarise the findings from qualitative studies on the experiences of mothers and fathers from different countries and cultures. 28 qualitative studies were found to meet the inclusion criteria for this review. Key findings included the parents' desire to feel in control, the need to continuously adjust to the unpredictable nature of cancer treatment, various coping styles were adopted, emotional and practical support was valued, and gender and cultural differences were reported. Clinical implications include the need for health care professionals to provide clear information and aid the sense of control, the care needs to be individualised with gender and cultural backgrounds taken into account, and fathers' needs should be acknowledged and met. Other implications for clinical practice and future research are discussed.

Keywords: Childhood cancer, parents, qualitative.

Proposed journal: Journal of Pediatric Oncology Nursing (see Appendix A for instructions to contributors).

Introduction

The incidence of childhood cancer is increasing, with 1 in 500 children from birth to 15 years old being diagnosed in Britain each year (Stiller, 2007). Around 75% of children with cancer in Britain survive for at least five years after diagnosis compared to only 10% in 1970 (Cancer Research UK, 2004). Children who have retinoblastoma, gonadal germ cell tumours and Hodgkin's lymphoma have the highest survival rates of about 95% (Cancer Research UK, 2004), while acute lymphoblastic leukaemia (ALL), the most common form of childhood cancer, has a survival rate of over 75% (Mitchell et al., 2005). The development of new drugs and the refinement of existing chemotherapy have meant not only higher survival rates but longer and often more intensive treatment courses for children with cancer. Treatments can include aggressive chemotherapy, radiation, surgery and transplants (Clarke & Fletcher, 2003). The illness combined with the treatment can be traumatic not only for the child but the whole family. As a parent, having a child with cancer is often considered "one of the most stressful experiences that a family can have" (Kazak & Nachman, 1991, p. 462).

The impact this stress has on parents has been recognised and researchers are continuing to add to this important area. Factors that contribute to overall coping and adjustment have increasingly become a focus in the literature. Grootenhuis and Last (1997a) reviewed studies between 1980 and 1997 on the adjustment and coping of parents whose children have cancer. Their review included empirical and descriptive studies of the parents' emotional reactions and coping behaviours. Longitudinal studies revealed that diagnosis was followed by increased insomnia, somatic problems where the function of bodily structures is impaired, social dysfunction, and negative emotions such as depression and anxiety in parents (Fife, Norton & Groom, 1987; Magni, Messina, De Leo, Mosconi & Carli, 1983; Powazek et al., 1980; Sawyer, Antoniou, Toogood, Rice &

Baghurst, 1993). The review found that common concerns for parents included fear of relapse, uncertainty about the future and concern over the child's fertility. Studies also reported an increase in marital distress post diagnosis (Cornman, 1993; Dahlquist et al., 1993; Fife et al., 1987; Lansky, Cairns, Hassanein, Wehr & Lowman, 1978; Schuler et al., 1985). Despite these negative factors, the review also revealed some positives as parents reported good support systems; new values and attitudes; changed life goals; and reported that they valued life more (Eiser & Havermans, 1992; Greenberg & Meadows, 1991; Grootenhuis & Last, 1997b; Peck, 1979). Some families also became closer (Koch, 1985) and some marital relationships were strengthened (Koocher & O'Malley, 1981; Marky, 1982).

It has been fourteen years since Grootenhuis and Last (1997a) published their review. Since then two quantitative reviews of work have been published in this area (Klassen et al., 2007; Vrijmoet-Wiersma et al., 2008), as well as a mixed methods review, focusing on cultural issues (Thibodeaux & Deatrick, 2007). Until recently, a qualitative review has not been possible due to the lack of qualitative studies in this area. However, this has changed in recent years. A review of qualitative papers is now timely and may provide different perspectives and information from the quantitative studies, as qualitative methods provide insights into emotional and experiential phenomena, which help to explore the perspectives of those being studied in greater depth (Giacomini & Cook, 2000).

Theoretical Background for the Review

The model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1993, 1996) assumes that families experience stress over the life cycle and they will seek to restore balance, order and harmony during a crisis, even in the face of great upheaval.

The model proposes that families possess strengths and develop competencies to manage stressors and strains to recover from a family crisis. Families can draw on the support from a network of relationships in the community and will search for a shared perspective and purpose to allow them to continue as a group (McCubbin & McCubbin, 1996). The family transition to living with childhood cancer model (Clarke- Steffen, 1993, 1997) suggests families move into a transitional stage when they realise the severity of the illness. They enter a "limbo" stage as they await the diagnosis, which causes a state of shock. Families then attempt to create a "new normal" by adopting new routines and cognitive and behavioural strategies to aid the integration of the childhood cancer experience into every day family life. Clarke-Steffen (1993, 1997) identified the strategies families adopt as managing the flow of information, reorganising the roles in the family, evaluating and shifting priorities, changing future orientation, assigning meaning to the illness and managing the therapeutic regimen.

Aim of the Review

The aim of this paper is to perform a systematic review of qualitative papers from 1998 to May 2011, exploring the experiences of parents whose child has cancer. The review will provide a qualitative update to the Grootenhuis and Last (1997a) review and will include added information on cultural perspectives and the experiences of fathers that were not available at that time. The review will complement the quantitative reviews (Klassen et al., 2007; Vrijmoet-Wiersma et al., 2008) and the culture review of quantitative and qualitative papers (Thibodeaux & Deatrick, 2007), by reviewing qualitative papers of the parents' experiences across different cultures and exploring the impact cultural factors may have on their experience. This will be an important addition, as most participants in the Grootenhuis and Last (1997a) review were white parents from western cultures,

which made generalisations to parents from other cultures and ethnic backgrounds difficult. The treatment advances and improved prognosis since Grootenhuis and Last's (1997a) review may have also changed the experiences of parents and this needs to be explored. The review aims to guide future research and improve the support for parents by raising awareness of their experiences and clarifying the support they value and need.

Materials and Methods

Literature Search Protocol

Searches were conducted using PsycINFO, Google scholar, Scopus, and PubMed. The key words were qualitative, parents, fathers, mothers, paediatric, childhood, child, and cancer. The search included all papers published between 1998 and May 2011. The references from each paper were examined to identify additional papers that met the review criteria.

Inclusions and Exclusion Criteria

Papers were included if they were (1) qualitative studies published since 1998 exploring the experience of parents whose child (aged up to 18 years old) was diagnosed and treated for cancer; (2) if they investigated the experience of the diagnosis and the treatment; and (3) were written in English.

Papers were excluded if they were (1) quantitative studies; (2) mixed methods studies (3) not a scientific paper; (4) focused solely on parental reactions to the death of their child; (5) used data from other family members or healthcare professionals; and (6) focused on the treatment rather than parental experience.

Studies that met the inclusion criteria were analysed against the guidelines provided by Letts et al., (2007) for qualitative reviews (see Appendix B).

Results

After the initial searches and reading through the studies to explore whether they met the criteria, 28 studies were selected for this review. Six of these studies were conducted in America, five from Canada, five from Australia, three from China, two from Taiwan, two from the Netherlands and one each from Ireland, Turkey, England, South Africa and Finland. A total of 784 parents took part in these studies. A critique of the methodologies used in the studies is presented before the main themes arising from the literature are discussed. A table containing the methodological details of the studies can be found in Appendix C.

Critique of Methodology

Overview of Characteristics and Methodology of Studies

The findings from these studies must be understood in the context of how they were carried out. Before the findings are discussed, it is important to critique the methodology and the clarity with which the studies were reported. The studies were analysed against the guidelines provided by Letts et al., (2007) for qualitative reviews. The studies all presented clear statements of the purpose and aims of their research. The selection of a qualitative methodology was appropriate for the studies. The studies all presented relevant background literature to provide context for their studies, although two studies

only presented brief rationales (Wong & Chan, 2006; Yeh, 2003). Despite the use of relevant literature, only three studies clearly discussed the theoretical perspectives that informed the project (Brody & Simmons, 2007; McCubbin, Balling, Possin, Frierdich & Bryne, 2002; Patterson, Holm & Gurney, 2004).

Qualitative Design of Studies

The qualitative designs of the studies were appropriate for the aims and research questions in the 12 studies that reported their design. Phenomenology was used in seven studies, grounded theory was used in four studies, and interpretative phenomenological analysis (IPA) was used in one study. Unfortunately, 15 studies did not clearly define the design and simply stated it was a qualitative study, making it difficult to assess the appropriateness of the designs and potentially limiting the interpretation of their findings.

Qualitative Methods of Data Collection

Twenty-five studies interviewed the parents to obtain their data, three studies used focus groups in addition, two studies solely used focus groups, and one study transcribed sessions from a larger problem-solving intervention study. Twenty-three of the interviews were semi-structured, one study adopted an open Rogerian style interview, and it was unclear in one study whether the interview was semi-structured. Two studies conducted their interviews over the phone (Clarke & Fletcher, 2003; Kylmä & Juvakka, 2007), which may have resulted in a missed opportunity to collect important observations and field notes. Three of the five studies using focus groups reported that the facilitators were trained to facilitate groups (Clarke, 2006; Patterson, Holm & Gurney, 2004; Yeh, 2003).

Most studies explained in detail how the interviews and focus groups were conducted. These methods were appropriate for qualitative studies exploring this area and they produced relevant data to be analysed. Unfortunately, not all the authors gave sufficient details to allow for the methodology and approach to be fully understood. This needs to be improved in future research to allow for replication and a more comprehensive critique of the methodologies of qualitative studies.

Sampling

Twenty-one studies reported obtaining ethical review approval. Only 15 studies reported gaining consent or explained that parents had opted in. Seven of the 11 studies where parents chose not to participate did not explain the refusal to consent. Although qualitative studies tend to have smaller samples than quantitative ones, three studies only recruited five or six participants, which may have limited the richness of their findings. Thirteen of the studies using interviews explained that recruitment continued until saturation of the themes was achieved. It was not clear whether data saturation was reached or needed in the remaining studies due to lack of clarity regarding the design.

Although the studies explained where they were carried out, only four reported the credentials of the researchers or their assumptions (Chesler & Parry, 2001; Johns et al., 2009; McGrath, 2001a; Wong & Chan, 2006). The participants were appropriate for the research questions and their selection was well explained. However, it is important to consider some potential limitations within the samples. The parents were self-selected, which means the participants may have been more willing to seek help, or be coping at a higher level than parents who chose not to participate. The data from these studies will not, therefore, be representative of all parents. Some participants were recruited from support groups (Clarke & Fletcher, 2003; Fletcher & Clarke, 2003), or parent teaching

courses (Johns et al., 2009). These groups and courses are also likely to attract parents more willing to ask for help and the data they provided may have been influenced by attending such groups.

Data Analysis

All the studies transcribed the data verbatim and 27 studies presented verbatim quotes to allow the reader to confirm the researchers' interpretations of the data. One study claimed their interpretations were confirmed by parents' comments, but did not substantiate this (Wills, 1999). The rules of analysis and the process of transforming data into themes and codes were described adequately in most studies, although only three researchers described their decision trails in detail (Chesler & Parry, 2001; Patterson et al., 2004; Yeh, 2003). Two studies did not describe their rules for analysis sufficiently to enable replication or to substantiate the findings (Leavitt, Martinson & Liu, 1999; Wills, 1999), their findings must, therefore, be interpreted cautiously. Twelve studies did not discuss whether measures were undertaken to ensure the trustworthiness of the data. One study claimed measures were taken but did not explain how this was achieved (Clarke, 2005). Qualitative research needs to include and report on how these important checks of rigour were made to minimise the systematic bias of interpretations and provide trustworthiness of the data (Letts et al., 2007).

Conclusions About the Studies' Methodologies

The studies adopted appropriate data collection methods allowing them to produce rich and robust data, which created meaningful pictures of the experiences of parents whose child has been treated for cancer. All but seven studies (McGrath, 2001a; McGrath, 2001b; McGrath & Chesler, 2004; Nicholas et al., 2009; Van Dongen-Melman, Van

Zuuren & Verhulst, 1998; Yeh, 2003; Yeh, Lee & Chen, 2000) thoughtfully discussed limitations of their studies and how this might impact on the trustworthiness of their findings. The studies all made contributions to the development of theories to help explain the experiences of these parents, they were able to provide context for their findings by linking and comparing their studies with the existing literature in this area. All but two of the studies (Clarke, 2005; Patterson et al., 2004) considered and discussed the practical implications of their findings. The authors drew appropriate conclusions and suggested future research to increase the understanding of how parents may be affected and how health care professionals (HCP) can help.

Themes Reported in the Studies

The findings from the studies were explored and several key themes were identified using thematic synthesis, which has been recommended for synthesising findings in systematic reviews of qualitative studies (Thomas & Harden, 2008). Thematic synthesis involves three stages, which can overlap: "free line-by-line coding of the findings of primary studies; the organisation of these 'free codes' into related areas to construct 'descriptive' themes; and the development of 'analytical' themes" (Thomas & Harden, 2008, p. 4). The themes from this review include confronting the reality, attempts to gain control and the need for information, continuously adjusting and different coping styles, negative impact, positive outcome, support, gender differences, and cultural differences. These will be discussed in turn.

Confronting the Reality

An important aspect of the experience of parents with children treated for cancer is coming to terms with the diagnosis, which was reported in 14 of the studies. Coming to terms was described as the "core construct of the parental reaction to caring for a child with cancer over the illness trajectory" (Yeh, 2003, p. 247). Parents felt they had to confront reality to regain control and deal with the situation (Hill et al., 2009). Parents reported being initially shocked, scared, frightened, in despair, upset and overwhelmed (Clarke, 2006; Clarke & Fletcher, 2003; Fletcher & Clarke, 2003; McCubbin et al., 2002; McGrath & Chesler, 2004; Patterson et al., 2004; Yeh, 2003; Wills, 1999; Wong & Chan, 2006; Yiu & Twinn, 2001). Some parents experienced an overwhelming sense of helplessness (Jithoo, 2010). Parents reported finding this period very stressful, which was, in part, due to feeling unprepared for the diagnosis (McGrath & Chesler, 2004; Yiu & Twinn, 2001).

Most parents found it helpful when the physician disclosed their child's condition and prognosis (Wills, 1999). Some parents had pushed for the diagnosis (Clarke, 2005) and felt relieved, as they finally had a diagnosis and could start treatment (Wills, 1999). Others were in disbelief and denial, as they were anticipating their child being diagnosed with a mild medical complaint (Wills, 1999; Wong & Chan, 2006; Yiu & Twinn, 2001), some explored whether there was a misdiagnosis (Yeh, 2003), or became angry and frustrated at HCP for not listening and delaying the diagnosis (Brody & Simmons, 2007; Clarke, 2005; Clarke & Fletcher, 2003; McGrath & Chesler, 2004; Patterson et al., 2004; Yeh, 2003). Parents also felt guilty and wondered if they were to blame for not spotting the illness earlier or for passing on their genes (Yeh, 2003). The uncertainty involved with the diagnosis, the treatment and whether their child would live caused a great deal of anxiety for parents (Hill et al., 2009; McGrath & Chesler, 2004; Nicholas et al, 2009; Van

Dongen-Melman et al., 1998; Yiu & Twinn, 2001). This uncertainty left parents feeling out of control (Hill et al., 2009).

Parents found telling other people about their child difficult, as it forced them to face their reality, often repeatedly and before they felt ready (Hill et al., 2009). Parents differed in their decisions on how much information to tell their child and healthy siblings, with only a few passing on complete information (Jithoo, 2010; Leavitt et al., 1999). Parents found it hard to use the word cancer and did not want to tell their child that it could be terminal due to the negative impact it may have (Jithoo, 2010). Some parents chose to give information to the child over time or wait until the child asked (Jithoo, 2010). Communication with children appeared to be influenced by cultural differences in Jithoo's (2010) study, as black South African parents had greater difficulty than white parents in talking about the illness with their child. This communication difference was thought to be partly caused by a culture of talking to elders in the family and not to children about important matters; and partly because parents also found it harder to directly question the doctors, as culturally they did not tend to question those in authority (Jithoo, 2010).

Parents tried to ignore their own needs, worries and fears to focus on their child's needs (Kars, Duijnstee, Pool, van Delden & Grypdonck, 2008) and were able to show great fortitude in caring for their child while being distressed (Yeh, 2003). After the initial shock, parents found acceptance with some viewing the cancer as fate (Wong & Chan, 2006), while others explained they needed to find a sense of acceptance before they could deal with their new reality (McGrath & Chesler, 2004). Acceptance often came at a cost, as parents experienced intense feelings of despair and fear (Hill et al., 2009). Parents also had to adapt to spending long periods in hospital, which was described as one of the most difficult experiences (Yiu & Twinn, 2001).

Attempts to Gain Control and the Need for Information

Parents wanted to learn as much about the illness as possible by talking to HCP, talking to other parents and using the Internet (Johns et al., 2009; Patterson et al., 2004; Van Dongen-Melman et al., 1998; Yeh et al., 2000). Parents wanted individualised information about the disease, prognosis and care of their child (Wills, 1999; Yiu & Twinn, 2001). The need for information was particularly important during times of crisis and stress (Chesler & Parry, 2001; Yiu & Twinn, 2001). Importantly, parents differed in the level of information they wanted and this seemed to vary by the stage of the child's treatment (Clarke & Fletcher, 2003). Parents' ability to comprehend information fluctuated throughout treatment, depending on their state of anxiety and the health status of their child (Clarke & Fletcher, 2003). Some parents wanted to avoid information, as the volume of information could further confuse, intimidate and distress them (Jithoo, 2010).

Parents wanted information to help make appropriate decisions and learn about the long-term consequences of cancer, and know how to answer questions from family and friends (Jithoo, 2010). Parents' need for information about the illness and treatment appeared to be driven by the need to feel in control (Fletcher & Clarke, 2003; Johns et al., 2009; Yeh et al., 2000; Yiu & Twinn, 2001). The overall wellbeing of the parents often depended on their attitude towards control, with parents with an extreme internal style of control being more likely to feel anxious, guilty and depressed (Patterson et al., 2004; Van Dongen-Melman et al., 1998; Yeh, 2003; Young et al., 2002). Parents with an extreme external style of control blamed their environment and were more likely to become angry and resentful (Van Dongen-Melman et al., 1998; Yeh, 2003). The parents with a more balanced need for control were more likely to be accepting and report less guilt (Van Dongen-Melman et al., 1998).

The need for control provided extra motivation for parents to participate in the care of their children (Yiu & Twinn, 2001). Being there for their child allowed parents to advocate for their child and feel they were contributing to their child's chances of survival (Kars et al, 2008; Patterson et al., 2004). The drive to feel in control was not always helpful, as some parents overcompensated and insisted their medical judgement was followed over medical protocols (Yeh et al., 2000). Some parents pursued alternative treatments even if these treatments did not have scientific evidence, such as Qi-Gung treatment, using Chinese herbs (Yeh et al., 2000), reikie practitioners, homeopaths and traditional healers (Jithoo, 2010). If information provided by the HCP was later contradicted it caused frustration and uncertainty for the parents (Clarke & Fletcher, 2003). The lack of consistency in who provided treatment reinforced the feeling that parents were the one constant figure in their child's health care, further reinforcing the desire for information and control (Clarke & Fletcher, 2003).

Continuously Adjusting and Different Coping Styles

Parents had to adapt every day to the changing impact of potential side effects, complications and the emotional needs of both their child and themselves (Yeh, 2003). The unpredictability of the treatment process could explain why parents felt their ability to cope with the diagnosis and treatment fluctuated throughout their experience (Yeh, 2003). The coping process was described in one study (Yeh, 2003) as consisting of five components, where parents need to confront the reality, manage treatments, shift their cognitions, recognise the situation and appropriately adjust. An important aspect of adjustment was the capacity to make changes quickly as a family in response to cancer (McCubbin et al., 2002). Parents reported needing to adapt family life to help take care of their child (Wong & Chan, 2006; Yeh et al., 2000).

Although changes were made in the family, parents worked hard to achieve as much normalcy as possible (Fletcher & Clarke, 2003; Hill et al., 2009; Leavitt et al., 1999; McGrath, 2001a; McGrath & Chesler, 2004; Patterson et al., 2004; Van Dongen-Melman et al., 1998), whilst always being prepared for the worst (Leavitt et al., 1999). Parents found taking one day at a time a helpful perspective to take (Johns et al., 2009; Van Dongen-Melman et al., 1998), whilst parents also valued taking breaks from the illness experience, and a degree of avoidance and escapism as ways of coping (Hill et al., 2009; Johns et al., 2009; Leavitt et al., 1999; McGrath, 2001a; McGrath & Chesler, 2004; Van Dongen-Melman et al., 1998).

Trying to be positive and maintaining hope was a common theme across studies (Fletcher & Clarke, 2003; Hill et al., 2009; Johns et al., 2009; Kylmä & Juvakka, 2006; McGrath & Chesler, 2004; Nicholas et al., 2009; Patterson et al., 2004; Yeh et al., 2000). This often resulted in new perspectives forming where positives were also considered alongside negatives (McCubbin et al., 2002). Some parents used 'downwards comparison' (Festinger, 1954) to cope by drawing strength from comparing their experiences with families perceived as less fortunate (Patterson et al., 2004). Some parents, however, became overly optimistic, rejected medical advice and ignored warning signs, which lead to negative consequences including relapses (Yeh, 2003).

Parents mainly adopted existing coping styles but also tried new strategies (Johns et al., 2009), and they shared their coping strategies with their partner (McGrath, 2001b). Parents discussed taking it in turns to be the strong one in the relationship (McGrath, 2001b). Some parents stressed the importance of togetherness in their family to help them cope, but this was not always a useful strategy, as some parents turned down help to avoid splitting the family up (McGrath, 2001a). Other general coping strategies included sharing experiences with other parents (Elcigil & Conk, 2010; Hill et al., 2009; Johns et

al., 2009; Wills, 1999; Yeh et al., 2000), using humour and fun (Johns et al., 2009; McGrath, 2001b; Patterson at al., 2004), and expressing emotional distress (Yeh et al., 2000). Crying, for example, was considered a helpful way of releasing worry and sadness (Johns et al., 2009; Patterson et al., 2004). Many coping strategies focused directly on helping the child, often at the expense of their own health, as parents neglected their own health care and engaged in unhealthy activities (Fletcher & Clarke, 2003). Other coping styles such as relaxation exercises, yoga, listening to music and eating comfort food seemed more focused on helping the parent themselves (Johns et al., 2009; Nicholas et al., 2009).

Religious beliefs helped some parents to cope (Brody & Simmons, 2007; Chesler & Parry, 2001; Fletcher & Clarke, 2003; Johns et al., 2009; Kylmä & Juvakka, 2006; McCubbin et al., 2002; Nicholas et al., 2009; Patterson et al., 2004; Wills, 1999; Yeh, 2003; Yeh et al., 2000). Parents became more reliant on their faith or found faith for the first time (Nicholas et al., 2009). They increased their spiritual and religious practices, such as praying (Johns et al., 2009), or attending spiritual counselling (Yeh et al., 2000). Parents reported handing their worries over to God and placing their child's life into His hands (Johns et al., 2009; Patterson et al., 2004). Spiritual practices helped parents feel they were doing something to help their child recover (Wills, 1999). Spiritual beliefs were used to understand the illness (Chesler & Parry, 2001; Nicholas et al., 2009; Patterson et al., 2004; Yeh, 2003; Yeh et al., 2000), with some believing the illness was caused by their past sins (Yeh, 2003), or viewed it as their child's fate (Wong & Chan, 2006; Yeh, 2003; Yeh et al., 2000). Fatalistic beliefs enabled some parents to be more positive and medically compliant (Leavitt et al., 1999; Yeh et al., 2000). Some parents felt that discussing the illness would be displaying a lack of faith in God's efforts to heal

the child (Yeh, 2003), while others became angry with God for their child's illness (Johns et al., 2009), or felt their faith was tested or reduced (Nicholas et al., 2009).

Negative Impact

Most of the changes brought on by the cancer were seen as negative by the parents (Van Dongen-Melman et al., 1998; Yiu & Twinn, 2001). Parents felt the loss of their previous way of life and explained their outlook on life had become more negative (Patterson et al., 2004; Van Dongen-Melman et al., 1998). Parents felt more vulnerable, emotionally, physically and mentally drained and less able to cope with new stressors (Brody & Simmons, 2007; Elcigil & Conk, 2010; Leavitt et al., 1999; Nicholas et al., 2009; Van Dongen-Melman et al., 1998; Yeh, 2003). Parents were prone to burning out, as they struggled to delegate care in case others did not look after the child adequately (Kars et al., 2008). Being emotionally drained also left parents feeling they did not have enough emotional resources to support their child through their cancer experience (Jithoo, 2010). Some parents felt overwhelmed by the experience and requested psychosocial help (Jithoo, 2010).

Many parents gave up jobs or reduced their hours to care for their child (Patterson et al., 2004; Wong & Chan, 2006). This placed demands on the parent still employed, who had to balance work and family commitments (Chesler & Parry, 2001; Nicholas et al., 2009). Some felt, however, that work was a welcome distraction (Hil! et al., 2009). Finances were another strain on parents, as lost income combined with transport costs, special diets and presents for the ill child left many families struggling (Brody & Simmons, 2007; Elcigil & Conk, 2010; Leavitt et al., 1999; McGrath & Chesler, 2004; Nicholas et al., 2009; Patterson et al., 2004; Yeh, 2003). Parents also felt guilty about ignoring the needs of their healthy children during this time (Clarke, 2006; Elcigil &

Conk, 2010; Leavitt et al., 1999; Nicholas et al., 2009; Yeh, 2003; Yeh et al., 2000; Young et al., 2002). Some couples' relationship became strained by the intense focus on their child; a clash in their coping styles; and from the on-going effort in dividing up responsibilities and labour (Clarke, 2006; Elcigil & Conk, 2010; Fletcher & Clarke, 2003; Leavitt et al., 1999; Nicholas et al., 2009; Patterson et al., 2004; Van Dongen-Melman et al., 1998). Parents did not have much time for each other (Clarke, 2006; McGrath, 2001b), marital problems arose (Leavitt et al., 1999) and they had to relearn how to work together (Patterson et al., 2004). Parents also reported strains in their relationships with the ill child and extended family (Patterson et al., 2004).

Parents grieved for the loss of the healthy child, with physical and psychological after-effects of the cancer treatment meaning many viewed their child as vulnerable and disadvantaged (Patterson et al., 2004; Van Dongen-Melman et al., 1998). Some parents found their ability to cope was directly affected by the physical condition of the child (McGrath & Chesler, 2004), and parents had to endure the emotional pain of seeing their child lose their hair, lose limbs, be sick, become weaker and have surgery (Patterson et al., 2004). The sense of powerlessness over their child's health was hard for parents, especially when their children had to have painful procedures (McGrath, 2001b). To avoid blurring their role as a comforter, some parents looked to delegate unpleasant procedures to the professionals (Kars et al., 2008). The fear of relapse and death caused anxiety in parents, even after long periods of remission (Brody & Simmons, 2007; Clarke, 2006; Leavitt et al., 1999; Nicholas et al., 2009; Patterson et al., 2004; Van Dongen-Melman et al., 1998; Yiu & Twinn, 2001). Parents reported the relapses and death of other children on the wards serving as reminders of the uncertainty they were facing (Jithoo, 2010).

Positive Outcomes

Although many negatives were reported, parents also reported finding new positive life perspectives and felt a need to live happily in the moment (Leavitt et al., 1999; Nicholas et al., 2009; Van Dongen-Melman et al., 1998). Parents also reported personal growth and felt proud of surviving the experience (Johns et al., 2009; Van Dongen-Melman et al., 1998). Some felt their parenting skills improved, as they became more lenient, supportive and understanding (Brody & Simmons, 2007). Gains were also noticed in their ill child, such as increased maturity (Wong & Chan, 2006). Parents also felt their relationship was strengthened through this experience (Brody & Simmons, 2007; Chesler & Parry, 2001; Leavitt et al., 1999; McGrath, 2001b; Wills, 1999). They explained how they worked as a team and divided the labour to match each partner's strengths (Van Dongen-Melman et al., 1998). The experience also strengthened relationships in the family (Brody & Simmons, 2007; Chesler & Parry, 2001; Johns et al., 2009; Nicholas et al., 2009; Van Dongen-Melman et al., 1998), and parents appreciated how the cancer experience had brought them closer to their child (Clarke, 2006; Kars et al., 2008; McGrath & Huff, 2003b; McCubbin et al., 2002; Nicholas et al., 2009; Van Dongen-Melman et al., 1998).

Support

Parents reported finding emotional support, which came from family members, friends, HCP and other parents at the hospital particularly helpful (Brody & Simmons, 2007; McCubbin et al., 2002; McGrath & Chesler, 2004; Nicholas et al., 2009; Wills, 1999; Wong & Chan, 2006; Yeh et al., 2000; Yeh, 2003; Yiu & Twinn, 2001). Extended families also offered practical support in the form of care for siblings, parental respite,

transportation and instrumental support (Brody & Simmons, 2007; McCubbin et al., 2002; Yiu & Twinn, 2001).

Parents valued support from their spouse and talking to their partner helped them to cope (Elcigil & Conk, 2010; Wills, 1999; Yeh et al., 2000; Yiu & Twinn, 2001). Support was also valued from other parents whose child had a similar diagnosis or prognosis (Clarke, 2006; Elcigil & Conk, 2010; Hill et al., 2009; Jithoo, 2010; Johns et al., 2009; Wills, 1999; Yeh et al., 2000; Wong & Chan, 2006). Parents felt they could support each other emotionally (Jithoo, 2010; Wills, 1999) and practically by buying groceries or watching other parents' children for them on the ward (Wills, 1999). Support helped parents to reduce their sense of isolation and keep them from despairing (Nicholas et al., 2009).

Parents appreciated support from the general community, with help with finances, child care, emotional support and home maintenance being offered by friends, neighbours, churches and other community groups (Brody & Simmons, 2007; McCubbin et al., 2002). Parents also discussed the importance of support from their workplace in the form of flexible hours, time off and job assurances being particularly helpful (Brody & Simmons, 2007; McCubbin et al., 2002). Support from work helped parents to be available and provide emotional support to their family without losing their jobs and income (Brody & Simmons, 2007). Parents with faith and spiritual beliefs reported receiving help from their church or other religious affiliated groups (Brody & Simmons, 2007; Nicholas et al., 2009; Yeh, 2003; Johns et al., 1999; Yeh et al., 2000). Churches offered financial support, prayers, provided meals, emotional support and also involved the healthy siblings in activities (Brody & Simmons, 2007; Johns et al., 2009; Nicholas et al., 2009; Yeh et al., 2000).

Parents appreciated support from HCP (Brody & Simmons, 2007; McCubbin et al., 2002; Wong & Chan, 2006; Yiu & Twinn, 2001) and valued the reassurance, information, realistic hope, assistance and respect given to them by the oncology staff team (McCubbin et al., 2002). Feeling listened to helped parents to maintain good relations with the HCP (Clarke & Fletcher, 2003). The HCP' hope, compassion, professionalism and clarity provided a strong source of support and helped parents to cope and be resilient (Brody & Simmons, 2007; Clarke & Fletcher, 2003). Some parents also received support from mental health professionals, who helped them to talk through their problems and find new solutions (Johns et al., 1999). Not all parents were happy with the support from HCP, however, as some felt the doctors avoided telling them the diagnosis (Clarke & Fletcher, 2003). Contradictory information undermined their confidence in the HCP (Clarke & Fletcher, 2003). Parents were also frustrated by frequent staff changes and by staff not knowing all the information and treatment plans (Clarke, 2005). Parents felt angry and frustrated if they did not feel listened to and when their concerns were downplayed or ignored (Clarke & Fletcher, 2003).

Some parents described having a child with cancer as an isolating experience (Clarke, 2006). Parents of children with a rare diagnosis felt less able to receive support from other parents on the ward due to the differences in treatment and potential outcomes (Clarke, 2006). Some felt that support was inconsistent and short-lived, which left them feeling angry and resentful (McGrath, 2001a; Nicholas et al., 2009). Parents also felt their social support reduced after their child was diagnosed (Elcigil & Conk, 2010; Patterson et al., 2004), with some friends being either insensitive or avoidant (Patterson et al., 2004). Others felt they had very little support at all, even from their spouse (Nicholas et al., 2009). Parents described finding it hard to share their experience with their friends and families (Wong & Chan, 2006).

Gender Differences

Gender differences in the parental role have also been explored in the literature. Nine studies focused on exploring how fathers experienced their child's treatment of cancer (Clarke, 2005; Chesler & Parry, 2001; Hill et al., 2009; McGrath, 2001b; McGrath & Chesler, 2004; McGrath & Huff, 2003a; McGrath & Huff, 2003b; Nicholas et al., 2009; Wills, 1999). Some fathers were found to react to the diagnosis with extreme emotional pain (McGrath, 2001b). Many reported finding it difficult to express their feelings openly (Chesler & Parry, 2001; Hill et al., 2009; McGrath, 2001b; McGrath & Chesler, 2004). Instead they chose to deny, ignore or cover up their feelings, which reduced the level of support they received (Chesler & Parry, 2001; McGrath & Chesler, 2004). Some fathers internalised their negative emotions, which resulted in somatic complaints such as ulcers (Jithoo, 2010). Fathers tended to prioritise other family members' needs over their own, which may cause others to also minimise their needs (Hill et al., 2009). Of those who did seek support, some felt their male friends did not know how to support them (Chesler & Parry, 2001; McGrath, 2001b). Fathers did, however, find it helpful to talk to other parents in the same situation (McGrath & Chesler, 2004).

Fathers experienced a sense of powerlessness, as they could not control the situation (McGrath & Chesler, 2004), which caused some to feel they had failed to protect their child (Nicholas et al., 2009). Fathers were quick to anger, which was often expressed at work, towards the family or just in general (McGrath & Chesler, 2004). Anxiety and fears about death, financial worries and worries about the future were all thought to be contributory factors in their anger (McGrath & Chesler, 2004). Fathers felt the need to be strong for their family (McGrath, 2001a; Nicholas et al., 2009), and it was important for them to feel that they were doing something active (Hill et al., 2009) and practical (Kars et al., 2008) to help. They tended to adopt problem focused coping styles

by attempting to actively seek solutions to the child's illness (Wills, 1999). Focusing on something practical helped distract fathers from their emotions (Hill et al., 2009). Some fathers also coped by taking time out of the hospital by going for walks (McGrath, 2001b). Fathers tried to maintain their health through exercising; eating well, and having sufficient sleep to keep them strong for their child and family (Nicholas et al., 2009).

Fathers tended to take on traditional gender roles, with the majority focusing on working and being the provider (Chesler & Parry, 2001; McGrath, 2001a; McGrath & Chesler, 2004; McGrath, 2001b), with going to work being seen as a welcome distraction (McGrath & Huff, 2003a). Some fathers did not like staying in the hospital and found it hard to witness the treatments (McGrath, 2001b; McGrath & Huff, 2003b). Some found it challenging spending all day in hospitals interacting with their child (McGrath & Huff, 2003b). Others reported struggling with the lack of privacy for men on wards mainly populated by women; fathers also felt isolated due to the lack of other men (McGrath & Huff, 2003b). Fathers felt the medical staff reinforced a peripheral role by focusing on the mothers, with conversations being directed at mothers even when the fathers were also present (Brody & Simmons, 2007; Chesler & Parry, 2001; Clarke, 2005; Hill et al., 2009).

The fathers did not all react in a gender-stereotyped manner, as they were also found to cry (McGrath, 2001b; McGrath & Chesler, 2004), give up their jobs to be with their child and express a need to talk and hug (McGrath & Chesler, 2004). Many fathers wanted to be with their child in hospital (McGrath, 2001b; McGrath & Huff, 2003a). Fathers discussed feeling pressured to continue working due to financial constraints or not being given the flexibility by their employers to take time off (Chesler & Parry, 2001; McGrath & Huff, 2003a; Nicholas et al., 2009). Other fathers, however, reported being able to take time off (McGrath & Huff, 2003a), to negotiate flexible hours and receive

support from their workplace (Brody & Simmons, 2007; Hill et al., 2009). Some fathers who had to work described finding it hard being away from their child and having to adjust to their child developing a stronger bond with the caretaking parent (McGrath, 2001a).

Some fathers were prevented from helping at home by their partner, who felt it intruded on their role as a mother (Chesler & Parry, 2001; Hill et al., 2009). This left them feeling like outsiders and unable to be there for their child (Chesler & Parry, 2001; Hill et al., 2009). This was not experienced by all fathers, with some reporting working well with their spouse as a team (Clarke, 2005). Some fathers became more involved and reported changes in their responsibilities in housework and childcare (Brody & Simmons, 2007; Clarke, 2005; McGrath, 2001a). Parents shared the hospital stays (McGrath, 2001a) and some fathers did all the hospital stays (McGrath & Huff, 2003a). Fathers described feeling confident and competent in helping with their child's treatment and their matter of fact approach was found to help calm the child during procedures (McGrath & Huff, 2003b). They were also actively engaged in advocating for their child in the hospital system (McGrath & Huff, 2003b). Fathers also reported becoming the primary caregivers for the healthy siblings (McGrath & Huff, 2003a; Nicholas et al., 2009). The fathers commented on being aware that the healthy siblings were missing out on attention and were taking on new responsibilities (McGrath & Huff, 2003a).

Five studies focused specifically on mothers (Clarke, 2006; Elcigil & Conk, 2010; Fletcher & Clarke, 2003; Johns et al., 2009; Young et al., 2002). Mothers felt they reacted differently to men to this experience (Clarke, 2006; Fletcher & Clarke, 2003), with women internalising the experience more than men (Fletcher & Clarke, 2003). Mothers found keeping a journal of personal thoughts and information about all the medical data and appointments helped them to cope (Clarke, 2006; Fletcher & Clarke,

2003; Johns et al., 2009; Patterson et al., 2004). Mothers also described physical symptoms such as backache, neck problems, lost appetite, insomnia, menstrual irregularity and headaches (Elcigil & Conk, 2010), while their emotional burden included increased nervousness, heightened sensitivity and being easily angered (Elcigil & Conk, 2010). Mothers were concerned not to show these emotions to their children (Young et al., 2002).

Mothers described a change in their self-identity and their role as mothers as they tried to meet the needs of their ill child (Young et al., 2002). Mothers wanted to be physically close to their ill child (Clarke, 2006; Kars et al., 2008; Young et al., 2002), and many mothers lived on the ward full time with their child, only returning home for a few hours (Young et al., 2002). They tended to feel isolated and restricted and reduced the importance of their own needs (Clarke, 2006; Fletcher & Clarke, 2003; Young et al., 2002). These demands and behaviours meant it was very difficult to maintain their previous roles as mothers to healthy siblings, as a partner, and as an employee (Clarke, 2006; McGrath, 2001a; Young et al., 2002). Mothers also felt responsible for their child cooperating with medical procedures, which placed extra stress on them (Young et al., 2002).

Cultural Differences

Two studies explored the impact of culture on the experience of parents during their child's diagnosis and treatment (Johns et al., 2009; Leavitt et al., 1999). Leavitt et al.'s (1999) study explored the differences between Caucasian and Chinese parents living in America. Caucasian parents were more expressive about their emotional distress and reported psychological problems such as stress, feeling pressured, having a short fuse and being on the verge of tears (Leavitt et al., 1999). They sought advice from HCP; reached

out for support in the community from friends, family and support groups and some had psychotherapy (Leavitt et al., 1999). In contrast, Chinese parents did not seek professional help or support from the community (Leavitt et al., 1999). Rather than reporting psychological problems, they reported insomnia, headaches, chest pains and weight loss (Leavitt et al., 1999). Chinese parents were more concerned about how to handle negative attitudes from society about cancer (Leavitt et al., 1999). Chinese parents also tended to adopt a more fatalistic view to help them cope, while Caucasian parents focused on retaining normalcy (Leavitt et al., 1999). Caucasian parents tended to communicate honestly with their child about their illness keeping them informed about both their illness and treatment, while Chinese parents tended not to talk to the child or other siblings about the illness (Leavitt et al., 1999). Chinese parents were also concerned with maintaining their child's yin and yang balance, increasing their appetite and strength and reducing swelling (Leavitt et al , 1999).

The study by Johns et al. (2009) focused on the differences between Latina and European American (EA) mothers. Although similarities were reported, EA mothers were found to compromise and negotiate with the medical team, whereas Latina mothers tended to follow the medical advice and treatment plan (Johns et al., 2009). Latina mothers discussed valuing the support they received from other mothers in the hospital and how this helped to normalise their experience, whereas EA mothers did not mention normalisation and their support generally came from outside the hospital (Johns et al., 2009). Latina mothers struggled to gather information about the cancer due to a lack of Spanish materials, whereas EA mothers relied on the hospital resources and the Internet (Johns et al., 2009). EA mothers reported using relaxation exercises, yoga and trying to think positively to cope, while Latina mothers reported more active coping styles, such as going to the beach and dancing (Johns et al., 2009).

Discussion

Clinical Implications

Importantly, although there are many negatives in parents' experiences, many also reported positives such as gaining new perspectives, finding new value in life and improved relationships in their families. It is important that HCP can help to build on these positives and strengthen the families' resilience rather than just focusing on dealing with the possible negatives (Clarke & Fletcher, 2003; Kylmä & Juvakka, 2007). The findings from this review suggest that good practice from HCP can help improve the parents' experience of having their child treated for cancer.

Providing Information and Aiding Sense of Control

Parents need time and support to confront the reality of the situation. Parents want to feel in control of the situation and this drives the need for information about cancer and treatment. It is important that HCP provide clear and consistent information (Clarke & Fletcher, 2003; Elcigil & Conk, 2010; McGrath, 2001b; Wong & Chan, 2006; Young et al., 2002). HCP also need to be aware that parents' ability to comprehend information will fluctuate throughout treatment and they may need to repeat information, provide written information and be patient if parents ask questions they have already answered. The need to feel in control can lead to overcompensatory behaviours in some parents, which has the potential to reduce adherence to medical treatments. By helping parents establish a sense of control, this negative consequence could be minimised and compliance improved (Yeh, 2003; Yeh et al., 2000). Parents may search out alternative treatments and the HCP should encourage parents to adhere to treatments with scientific

evidence for their effectiveness (Yeh, 2003). Adherence could also be improved by providing advice about how to emotionally prepare children for treatments (Yeh, 2003).

Providing Individualised Care

Due to differences in how individuals cope, HCP need to establish each parent's coping styles and their concurrent stressors (McCubbin et al., 2002; Wills, 1999; Yiu & Twinn, 2001). It is important to help parents build on their existing resources and adjust their ways of coping so that they can manage this difficult experience (Brody & Simmons, 2007). Some families' coping styles may not match with the rapid response needed for cancer treatment and the unpredictability of the process, these families may need more assistance in developing alternative coping strategies (McCubbin et al., 2002; Yeh et al., 2000). HCP also need to be aware that parents' ability to cope and the level of support they will need is likely to vary across the treatment (Elcigil & Conk, 2010).

It is also important to consider the parents' culture when providing individualised care. Both Johns et al. (2009) and Leavitt et al. (1999) found differences in the experiences of parents from different cultures and HCP need to be sensitive to these differences. They should reflect on how this may impact on how families manage and express their distress (Leavitt et al., 1999) and support them accordingly. Although there were also similarities in the experience of parents across different cultures, it is important to pay attention to each parent and adapt the care and support offered according to their needs and communication preferences (Brody & Simmons, 2007; Kylmä & Juvakka, 2007).

Increasing Awareness of the Needs of Fathers

It is important that the father's position is both respected and validated by the staff to ensure that both parents are involved and supported (Chesler & Parry, 2001; Hill et al., 2009; McGrath, 2001b). HCP should not assume fathers do not want to be involved in their child's care, as many have to continue working (McGrath & Huff, 2003a). Services should ensure the hospital environment is welcoming and supportive for men (McGrath & Huff, 2003a; McGrath & Huff, 2003b). Counselling and support programmes may also need to be altered to meet the needs of fathers (Chesler & Parry, 2001). Services should explain and challenge the gender stereotypes and help fathers and their family establish new patterns of male role behaviour during difficult times (McGrath & Chesler, 2004; McGrath & Huff, 2003b). Fathers should have the opportunity to meet with other men in the same situation to discuss their roles and coping strategies, especially in regards to coping with anger (McGrath, 2001b; McGrath & Chesler, 2004).

Providing Emotional and Practical Support

Support from families, friends and other parents on the ward were reported to be important moderators in the parents' ability to cope, which supports the findings from qualitative studies in Vrijmoet-Wiersma et al.'s (2008) review. HCP should normalise the experience for parents and provide them with the space to talk about their experiences (McGrath, 2001b). Parents should be helped to establish a support network (Kylmä & Juvakka, 2007). Nurses can play an important role in encouraging parents to achieve this and if appropriate to encourage them to meet their spiritual needs (Kylmä & Juvakka, 2007; McCubbin et al., 2002; Yeh et al., 2000), have marital counselling (Clarke, 2006), or access professional counselling (McCubbin et al., 2002). Hospitals should also consider running on-going support groups for parents (Clarke, 2006; McGrath, 2001b).

Parents also need financial support, as too many parents have to remain at work, despite wanting to be there for their family. Changes should be made in the workplace and in health care policies to provide adequate assistance, leaves of absence and flexible hours to help ease this burden (Nicholas et al., 2009). Families should be supported with practical assistance such as child minding for healthy siblings, travel, accommodation and domestic help (McGrath, 2001b).

Parents should be encouraged to look after themselves, which will also help them to care for their ill child and their family. Parents may need support and encouragement to take better care of themselves (Fletcher & Clarke, 2003). Nurses need to monitor for parents burning out due to their desire to always be there for their child (Kars et al., 2008). Parents should be encouraged to spend time with their spouse, as many parents reported that their spouses offered them a great deal of support and talking to them helped them to cope (Yiu & Twinn, 2001). For those parents who are no longer living together there may be an additional need for support in reorganising their family life in the context of other family or personal demands (McCubbin et al., 2002).

Theoretical Implications

The findings support the resiliency model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1993, 1996) in helping to explain the experiences of parents going through childhood cancer. This review found that parents react to the crisis caused by the cancer, by reorganising their family and work life to be able to support their child. Parents discussed the importance of emotional and practical support from their family, the community and the hospital staff in helping the family to cope. Despite being exhausted and facing the difficulties of reduced time with their partner and other children, they were able to support their child and many discussed gaining new perspectives and

finding positives from this experience, such as closer bonds with the ill child. Although negatives will be experienced, the model suggests that if parents are helped to explore existing strategies and to build on this base, then they can become more effective in their attempts to cope and adjust. The findings also fit well with the family transition to living with childhood cancer model (Clarke-Steffen, 1993, 1997), with this model providing a useful framework for HCP to use to help understand the experiences of parents and what strategies they should help assisting the families to put in place to help them to cope with this transition.

Conclusions

The 28 qualitative studies included in this systematic review have helped to develop the understanding of how parents experience their child being diagnosed and treated for cancer. This systematic review has provided an important update from the Grootenhuis and Last (1997a) review, by bringing together valuable qualitative data that have been collected across different cultures and genders. This review supports and builds on the findings from Grootenhuis and Last's (1997a) review, with overlapping themes such as adjustment, coping, changes in family functioning, gender differences, the importance of communication, support, negative and positive experiences. By including studies from other cultures and focusing on the qualitative data, this review has provided useful information that complements the findings from Thibodeaux and Deatrick's (2007) review and can be used to evidence the need for more individualised care. The review also provides a greater insight into the different ways that mothers and fathers may experience their child's illness, which builds on the findings of gender differences in Vrijmoet-Wiersma et al.'s (2008) review. Important practical implications have been

discussed for the medical staff to consider when working with these parents. It is also important to acknowledge the good clinical practice of HCP who are providing valued support to the parents and there is growing evidence for positive change in the parents' experience of childhood cancer. Further research is needed in this area to ensure the understanding of the experiences of parents and how to best support them continues to grow. Future studies need to document their methodology clearly and explain whether trustworthiness checks were made to allow a more comprehensive critique of their findings.

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Appendix A

Publication Guidelines from the Journal of Pediatric Oncology Nursing

MANUSCRIPT SUBMISSIONS

The Editorial Board welcomes submission of manuscripts for review for publication in the *Journal of Pediatric Oncology Nursing.* Query letters are also welcomed. All manuscripts should be submitted online through Manuscript Central: http://mc.manuscriptcentral.com/jopon where authors be required to set up an online account on the SageTrack system powered by ScholarOne.

Authors may download a copy of the submission guidelines from the Sage Publications Web site at http://www.sagepub.com. Manuscripts are accepted for publication on the conditions that they are submitted solely to this journal, that the material is original, and that it has not been previously published. This is a refereed journal. All manuscripts are reviewed by at least three members of the Editorial Board. Accepted manuscripts are subject to editorial revision.

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PREPARING THE MANUSCRIPT

The first page of the manuscript should include the following information: (1) title of the paper, (2) author name(s), degree(s), and current position, (3) complete addresses for every author, (4) name and address of the author to whom communications should be addressed. E-mail addresses for each author should be included. The second page should include a 175-word or less abstract, 4-5 keywords, and a short bio for each author.

ILLUSTRATIONS AND TABLES

The use of figures is encouraged. Original glossy photographs or electronic image files (TIF, JPG or EPS for-mats),preferably in black and white,must be supplied with the manuscript (photocopies cannot be used for repro-duction). Files should be in TIF, JPG, or EPS format and line art images should be saved at 1200 dpi,and grayscale images should be saved at 300 dpi. Figures should be presented in separate electronic files and not incorporated into the Word document. When original photographs are supplied, the figure number and author name should be identified on the back of each figure in soft pencil.

Use of a human being's photograph requires written consent from the individual. Release forms can be obtained by contacting the Editor, Nancy Kline.

Figure legends should be included at the end of the manuscript. A legend must accompany each illustration. Contributors must bear the cost of reproducing color

illustrations.

Each table should be typed on a separate sheet at the end of the manuscript file. The author should provide table titles on the same sheet as the table.

Figures and tables should be cited in order in the text using Arabic numerals. The author must provide per-mission to reprint figures and tables from other sources. Standard copyright permission forms are available from the Editor.

REFERENCES

References follow the style used by the American Psychological Association (APA). References should be cited in text with an author-date citation system and are listed alphabetically in the Reference section in APA style. They should be typewritten and double-spaced, under the heading REFERENCES.

Examples of References

Journal articles:Enskar, K., Carlsson, M., Golsater, M., Hamrin, E., & Kreuger, A.(1997). Parental reports of changes and challenges that result from parenting a child with cancer. *Journal of Pediatric Oncology Nursing*, *14*,156-163.Kennedy, L., & Diamond, J. (1997). Assessment and management of chemotherapy-induced mucositis in children. *Journal of PediatricOncology Nursing*, *14*, 164-174.

Complete book:Walker, L.O. (1992). *Parent infant nursing science: Paradigms, phenomena, methods.* Philadelphia: F.A. Davis.

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PROOFREADING

Contributors are provided with printed proofs and are asked to proofread them for typesetting errors. Important changes in data are allowed, but authors will be charged for excessive alterations. Proofs should be returned to the publisher within the due date given.

Appendix B

The Criteria for Evaluating Studies

The following criteria are based on the guidelines provided by Letts et al., (2007) for qualitative reviews:

1. Was there a clear statement of the research's purpose and aims?
2. Is a qualitative methodology appropriate for the study?
3. Was relevant background literature reviewed?
4. Is the design of the study appropriate for the research question and its aims?
5. Was a theoretical perspective identified?
6. Does the study describe the methods used to generate data?
7. Was the method appropriate for the chosen study design?
8. Were participants relevant to the research question and was their selection well reasoned?
9. Was sampling done until saturation or redundancy in data was reached?
10. Was informed consent obtained and is it clear why some individuals chose not to participate?
11. Is there a clear and complete description of where the data was collected, of the participants and the researcher's credentials? Are the researchers assumptions clearly described?
12. Were the data collection strategies comprehensive enough to support rich and robust descriptions of the observed events?
13. Were the data collection methods appropriate for the research objectives and setting?
14. Was the data analysis inductive and the findings adequately corroborated?
15. Were findings consistent with and reflective of data?
16. Was a decision trail developed and rules of analysis reported?
17. Was the process of transforming data into themes/codes described adequately?
18. Did a meaningful picture of the phenomenon under study emerge?
19. Was triangulation reported?
20. Were conclusions appropriate given the study findings?
21. Did the findings contribute to theory development and future practice or research?

Table 1
Details of papers included in the review

Author (s) and date	Study aim	Design of study	Data collection	Ethical approval mentioned	Consent mentioned	Number of participants	Place of research	Discussed trustworthiness
Brody & Simmons (2007)	To understand the experience of fathers during childhood cancer.	Not stated	Semi structured interview	Yes	Yes	8	America	Yes
Chesler & Parry (2001)	To explore whether gender shapes fathers' experiences of parenting children with cancer.	Not stated	Focus groups using semi structured interviews	Yes	Yes	167	America	No
Clarke (2005)	To explore the work fathers do when they have a child sick with cancer.	Not stated	Interviews	Not mentioned	Not mentioned	16	Canada	Mentioned but not explained what was done to achieve them.
Clarke (2006)	To explore the emotional aspect of the home healthcare work undertaken by mothers when their children have cancer.	Not stated	Focus group	Yes	Not mentioned	49	Canada	Yes
Clarke & Fletcher (2003)	To explore the defining moments in parents' experiences when their children had cancer.	Not stated	Semi structured interview	Not mentioned	Not mentioned	29	Canada	Yes
Elcigil & Conk (2010)	To determine the "burden of care" of mothers with children diagnosed with cancer.	Not stated	Semi structured interview	Yes	Yes	23	Turkey	No

Author (s) and date	Study aim	Design of study	Data collection	Ethical approval mentioned	Consent mentioned	Number of participants	Place of research	Discussed trustworthiness
Fletcher & Clarke (2003)	To explore the home health care parents do and the factors that affect mothers' abilities to cope.	Not stated	Semi structured interview	Yes	Not mentioned	25	Canada	No
Hill et al (2009)	To explore fathers' perception of the roles they played in their family across the different stages of their child's treatment.	Interpretative phenomenological analysis (IPA)	Semi structured interview	Yes	Yes	5	Ireland	Yes
Jithoo (2010)	To investigate parents' perceptions of their knowledge-seeking behaviour, experience of the communication process and to identify what support and guidance they desired.	Not stated	Semi structured interview	Yes	Yes	100	South Africa	No
Johns, Oland, Katz, Sahler, Askins et al. (2009).	To explore specific coping strategies used by Latina and European American mothers of children recently diagnosed with cancer.	A phenomenological framework was selected	Transcripts were taken from a problem-solving intervention study	Not mentioned	Not mentioned	6	America	Yes

Author (s) and date	Study aim	Design of study	Data collection	Ethical approval mentioned	Consent mentioned	Number of participants	Place of research	Discussed trustworthiness
Kars, Duijnstee, Pool, van Delden & Grypdonck (2008).	To gain insight into the lived experience of parenting a child with leukaemia during treatment.	Grounded theory	Semi structured interview	Yes	Yes	23	The Netherl-ands	Yes
Kylmä & Juvakka (2007)	To explore how parents of adolescents living with cancer define hope and what factors are associated with their hope.	Not stated	Semi structured interview	Yes	Yes	9	Finland	Yes
Leavitt et al (1999)	Exploring the care giving practices of families who must manage their child's cancer care at home.	Not stated	Semi structured interview	Not mentioned	Not mentioned	36	America	No
McCubbin, Balling, Possin, Frierdich & Bryne (2002)	To identify family resiliency factors and what helped, from the parents' perspective.	Not stated	Semi structured interview	Not mentioned	Yes	42	America	No
McGrath & Chesler (2004)	To explore the paternal experience of treatment for paediatric ALL.	A phenomenological approach	Semi structured interview	Yes	Yes	19	Australia	Yes
McGrath & Huff (2003a)	To record the experience of treatment from the perspective of the family.	A phenomenological approach	Semi structured interview	Yes	Yes	Same sample as McGrath & Chesler (2004)	Australia	No

Author (s) and date	Study aim	Design of study	Data collection	Ethical approval mentioned	Consent mentioned	Number of participants	Place of research	Discussed trustworthiness
McGrath & Huff (2003b)	To explore the specific issues associated with the fathers' hospital experience.	A phenomenological approach	Semi structured interview	Yes	Yes	Same sample as McGrath & Chesler (2004)	Australia	No
McGrath (2001a)	To explore the emotional, social and spiritual needs of families coping with paediatric cancer.	A phenomenological approach	Semi structured interview	Yes	Yes	16	Australia	No
McGrath (2001b)	To explore how fathers cope with the treatment for childhood ALL.	A phenomenological approach	Semi structured interview	Yes	Yes	Same sample as McGrath (2001a)	Australia	Yes
Nicholas et al., (2009)	To explore the experiences of fathers who have a child with cancer.	Grounded theory	Semi structured interview	Yes	Not mentioned	16	Canada	Yes
Patterson, Holm and Gurney (2004)	To explore aspects that parents perceived as difficult during their child's diagnosis, treatment and recovery and what help was valued.	Not stated	Focus group	Yes	Yes	45	America	No
Van Dongen-Melman, Zuuren & Verhulst (1998)	To explore what it is like for parents to live through childhood cancer.	Not stated	Rogerian open-ended questions	Not mentioned	Not mentioned	16	Netherl-ands.	Yes

Author (s) and date	Study aim	Design of study	Data collection	Ethical approval mentioned	Consent mentioned	Number of participants	Place of research	Discussed trustworthiness
Wills (1999)	To explore the experience of Chinese parents in Hong Kong who have a child with ALL.	Not stated	Semi structured interview	Yes	Yes	17	Hong Kong	Yes
Wong and Chan (2006)	To describe the coping experiences of Chinese parents with children with cancer.	A phenomenological study	Semi structured interview	Yes	Yes	9	China	Yes
Yeh (2003)	To explore the process that Taiwanese parents go through during their child's cancer.	Grounded Theory	Focus groups using semi structured interviews	Not mentioned	Yes	32	Taiwan	Yes
Yeh, Lee & Chen (2000)	To address the adaptational process of Taiwanese parents of paediatric oncology patients.	Grounded theory	Focus group and semi structured interview	Yes	Yes	32	Taiwan	Yes
Yiu & Twinn (2001)	To identify the needs of Hong Kong Chinese parents with a child with cancer during the period of hospitalization.	Not stated	Semi structured interview	Yes	Yes	5	Hong Kong	Yes
Young, Dixon-Woods, Findlay & Heney (2002)	To investigate experiences of mothers living with a child with cancer.	Not stated	Semi structured interview	Yes	Yes	20	England	No

PAPER B

An Exploratory Study into the Experiences of Being a Healthy Sibling of a Child Treated for Cancer

Jonathan Andrew Gibbins

A thesis submitted in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology validated by the University of Oxford

July 2011

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An Exploratory Study into the Experiences of Being a Healthy Sibling of a Child Treated for Cancer

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University of Oxford, Doctorate in Clinical Psychology,
Trinity Term, 2011

Abstract

The diagnosis of childhood cancer is recognised as a significant stressor for families. Although much of the literature focuses on the experiences of the patient and of parents, a growing body of research has focused on outcomes for healthy siblings. Few studies, however, have addressed the experiences of adolescent healthy siblings as they move through this process from diagnosis to treatment end. This study uses grounded theory to develop a model, which aims to explain this process. Retrospective semi-structured interviews were carried out with eight participants recruited through a UK principal treatment center (PTC). The model presented illustrates how the healthy siblings' experience changed over time, with the most challenging period being the diagnosis and initial phase of treatment. Their experiences as treatment progressed appeared to depend on a number of factors including: how they managed the stressors; temperament; family relationships; individual coping strategies; and support received. Developmental changes associated with adolescence appeared to further serve as a potential protective factor. The clinical implications of these findings are discussed.

Keywords: Healthy siblings, adolescents, childhood cancer, grounded theory.

Proposed Journal: Journal of Pediatric Oncology Nursing (see Appendix A for instructions to contributors).

Introduction

This study explores the experiences of adolescent healthy siblings (HS) across the duration of their brother or sisters' treatment for childhood cancer. The incidence of childhood cancer is increasing with 1 in 500 children from birth to 15 years old being diagnosed in Britain each year (Stiller, 2007). Approximately 80% of these will have siblings (Dunn, 1992), which suggests a significant number of HS may be affected by childhood cancer in their family. The diagnosis of cancer has implications for the individual and their family and the experience appears to be more traumatic when the diagnosis is made in childhood (Murray, 1995). Childhood cancer causes family dynamic to change and HS can become isolated from family and social support and face significant psychosocial distress (Van Dongen-Melman, De Groot, Hahlen & Verhulst, 1995). The impact of having a sibling with childhood cancer has been described as particularly challenging for HS (Sharpe & Rossiter, 2002), as the family turn their attention to the ill sibling (IS; Giovanola, 2005; Nolbris & Hellström, 2005; Spinetta, 1981), leaving the HS with reduced time with their parents (Giovanola, 2005; Iles, 1979). HS also report a loss of attention and status when their sibling became ill (Murray, 1998; Sloper, 2000; Woodgate, 2006). This reduced support comes at a time when HS may well be attempting to manage their own developmental challenges alongside their siblings' cancer.

Treatment advances have resulted in improved survival rates but often include aggressive chemotherapy, radiation, surgery and transplants (Clarke & Fletcher, 2003), which can be emotionally demanding for the IS and their family. Approximately 75% of children with cancer in Britain survive for at least five years after diagnosis, compared to only 10% in 1970 (Cancer Research UK, 2004). Children who have retinoblastoma,

gonadal germ cell tumours and Hodgkin's lymphoma have the highest survival rates of about 95% (Cancer Research UK, 2004), whilst acute lymphoblastic leukemia (ALL), the most common form of childhood cancer, has a survival rate of over 75% (Mitchell et al., 2005). Advances in treatment have changed the HS' experience of childhood cancer, as the treatment can last for several years, which can cause long-term disruption to family life during important formative years.

A systematic review of psychological interventions for HS of childhood cancer patients found positive outcome data on HS' adjustment (Prchal & Landolt, 2009). Unfortunately, these interventions are not uniformly available, which is in part due to clinical psychology input in paediatric services varying across geographic regions and hospitals (Houghton, 2005; Spinks, 2009). The lack of interventions may also be attributed to the lack of attention HS receive, with most research in paediatric oncology focusing solely on the patients or on the patients and their mother (Kazak, 2005). Improving health outcomes for young people has long-term benefits for the individual, and reducing future problems benefits the National Health Service (NHS), other support agencies and society as a whole (Department for Children, Schools and Families & Department of Health, 2009). However, little is known about HS' experiences. It is important, therefore, for research to be carried out to explore the experiences of HS whose brother or sister are treated for childhood cancer, so that the appropriate support can be offered to help HS and their families to manage this experience and avoid long-term difficulties.

Current research has found that HS report feelings of isolation, jealousy, fear and guilt, as they try to adapt to changes in the family (Houtzager, Grootenhuis, Caron & Last, 2004). Additionally, changes in family roles and new responsibilities can reduce the HS' opportunity to socialise (Snyder, 1986), which can leave them feeling further isolated

and they may struggle to establish important social support networks that can boost well-being and general health (Carr, 2006). HS' academic achievement and social interactions are often impaired and they are at risk of withdrawing, becoming anxious, aggressive and tearful (Sahler et al., 1994; Sahler et al., 1997). The cancer experience does not, however, result in only negative consequences (Woodgate, 2006). Challenging circumstances, such as cancer in the family, may strengthen attachment bonds, as when both children and adults feel threatened they want to be close so they can protect and help each other (Ainsworth, 1991; Bowlby, 1988). HS also appear to draw emotional and psychological strength from the experience (Wilkins & Woodgate, 2006). These gains include increased maturity, compassion, understanding and closer family relationships (Sloper, 2000).

To date HS research has mainly focused on outcomes for this group and there is currently a lack of research exploring the experiences of the HS over the duration of the treatment. In particular, there is a lack of information about how adolescent HS experience childhood cancer in the context of their developmental changes. As children mature into adolescents they become more aware of the impact of cancer through the increasing burden, lack of control and impaired relationships with their peers (Murray, 2000). Piagetian theory (1969) proposes that as children enter adolescence they develop the capacity for formal operational thinking, which includes the ability to think systematically about logical relations and being interested in abstract ideals and the process of thinking. They also develop the capacity for relativistic thought, where they understand how situational factors can impact on both their own behaviour and the behaviours of those around them (Piaget, 1969). This ability is thought to develop as adolescents' social lives expand and they spend more time with peers (Brown & Klute,

2003), which increases their exposure to different points of view and values (Kramer, 1989).

Theoretical Background to the Study

The theoretical orientation of this study was derived from Wallander and Varni's (1992) disability-stress-coping model and Clarke-Steffen's (1993, 1997) model of the family transition to living with childhood cancer, which are described below. The definitions of coping and adjustment used in this study are also detailed below.

Coping and Adjustment

Coping has been defined as an individual's cognitive and behavioural attempts to manage their stress (Katz, Ritvo, Irvine & Jackson, 1996). The coping process involves individuals continuously evaluating the event, to try to understand its demands, its significance and how to respond (Lazarus & Folkman, 1984). Individuals adopt their own coping styles based on their personality and how they usually respond to stress (Towsley, Beck & Watkins, 2007). These coping styles are likely to influence the coping strategy adopted by the person (Brennan, 2001). Adjustment is the result of successful coping (Brennan, 2001) and it has been defined as the "effectiveness of coping in improving the adaptational outcome" (Filipp, Klauer, Ferring & Freudenberg, 1990, p. 237).

The Disability-Stress-Coping Model

Wallander and Varni (1992) propose that children's reactions to stress will depend on a combination of both risk and resistance factors. These factors impact on the adaptation of both the ill child and their families. The risk factors are the disease parameters including

the severity of the illness and the disruption it brings to the individual's life, psychosocial stressors including stressful life events and day-to-day struggles, and any functional limitations that restrict the child's independence, such as being unable to talk or walk without assistance (Wallander & Varni, 1992). The resistance factors include personal resources, appraisal and coping and support from both social and family contexts (Wallander & Varni, 1992). The model suggests that children who have adequate numbers of resistance factors are less vulnerable to psychosocial adjustment disorder (Wallander & Varni, 1992).

The Family Transition to Living with Childhood Cancer Model

Clarke-Steffen's (1993, 1997) model suggests that the family transition begins when they realise the severity of their child's illness. This causes the family to enter a stage of "limbo", whilst waiting for a diagnosis. Following the shock of the diagnosis, the family attempts to create a "new normal" by developing new routines and adopting cognitive and behavioural strategies to help integrate the experience of childhood cancer into every day family life. Clarke-Steffen (1993, 1997) identified the coping strategies as managing the flow of information, reorganising the roles in the family, evaluating and shifting their priorities, changing their future orientation, assigning meaning to the illness and managing the therapeutic regimen.

Summary and Rationale for the Study

Although research has explored the impact of childhood cancer on HS, there is a lack of research exploring the experiences of adolescent HS from diagnosis through to ending of treatment. This study aims to develop a theory using grounded theory (GT) to explain the experiences of adolescent HS, as their family go through the diagnosis and different

stages of treatment for childhood cancer. The research aims to explore the challenges they face, identify factors that affect this experience, whether it impacts on their ability to manage their own developmental challenges, what helped them and what they take from the experience. The aim is to develop a theoretical framework to help understand the HS' experience, to help identify children who may need additional support, to aid clinical formulation with HS, and aid the development of treatments for the HS. The knowledge gained could also be used to help guide future theory development and research in this area.

The study aims to address the following research questions:

1. How do adolescent HS of children with cancer experience cancer in the family?

2. How does the experience change over the course of the illness?

3. What factors have affected this experience?

Method

Design

This was a retrospective semi-structured interview based qualitative study, using GT (Glaser and Strauss, 1967). The methodology was based on Charmaz's (2003, 2006) version of GT, which takes a constructivist approach where the priority is placed "on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants" (Charmaz, 2003, p.130). The main principles of GT are to discover new ways of understanding the social world, to generate a theory grounded in the data to aid understanding of the phenomenon being researched (Glaser &

Strauss, 1967). McLeod (2001) summarised the aim of grounded theory as attempting to "uncover the basic social processes that underlie behaviour" (p. 72). GT was selected over other qualitative methodologies for this study as GT, unlike other methodologies, allows the researcher to develop codes and categories that are grounded in the data, rather than imposing interpretation on it (Glaser & Strauss, 1967).

Epistemology

Constructivism emphasises the subjective interrelationship between the researcher and the participants and how the meaning is co-constructed (Hayes & Oppenheim, 1997; Pidgeon & Henwood, 1997). It has been argued that categories are formed from three sources; the researcher's own constructs; technical terms from theoretical or professional literature; and the language of the participants (Strauss & Corbin, 1990). Researchers are considered as part of the research and their values need to be considered by themselves and the readers as an inevitable part of the analysis and outcome (Appleton, 1997; de Laine, 1997). Researchers are ethically obliged to "describe the experiences of others in the most faithful way possible" (Munhall, 2001, p. 540).

It has been acknowledged, however, that it is "not possible to be completely free of bias" (Strauss & Corbin, 1998. p. 97). Charmaz (1995, 2001) recommends that researchers include raw data in their memos to ensure the participant's voice and meanings are kept in the theoretical outcome. Researchers need to be aware of their values, assumptions and interests and how these may influence their understanding of what they are studying (Elliot, Fischer & Rennie, 1999). By reflecting on their perspectives it allows the reader to understand the researcher, their data and consider whether there are possible alternatives (Elliot et al., 1999). The researcher's perspectives are considered in Appendix D and verbatim quotes will be presented in the results section

to demonstrate that the participant's voice was kept in the analysis.

Participants

Glaser and Strauss (1967) recommend between 8 and 20 participants for GT analysis. The study aimed to recruit between 8 and 15 participants using theoretical sampling, where participants are approached for their potential to help generate new theory by extending or furthering the researcher's emergent understanding (Pidgeon, 1996). Eligible participants were biologically related siblings of children treated for cancer in the oncology ward from one children's hospital. The sibling with cancer must either have completed treatment in the last 18 months or be nearing the end of their treatment protocol. Participants were included if they lived together, were aged between 12 and 19 at the time of the interview and aged between 12 and 16 years old during their sibling's cancer treatment. This age group was selected to ensure formal operational thinking in the participants guided by Piaget's (1969) developmental theory.

Siblings were excluded from the study if they suffered from a chronic illness themselves, had a learning disability, or did not speak English. Siblings who had received psychological treatment due to this experience were excluded, as their views may have been changed by the therapy. Siblings of children who had relapsed were excluded due to possible distress. Siblings of children who had died were not included in this study, as the focus was on their experience of their sibling being treated for cancer, rather than a death in the family.

Procedure

Recruitment

The recruitment procedure for this study can be found in Appendix E. Twelve HS and

their families were invited to participate. One child deciding not to participate, as she did not want to discuss her experience; and three parents chose not to consent, as they wanted their family to forget the experience. In total, 8 participants were interviewed. The first participant was selected due to meeting the inclusion criteria and thereafter participants were selected through theoretical sampling. After the eighth interview was analysed, the researcher and both supervisors agreed that data saturation had been achieved, due to sufficient consistency in the data suggesting further interviews would be unlikely to provide additional information.

Measures

Participants completed a demographic questionnaire (see Appendix F) before the interview to situate the sample (Elliot et al., 1999), which allows the reader to judge the range of participants in the study and provide context to the participants' experience. The information collected is presented in table 1 below.

A semi-structured interview was developed in collaboration with both supervisors to explore the HS' experiences of their IS' cancer (see Appendix G). HS were interviewed alone; four chose to be interviewed in the hospital, and four were interviewed in their home. The researcher personally conducted the interviews, which lasted between 35 and 70 minutes.

Ethical Considerations

The study received ethical approval from the Oxford Research Ethics Committee (Appendix H) and was sponsored and indemnified by Oxford Health NHS Foundation Trust (Appendix I). The study received approval from the Research Sub-Committee of the Oxford Doctoral Course in Clinical Psychology (Appendix J), and the hospitals'

research and development department (Appendix K). Informed consent was gained for HS aged 16-19 (Appendix L) and parental consent and assent was gained for HS aged 12-15 (Appendix M). Appropriate steps were taken to help eliminate "potential risks to psychological well-being, physical health, personal values, or dignity" (British Psychological Society, 2009, p. 19), and to ensure that participants were treated ethically (see Appendix N).

Data Analysis

The researcher transcribed all interviews verbatim and the transcripts were read carefully to aid immersion in the data. Figure 1 summarises the data analysis process.

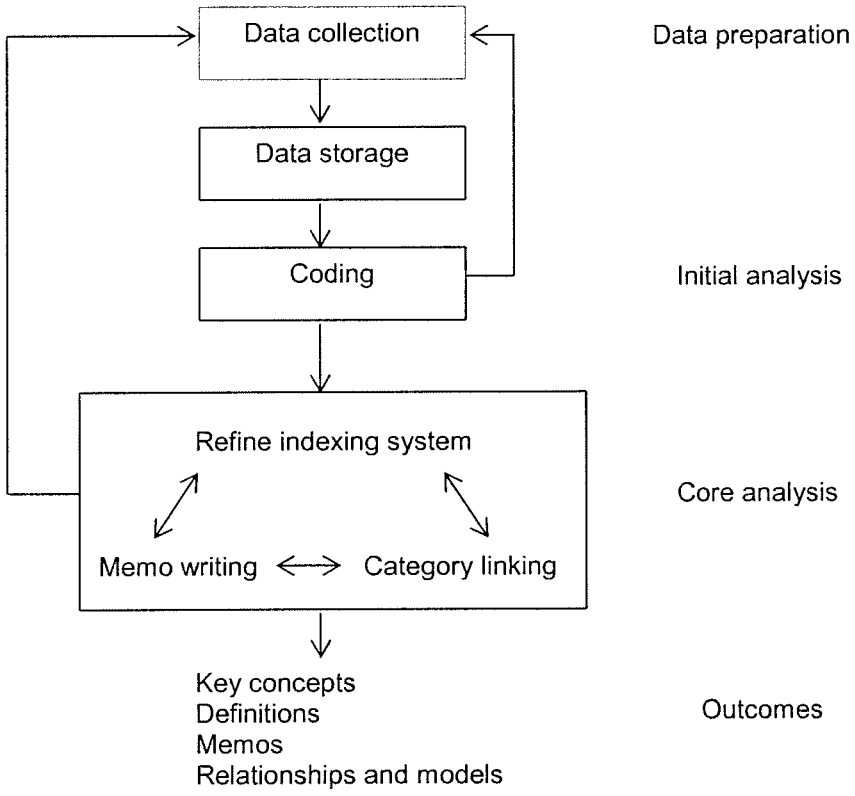


Figure 1. Data Analysis Process (Pidgeon & Henwood, 1998, p.88)

Figure 1 demonstrates how in GT, data collection and analysis coexists, as researchers respond to emerging codes and categories in their future selection of participants and areas of enquiry (theoretical sampling). This dynamic relationship between data collection and analysis is a key aspect of GT (Pidgeon, 1996). This process continues until data saturation is achieved, which is the point when the researcher gains no new insights or ideas from the interview or observational material (McLeod, 2001). The analytical process needs to be documented in detail to act as a trace and to prompt further analysis (Pidgeon & Henwood, 1996). This involves using direct quotes, writing memos or drawing diagrams, which keeps the work 'grounded' by keeping the researcher close to the material, and allows the emerging theoretical framework to be documented for future reference (McLeod, 2001). Memo-writing and constant comparative methods (Glaser & Strauss, 1967) help researchers develop tentative categories from focused codes, refine categories and compare them with concepts to develop a theory (Charmaz, 2006).

Initial Coding

Coding is the first step in making analytic interpretations from the concrete statements in the transcripts (Charmaz, 2006). Coding breaks data down into concise terms, providing the opportunity to develop abstract and analytical ideas about sections of data (Charmaz, 2006). The coding involves tentatively developing and labelling different concepts in the text that are potentially relevant to the participants' experiences (Pidgeon & Henwood, 1996). Each line, word or segment of the data is examined closely to define the actions, events and contexts found in the data (Charmaz, 2006). Careful coding keeps the analysis grounded in the data by preventing researchers' personal issues, motives or fears from influencing the analysis of the data (Charmaz, 2006). The researcher wrote the initial

codes the right hand side of each line of the transcripts (see Appendix O).

Focused Coding

Focused coding allows the researcher to integrate, sort, synthesise and organise large amounts of data by using the most significant and frequent codes (Charmaz, 2006). This allows researchers to compare people's experiences, interpretations and actions across the interviews (Charmaz, 2006). Researchers need to make decisions about which codes make the most analytical sense to be able to create more accurate and complete categories from the data (Charmaz, 2006). The researcher wrote down the focused codes to the left of the data on the transcripts (see Appendix P). Sample memos about collapsing and merging codes and categories can be found in Appendix Q.

Forming Categories

The aim is to develop as many different categories around activities and processes as possible (Strauss & Corbin, 1990). Throughout the analysis 'constant comparison' is used to compare and contrast the categories and their meanings by sifting through and comparing the different elements of the data (Pidgeon, 1996). This allows researchers to become familiar with the similarities and differences within the data set, which helps promote both conceptual and theoretical development (Pidgeon, 1996).

Theory Construction

The researcher used constant comparison and memo writing to compare and refine the categories. Through this process the researcher was able to develop a model to describe and demonstrate the relationships between the categories and the theoretical relevance of the model. This completed the analysis of the data as a theory that was grounded in the

data was created.

Credibility and Trustworthiness

Lincoln and Guba (1985) put forward criteria, including having an 'audit trail' to enable others to check the process of theory generation and interpretation; checking for over-interpretation; considering potential transferability of findings from original inquiry to other settings; and the level of reflexivity in the process. The researcher kept a reflective diary (Appendix R), as suggested by Lincoln and Guba (1985), to document the methodological decisions and reflections about the role of the researchers' interests and values. The researcher consulted with a specialist in GT and attended a group with other researchers using GT to discuss, check and evaluate the decisions with peers along with supervisors to improve its "trustworthiness". Finally, to aid credibility random transcripts were coded by both supervisors and compared to the researcher's codes.

Results

Demographic Information

Eight HS of seven children diagnosed with cancer participated in this study (two participants were brother and sister). The participants lived at home, with two participants living at boarding school during term time. Seven participants were in contact with their extended family. For details on demographics of the participants and their IS see table 1.

Table 1

Demographic information about the participants and the ill siblings

	Participant information
Age range of participants	12-19 (m= 15)
Age range of participants at diagnosis	11-16 (m= 13)
Gender of the participants	6 females and 2 males
Ethnicity of participants	7 White British and 1 Vietnamese
Age range of siblings with cancer	12-17 (m= 14)
Diagnosis	3 x ALL, 2 x Ewings, Wilms, Pineal brain tumour and Medulloblastoma.
Age range of other siblings	10-26 (m= 16)
Age range of parents	40-59 (m= 46)
Parents marital status	7 were married and 1 was divorced but was cohabiting with their partner

Findings

The data can be divided into eight main categories (see Appendix S for a list of categories, focused codes and quote references); life before the diagnosis, the diagnosis, stressors and negative outcomes, family relationships, temperament and coping strategies, support received, positive impact and outcomes, and experiencing end of treatment. The categories and focused codes are described below. Verbatim quotes and memos are used to demonstrate evidence of the participant's experiences and explain the interpretation of the researcher. The theoretical model of the adolescent HS' experience is then presented (see figure 2) and explained.

1. Life Before the Diagnosis

This category consisted of two focused codes: life normal before diagnosis and no

problems before the diagnosis.

(a) Life Normal before Diagnosis

All participants described their life before the diagnosis and reflected on how their life had been "normal" before the diagnosis:

> S3: *It was pretty normal. Nothing much was going on. Work was fine, friends were fine, it was just a normal period in my life and then it got quite shaken up!*

> *S6: For me things were going along like usual, then this happened.*

(b) No Problems Before the Diagnosis

Three participants felt they did not have any problems before the diagnosis was made, which was also linked to their age as they did not yet have any exams at school:

> S1: *We had nothing to worry about, because obviously things like school and stuff wasn't that important then.*

2. The Diagnosis

This category consisted of four focused codes: experiencing early symptoms, being told of the diagnosis, experiencing shock and disbelief, and timing and stages of the illness.

Memo – forming and collapsing categories. A GT expert recommended I put the categories into a story to see how they linked together. The story was shared with my supervisors and it was discussed how a diagnosis category was missing. The diagnosis category was formed with codes previously placed in the "stressors and negative outcomes" and "life before the diagnosis" categories, which ensured this important aspect of the participants' experience was explained.

(a) Experiencing Early Symptoms

All participants described their sibling's early symptoms before the diagnosis was made. Some IS had been ill for a while, whilst others were diagnosed quickly.

> S3: *It was a very short time that he was ill; he was literally only ill for like ten days. So it was pretty quick. It was weird, surreal.*

> S7: *Every morning she was sick and we were like "that's not good" and she had migraines and everything.*

(b) Being Told of the Diagnosis

All participants described how they found out the diagnosis; most explained being told whilst with family but one participant was being looked after by a neighbour:

> S7: *I was next door as mum, dad and my sister had gone to the hospital and you kind of knew it was not going to be good.*

Some participants felt relieved that a diagnosed was made:

> S5: *Well I kind of knew she was ill and my mum said what it might be. It was kind of a relief to know.*

One participant did not find out it was cancer until a few months into treatment, as their parents did not explain the nature of the IS' illness:

S6: *I didn't really ask because I assumed it was something. I think it was a few months after when I found out it was cancer.*

(c) Experiencing Shock and Disbelief

All participants reported feeling shocked by the cancer, as they knew about cancer but did not think it would happen to their sibling:

S6: *It was shocking, because you hear about it a lot on the telly and cancer research and quite a few things, and it's quite common, but you wouldn't think it would happen to you.*

S3: *Nothing really bad had happened to our family, so when that happened it was like wow, suddenly, my God, so it was quite a big shock.*

Participants also discussed noticing the shock in their ill sibling and the whole family at the news of the diagnosis:

S7: *So the shock, [sibling] was trying to get over it, as well.*

S1: *Everybody was really shocked. How could it happen to [sibling]?*

(d) Diagnosis and Initial Treatment was the Hardest Time

Six participants explained the timing of the diagnosis made the experience more challenging and the experience was harder at the beginning of treatment:

S1: *It was kind of a shock to the system because it was my thirteenth birthday when we found out.*

S6: *I suppose at the beginning, which was the worst bit, I was...problem wise I was ok because I didn't really know what was happening. But as things went on you know with chemo, I sort of got a bit more worried.*

3. Stressors and Negative Outcomes

This category consists of twelve focused codes; changed family routine due to illness, loss of attention, negative impact on the ill siblings, negative impact on other healthy sibling, negative impact on school life, taking on new responsibilities, seeing parents upset, not liking being in the hospital, negative impact on social life, not feeling understood, more emotional and worried, and losing their faith.

(a) Changed Family Routine Due to Illness

Seven participants explained the cancer changed their family life, as family members were often at the hospital and family life was no longer "normal":

S8: *I would often have to just carry on doing things without my mum or my brother and it would be different to how it would normally be.*

S4: *Sometimes when both of them [parents] aren't here you only have one to talk to, so when you are arguing with one you want the other one to talk to.*

S2: *The family were never really together and if they were, [sibling] wasn't feeling*

great, mum and dad probably weren't feeling great because they were so tired, so busy... I was just pretty low probably because everyone else was pretty low.

Participants described how events that orientate around the family, such as Christmas and birthdays, became more challenging:

S7: *Her nine hour surgery was the day after my birthday so a bit of worrying was going on, on my birthday.*

S2: *So that Christmas my mum was there and it was just me and my sister sitting around a table on our own with a massive turkey and it was like both of my parents were both exhausted. [Sibling] was just feeling really ill. Um, that was pretty bad.*

(b) Negative Impact on the Ill Siblings

All participants described witnessing the negative impact the cancer had on the ill sibling; this included witnessing the illness and the treatment:

S1: *Just seeing her lying in the bed was so horrible, the way she used to be so active.*

S7: *She couldn't talk to you, she didn't know who you were, it was really hard. Her face was all swollen and she couldn't eat anything.*

(c) Negative Impact on Other Healthy Sibling

Two participants also described the negative impact the experience had on their healthy brother or sister:

> S4: *It was upsetting to see him upset, because when he gets upset he gets really upset, really worried and he panics.*

(d) Negative Impact on Academic Performance

Six participants described how their siblings' illness impacted on their academic performance and their ability to focus in lessons:

> S3: *It probably affected me academically, my GCSEs were fine, but I think during the first year or so it dipped a bit, not drastically, but I had other things on my mind.*

> S4: *I just had a lot more things to think about and deal with. It put me off a little bit from my work but I think I did alright.*

(e) Taking on New Responsibilities

Six participants described taking on new responsibilities during the experience and the impact the multiple demands had on their social life and school:

> S1: *I don't have time for work. I have to go home and cook dinner for dad and me, sometimes it is hard to fit it all in.*

S4: *It was just hard with her being ill and everything and trying to deal with it and deal with other stuff as well like normal life really.*

(f) Seeing Parents Upset

Seven participants described seeing their parents upset and how this made them feel they should not burden them with their worries, preferring to support their parents instead:

S7: *You don't really see your parents cry, especially dad, he is meant to be the man of the family and I have never seen men cry. That was really upsetting, because it makes you think "oh my God, if they are crying then what is the outcome?" So that was really hard.*

S7: *But knowing that my sister needed mum and dad, I had to sort myself out so that was one less thing for them to do and try to make it easier for them really, which I hope helped, if that is what I achieved.*

Memo – Merging focused codes. The "seeing parents upset" code was originally split into two codes: "supporting and protecting parents" and "seeing parents upset". After comparing and contrasting these codes, they were merged, as they both described the experience of seeing parents upset and how this caused HS to attempt to protect the parents by not adding to their worries.

(g) Not Liking Being in the Hospital

Seven participants described not liking being in the hospital due to the atmosphere and seeing ill people:

S3: *All these sick people around you, it isn't nice.*

S6: *I didn't like it, it was, it always felt really...it's just not a nice atmosphere. I*

wanted to visit but I didn't enjoy it.

(h) Negative Impact on Social Life

Seven participants described not being able to see their friends as often due to needing to be with the family:

S5: *I was at home looking after my [healthy] sister a lot, so I couldn't go out and see my friends as often.*

S2*: It wasn't good because I was spending a lot of time at home. I didn't see my friends as much.*

One participant feared what their peers would think if they became upset in front of them or were seen to be getting extra help:

S1: *I was just always scared that I was going to cry in front of people and I thought they would think I was a right idiot.*

(i) Not Feeling Understood

Three participants discussed finding it frustrating when peers or teachers did not relate to their experience:

S1: *My friends sometimes struggled to understand, so has my boyfriend, which is understandable because obviously they haven't experienced anything like it.*

S6: *I don't know if [teachers] are...I just think they are being a bit too, the opposite of sympathetic, not being understanding.*

(j) More Emotional and Worried

Six participants explained feeling more emotional, worried and stressed in general since the diagnosis:

S1: *There is always, she has a scan, and it's always oh what are the results going to be and its just like, every time is just so nerve racking.*

S7: *I think it was from fear and the not knowing. Obviously from that day onwards we did not know what was around the corner.*

(k) Loss of Attention

Six participants described having less attention than they would have liked:

S4: *But then again, her getting attention all the time...I mean I know she is ill but, well we did get attention but not as much as we hoped we would if you know what I mean.*

S6: *When no one was at home that was when I really needed more attention.*

Some participants explained they understood that their sibling needed the attention:

S7: *It wasn't too bad, because mum and dad realised that straight away and I*

realised straight away that my sister needed the attention, so I didn't really mind too much.

S8: *The attention went where it is due, so he needed it, so it was all right.*

(l) Losing Their Faith

Two participants described losing their faith, turning away from religion or the experience confirming their lack of faith:

S3: *I think that is probably because of the whole thing that has happened has made me question it. I was never that religious before but it has made me question it even more.*

4. Family Relationships

This category consists of five focused codes; close family, relationships with parents, relationship with ill sibling, sibling coping helped, and difficult relationships in families.

Memo – renaming and organising categories. The "family relationships" category was originally named "mediating factors". Following discussions with my supervisors, it was decided that the category name was too vague and did not capture the data within it. It was agreed that instead, the category involved important aspects about family relationships, which influenced HS experiences.

(a) Close Family

Seven participants talked about having a close family before the diagnosis, how they spend time and enjoy shared activities together:

S1: *We always have been close. We all play golf as a family, so it's kind of like a family thing we do together, which is really nice, so yeah we have always been*

close, we still are.

S2: We all get on pretty well. We all work well together and when we are all around the table together and eating and stuff like that.

(b) Relationships with Parents

All the participants described having good relationships with their parents before the illness, how they grew closer and found this helpful during the experience.

S1: *They are always there for you. You can talk to them. I don't know really, it is just nice to have someone there, you can just go and have a cuddle with or yeah.*

S8: *We get on really well, before and after as well.*

(c) Relationship with Ill Sibling

All the participants discussed their relationship with their sibling with cancer. Most participants explained that they had always been close but now feel closer to their sibling:

S7: *We always used to mess around with each other; we never really fell out much. But we are really close now, which is nice.*

Three participants felt the experience improved their relationship with their sibling, as they argue less and talk more:

S2: *Probably better than I used to actually. You know like when you are younger*

you just bicker a lot and stuff like that but now it's not like that at all. The relationships got better I reckon.

(d) Sibling Coping Helped

Five participants explained how their sibling coped impressed them and helped their own coping:

S1: *[Sibling] was fine and that's kind of what got me through it as well, like most of this, she has helped people get through because she just made jokes out of everything and has just been herself the whole way through.*

S3: [Sibling] has probably been the most helpful because he has been so good about it all and that makes it so helpful for the rest of us, makes it easier.

(e) Difficult Relationships in Families

Four participants explained that difficult relationships in the extended family made the experience more challenging, as it reduced the family's support:

S3: *It was at a time when mum needed her family the most. So they stormed out and mum and Gran didn't speak for about a year and mum and her sister hardly talk even now.*

S6: *There are just some uncles and cousins I haven't seen, I know I have them, but something has happened in dad or mum's life that has distanced them.*

5. Temperament and Coping Strategies

This category consists of eight focused codes; temperament, using humour, importance of positive outlook, valuing normality, escapism and distraction, valuing shared experiences with others, valuing talking, getting on with it, and choosing not to talk about it.

(a) Temperament

All participants discussed their personality and the attributes they felt helped them during the experience:

> S7: *It was quite scary at first but I can adjust to things strangely quickly. Almost within a couple of days it felt normal to me, which was quite weird.*

Other useful traits discussed included being mature and trying to remain happy:

> S6: *I have probably got an older mental age than my actual age; I am quite mature in some ways.*

> S2: *I am pretty chilled, I don't mind, if it happens and it happened.*

> S3: *I try to be happy as much as I can; I keep a smile on my face.*

Four participants felt they had changed over the duration of the treatment due to developmental changes, which impacted on their experience and their coping strategies:

> S1: *I am more independent than I realised, I don't need people to tell me what to*

do. I can make decisions on my own. I think that is gradually with age as well that I have realised that.

S3: *I was a lot younger than now when it happened, so I have changed just generally.*

One participant felt that being younger at the time of diagnosis helped them, as they did not understand the implications of the cancer:

S3: *I think now I am more grown up I'd find it harder now, probably than I did then, for some reason - probably because I just got on with it.*

(b) Using Humour

All participants explained that humour helped them and their family to cope:

S7: *Laughter is kind of the best medicine and when she was first in the hospital we would try to make her laugh as much as we could just because otherwise it is playing on your mind the whole time, what is ahead of us, so you might as well have a laugh.*

S1: *Make jokes out of things and just laugh and smile your way through it because you're not going to get through it otherwise.*

(c) Importance of Positive Outlook

Five participants explained keeping a positive outlook was important in helping to get

through the experience:

> S3: *From the very beginning you can't think negatively, you've got to think positively and positive vibes. Keep the morale up and be as strong as possible. That worked for me.*

> S7: *Try to look on the positive side and the funny side of everything and make jokes out of really stupid things, because it cheers everyone up.*

(d) Valuing Normality, Escapism and Distraction

Five participants discussed the desire for normality and to feel like their peers at school rather than having to cope with their sibling's cancer:

> S1: *I didn't tell my friends for ages after the diagnosis because I just wanted that to be normal, I didn't want them to think differently of me. I wanted to be treated like a normal person.*

They discussed enjoying having moments of normality by being with friends, going to school and doing activities they did before the diagnosis:

> S3: *We are at each other's houses quite a lot, have a few people around, chill and talk about stuff, it's fun...it's normal.*

> S7: *Going back to school and trying to be normal really did help. Then it would be going to the hospital and it would be all change and then coming back home it*

would be normal again, well normalish. It was quite hard but normality did help.

Memo – merging focused codes. I realised an original focused code called "stable period in condition" only had one quote in it. After rereading the quote, I realised the participant was discussing how the stable period had provided a sense of normality, so I collapsed the code into the "valuing normality, escapism and distraction" focused code.

All participants explained finding escapism and distraction helpful, as it gave them breaks from worrying about their sibling:

S1: *I have listened to music much more. It kind of relaxes me and makes me forget about things.*

S8: *Yeah very, [friends] were a distraction, which was good in a way because you need to maintain that kind of thing, rather than just sitting around and mope.*

(e) Valuing Shared Experiences with Others

Six participants described the value of talking to other people whose sibling or relative had cancer, as it normalised their experience, they felt understood and could exchange coping strategies:

S3: *There was another girl in my year whose brother has the same diagnosis as [brother], but he is older and was one year ahead so I could talk to her about it and that was helpful because she knew exactly what I was going through.*

One participant reflected on their experience of going on an activity day with other siblings of children being treated for childhood cancer:

S1: *They understand you more than people who aren't going through the experience... they like don't understand it. It was nice to have two-way conversations and that kind of helped to cope as well because they shared ways in which they coped.*

One participant did not have the opportunity to meet another sibling in the same situation but felt it would have helped:

S7: *It would have been quite nice to talk to someone about it and share experiences, like is it going to get better? And see what stuff they faced and overcame, and seeing how they coped with things.*

(f) Valuing Talking

All participants described finding talking about the experiences to other people helpful:

S5: *Make sure you talk about it and if you feel that you need help then ask for it.*

S4: *Don't hold back any feelings, if you need to talk to someone talk to them.*

Seven participants described specifically finding it helpful talking to their parents about the cancer and their experiences:

S1: *Because obviously my mum is there for me, and my dad is there for me, and I can talk to them about anything.*

S6: *If there is anything worrying I just talk to my parents really, so that's been quite good. It's been quite good to confide in someone.*

Two participants also valued talking to people outside of the family:

S1: *It has been quite important because I can say things that I would never say to my mum.*

(g) Getting on With It

All participants felt the need to "get on with it" and explained they could not do anything but try to cope:

S3: *At the time it was awful but you just got on with it, you just have to, you can't just sit there and mope and think how unlucky you are, you have just got to keep going so you might as well soldier on.*

(h) Choosing Not to Talk About It

Six participants explained that at certain times they did not want to talk about their experiences, either because they did not feel the need, or because they thought it would make them upset.

S2: *I didn't feel the need to talk to anyone really. I was just like I'm fine just get on with it.*

S6: *I wouldn't really want to talk to other siblings I don't think, no. I wouldn't*

really want to hear if they had something worse, or if they were terminal or something.

One participant chose not to tell her teachers or her school friends:

S8: *It would be too hard to explain it all to them and they would ask lots of questions and things, I wouldn't be comfortable with that.*

6. Support Received

This category consists of five focused codes; support from family, support from friends, support from school staff members, support from the hospital staff and not needing additional support.

(a) Support From Family

Seven participants described the support from their family, how much they value their family and how they would not have coped without them:

S1: *We are lucky as a family to be so close. I can't imagine how people can do it without their family.*

S7: *It is quite nice just having family there to lean on.*

Five participants described receiving support from extended family members such as grandparents, aunts and uncles:

S7: *Mum's parents sit and chat to you and just listen even if it is really boring, just about day to day life, just to give you some breathing space really, it is quite nice.*

S4: *My auntie didn't mind doing stuff for us, so [parents] were able to spend more time with me and my brother.*

(b) Support From Friends

All participants discussed how important their friends were in helping them through this experience by offering support, by spending time with them and helping to create a sense of normality:

S2: *I prefer to talk to my mates rather than anyone else really. They understand me.*

S3: *They are all a nice bunch of people who are supportive. Whenever I have a problem with it they were always up for a chat.*

S7: *My friends have been really good, they have kept me happy. Just by being random and being them.*

(c) Support From School Staff Members

Six participants described appreciating support from teachers and the school counsellor:

S4: *The teachers used to give me a little break if I was getting upset, like when I first found out, they would talk to me and give me little breaks from lessons, or get*

me to sit with my friends if I get upset, or have a chat with me.

(d) Support From the Hospital Staff

Six participants described appreciating support from health care staff:

S8: *They were really nice and supportive. I think they just really understand you.*

S1: *The nurses have been really lovely and they have taken us on trips out that have been funded by the ward. Our social worker is amazing as well, she is really nice and I can speak to her about things outside of the family.*

Two participants also thought the hospital had a nice environment and was interesting to visit:

S7: *[The wards] don't look like dull dreary hospitals, especially with the televisions on the wall, they are quite impressive. They are really nice and that makes you feel more reassured.*

(e) Not Needing Additional Help

Three participants did not want any additional help, as they did not have many problems:

S8: *I don't really have any problems so I don't need to talk to anyone about it.*

7. Positive Impact and Outcomes

This category consists of six focused codes; personal gains, family gains, new

perspectives, continuity and closer relationships and friendships, and education going well.

(a) Personal Gains

All participants described gaining positives, such as feeling more mature, confident, stronger and appreciating their siblings, friends and family more from the experience:

> S4: *I think I am a lot stronger, because of going through it and if anything like this happens again I will be ready for it and know how to cope.*

> S6: *I think on the whole the change has been being able to deal with things more and I have become more mature.... it just gradually, it was a process from going through it.*

(b) Family Gains

All participants felt the experience had brought the families closer together and they now spend more time together:

> S3: *Some families break up because of these sorts of things but we are definitely closer I would say.*

> S7: *We were quite a close family, we still are. If anything we are closer.*

Six participants explained how they felt closer to and more protective of their sibling after this experience:

S1: *If anything it has brought us closer because we care about each other more and appreciate each other more.*

S3: *I think maybe I am slightly more...not protective of him, but that sort of area. I feel quite strongly about making sure he is all right.*

Participants also noticed positive gains for their family members:

S3: My older brother has got way better, he used to be tricky but he has calmed down a lot.

S8: His high school sent lots of sympathy and get well soon cards and comments like we think you are really funny and we miss you. And he got an X-box. I think it has improved his social life.

(c) New Perspectives

Seven participants reported gaining new perspectives and seeing the good in bad situations:

S1: *Coming in to the ward and seeing how many children are actually ill because of cancer, it just makes you realise how important your life is and how you should live it to the full every day.*

S3: *I think I have got a massively different perspective on life from it all. People irritate me at school when they get upset about stupid things, its like you don't*

really know do you.

S7: I think as a family we appreciate life a bit more, if you get an opportunity we will go for it sort of thing, don't hold back because life is too short, you don't really know what is coming.

(d) Continuity and Closer Relationships and Friendships

Seven participants described being pleased to have found continuity in their friendships and relationships throughout their experience, which was helpful to them:

S1: *It is the same group of friends, because we are a group of girls it is nice to have the girls there and they have always been there for me.*

S3: *It's nice that It's not...it sounds really selfish, not like changed because of [brother], we are still family so surely I don't know, it's nice that that has stayed the same, the family is still the family kind of thing.*

S8: *I think it was helpful that there weren't too many changes.*

(e) Education Going Well

Five participants reported that school was going well despite the experience:

S5: *I am probably doing better there now than before she was ill.*

S8: *I think it has made me concentrate a bit more on my work because I don't*

want to just go down, I want to stay the same.

8. Experiencing End of Treatment

This category consists of four focused codes: experiencing end of treatment, hard to remember experience, difficulties reflecting on the impact of the experience and regretting not taking support.

(a) Experiencing End of Treatment

All participants discussed the positives of the end of the treatment and felt relieved it was over:

S1: *It's like the cancer has gone, it's just all the other complications now. So that's a relief in a way anyway. It was amazing. It was really good.*

(b) Hard to Remember Experience

Six participants found it difficult to recall their experiences clearly:

S2: *I can't remember exactly what happened.*

S3: *It is all a bit of a blur now.*

(c) Difficulties Reflecting on the Impact of the Experience

Four participants explained they did not know how the experience had affected them or what they had learned from it:

S2: *I mean the diagnosis would definitely have changed me but I don't know where or when.*

S6: *I think things have changed but I am not really sure what I have learned about myself.*

(d) *Regretting Not Taking Support*

Five participants felt they wished they had taken or been given more support:

S1: *That is one of my mistakes that I should have done looking back, talk to people more about things instead of bottling it up and just getting stressed yourself because it is not really worth it.*

Memo – collapsing categories.
An original category called "unsure of impact on self" was collapsed following discussions with my supervisors, as it was not clear what this category contributed to the model. The "difficulties in reflecting on impact of the experience" and the "hard to remember" focused codes from this category fit better with the "End of treatment" category. The "not needing help" code was moved into the "Support" category.

Grounded Theory Model: Overview

The theoretical model of the adolescent HS' experience over the course of their siblings' treatment for childhood cancer is illustrated in figure 2 below.

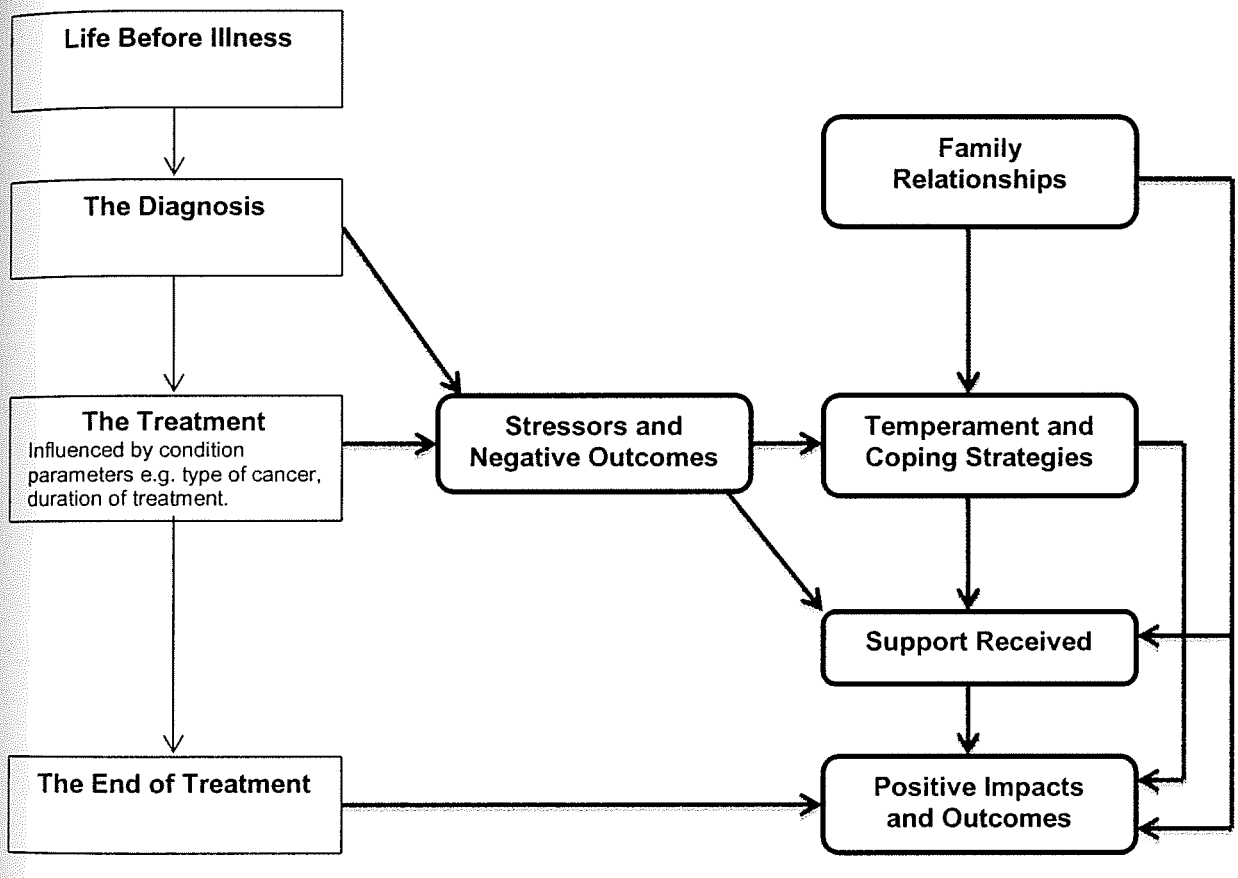


Figure 2. The theoretical model of the adolescent HS' experience of having a sibling being treated for cancer.

Cancer Timeline

The model illustrates the linear experience of HS, which begins with life before the diagnosis and moves on to when their IS becomes ill and a diagnosis is given. The experience then moves on to the treatment phase, which will vary in length and the nature

of treatment depending on the type of cancer and how the IS responds to the treatment. The final part of this linear story involves the end of treatment.

The Impact of the Stressors and Negative Outcomes

The model illustrates how the diagnosis and treatment phase results in stressors and negative outcomes for the HS and their family life. The impact these stressors and negative outcomes have on the HS' overall experience will depend on their temperament, coping strategies and the level and quality of support.

The Importance of Family Relationships in Supporting and Aiding Coping Strategies

The model illustrates the important role family relationships play in HS' experience. Family relationships can impact on how HS cope, as they valued talking to their parents and found it helpful that the family used humour. The relationships also impact on the support they receive, as HS explained having close family relationships was helpful and they also gained support from extended family members. Difficult relationships with some members of the extended family left some families with reduced support, which disappointed the HS. HS also felt the experience had brought them closer to their family and reported valuing their family more.

Achieving and Acknowledging Positive Impacts and Outcomes

The model demonstrates that HS are able to identify positive impacts and outcomes along with the negatives. If HS have good relationships within their family and can draw upon appropriate coping strategies and support from their family, friends, their school and the hospital, then they are more likely to cope and adjust to their sibling being treated for childhood cancer. Peers were important to the HS and friendships provided them with

distraction and someone to talk to outside of the family. The quality of support from friends and family meant some HS felt additional help was not necessary. The model also illustrates how approaching the end of treatment was experienced as a positive and a "relief".

Discussion

To the researcher's knowledge, this is the first study to use GT to create a theoretical model to explain the experiences of adolescent HS over the course of their siblings' treatment for cancer. The areas explored were guided by three main research questions: 1) how do adolescent HS of children with cancer experience cancer in the family, 2) how does the experience change over the course of the illness and, 3) what factors have affected this experience? The findings suggest the HS' experience from the moment of the diagnosis through to the end of treatment will depend on how HS manage the stressors and negative outcomes, with their family, their temperament, coping strategies and the support received all combining to help HS to cope and find some positive outcomes from the experience. The HS' experience changed over time, with the most challenging period being the diagnosis and the initial treatment. The HS gradually adjusted to their new normality by "getting on with it" and using existing or developing new coping strategies and sources of support. The temperament of the HS influenced how they coped, and HS felt their personality changed over time. They found it hard to reflect on whether their changes came from going through the experience, from normal developmental changes or from a combination of the two.

The model shares similarities with the disability-stress-coping model (Wallander & Varni, 1992), which proposes that children's reactions to stress will depend on a

combination of risk and resistance factors. Both models, therefore, are in agreement that adequate resistance factors can help individuals to be less vulnerable to psychosocial adjustment difficulties. The model also shares similarities with Clark-Steffen's (1993, 1997) model of the family transition to living with childhood cancer. Both models suggest a linear story whereby the cancer breaks the normality and after initial shock, strategies are put in place to help create a new normality where both positives and negatives can be considered and appreciated. The findings from this study also provide an important addition to the literature, as they provide an explanation of the factors that influence adolescent HS' experience of childhood cancer, from their sibling's diagnosis through to the end of treatment. The coping, support and family factors enable HS to achieve and identify positives as well as the stressors and negatives from this experience. The findings also demonstrate that developmental changes play a role in shaping the HS experience.

Stressors and Negative Outcomes

The findings in this study suggest that adolescents are aware of the increased burden, lack of control and impaired relationships with peers due to their IS' cancer (Murray, 2000). The HS reported a loss of attention (Murray, 1998; Sloper, 2000; Woodgate, 2006), which was mainly caused by the changed family routine and parents being in hospital. Their social lives became disrupted by new responsibilities and visiting the hospital, they also found it difficult to focus at school (Sahler et al., 1994; Sahler et al., 1997). They also discussed feeling more emotional and worried (Houtzager et al., 2004). HS were found to struggle witnessing the negative impacts on their IS and found it difficult seeing their parents upset. Although many friends were supportive, HS were frustrated by those who were not understanding, which is a problem more likely to affect adolescents than

younger children, as peer groups become increasingly important to their identity (Murray, 2000).

Developmental Impact

Relativistic thinking appeared to help the HS moderate some of the negative impacts of childhood cancer, such as a loss of attention and status in the family (Murray, 1998; Sloper, 2000; Woodgate, 2006), as they understood why their IS received more attention and why they needed to take on new responsibilities. Relativistic thought was not always helpful, however, as support from parents was at times reduced by their realisation that expressing their concerns to their parents would place additional stress on them. These findings support Piaget's (1969) theory of cognitive development, as thinking styles appeared to influence the adolescents' experience of childhood cancer in the family. Future research could compare these findings with children yet to develop formal operational thinking to see whether the loss of attention and added responsibilities causes greater distress. HS also described developing maturity from the experience and future research could explore the impact of emotional maturity on the HS experience.

Positives Impacts and Outcomes

The findings demonstrate that challenging circumstances in families can strengthen the attachment bonds (Ainsworth, 1991; Bowlby, 1988). All HS reported that their family became closer (Sloper, 2000) and they felt more protective and close to their IS. Bonds were also strengthened with HS' friends and they explained continuity in relationships was helpful throughout the experience. HS' reported gains supports the idea that HS can draw emotional and psychological strength from the experience (Wilkins & Woodgate, 2006); they can feel stronger, more confident, and more mature (Sloper, 2000). HS also

reported noticing similar gains for family members. Some HS also felt their education was going well, as their attention and focus increased to make sure they did not waste opportunities.

Coping Strategies

The HS' coping strategies fit within Folkman and Lazarus' (1980) definition of coping "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them" (p. 223). The findings suggest adopting appropriate coping strategies can reduce the chance of HS developing psychosocial adjustment problems. The temperament of HS was found to influence the coping strategies they adopted, which indicates that HS' coping styles might be based on the individual's personality and their normal responses to stress (Towsley et al., 2007). In this study, humour was found to be a helpful coping strategy, as it could turn negative experiences into more manageable scenarios. Humour helped HS keep their spirits high and keep a positive outlook, which was another important coping strategy. HS also emphasised the importance of normality, escapism and distraction in helping them cope.

HS valued talking about their experiences to parents and friends. HS explained talking to people outside of the family allowed them to talk freely without worrying about upsetting their parents. Talking to people with similar experiences was considered to be particularly helpful, as they understand what HS are going through, they can support each other and share coping strategies. HS did not always want to talk about their experiences, as they did not feel the need to, they did not want to hear other people's upsetting stories, or they wanted to avoid questions. HS desire to "get on with it" was a theme repeated across the interviews, with HS explaining they had to cope, as there was no point in just worrying and moping.

Support

The findings suggest appropriate support can help HS cope with their experience. The HS valued the support from family, friends, school staff and the hospital staff. Support from friends has been found to boost well-being and general health (Carr, 2006). The HS reported that their friends provided a sense of normality and distraction, which helped to keep their spirits up. HS appreciated support from schools, as they valued knowing they could turn to teachers for support who also took the pressure off their work. HS also valued support from hospital staff, describing the nurses and social workers as helpful to talk to, understanding and supportive. Not all HS needed the support of professionals, as they either did not have any problems or they felt support from their friends and family was sufficient.

Clinical Implications

The findings from this study have applications to clinical practice. Health care professionals (HCP) need to be aware of HS' experiences and how best to support them. The diagnosis and early stages of treatment are likely to be the most difficult time for HS, which suggests HCP should address their needs early on. Families should be informed about the common stressors for HS and the experience should be normalised. HS should be helped to identify appropriate coping strategies and support systems so they can manage the stressors.

Parents' ability to process and retain information varies across their child's cancer treatment (Clarke & Fletcher, 2003). Therefore, a leaflet about HS' experiences including the stressors, common coping strategies and support systems should be created for families and HS. Hospitals should also consider running optional sibling support

groups, organising events for HS, or help HS to swap contact details to enable them to gain valuable peer support. Some HS are likely to also benefit from individual psychological interventions. There is currently a lack of individual psychological interventions for HS of children with cancer (Prchal & Landolt, 2009). This needs to be addressed and HCP should consider the child's temperament when they are considering how best to support the HS.

Families were found to help facilitate coping, provide support and help HS find positives from this experience. Difficult relationships in families were found to reduce the level of support for HS. HS who cannot rely on gaining help from their immediate or extended family are likely to need additional support from HCP. HS also found moments of normality, escapism and distraction helpful, as it gave them a break from their worries. HCP should encourage HS to participate in activities and interests they enjoy, especially those involving school and friends. Offering families practical support, including lifts and domestic help, will also benefit HS, as this could reduce their responsibilities and give them more time with parents and friends.

Limitations of the Study

The findings must be considered in the context of some methodological limitations. The interviews were retrospective and participants reported finding it hard to recall some aspects of their experience. Due to the qualitative nature of the study design, only eight participants were interviewed before data saturation was reached. The sample did not vary greatly in terms of social economic status, ethnicity, or marital status of the parents. The IS were treated at the same hospital, which means some experiences may have been influenced by visiting the same hospital and receiving support from the same staff. Additional research is needed, therefore, to further explore the role of contextual factors

to confirm or modify this theoretical model. In particular, further research should explore whether cultural factors or being in a single parent family impact on HS' experiences. The views expressed came from HS who were interested in participating; different data may have come from HS that chose not to participate.

Conclusion

This study used GT, based on Charmaz's (2003, 2006) methodology, to develop a model explaining the process of adolescent HS' experience over the duration of their siblings' treatment for childhood cancer. The model developed from this study has provided a greater understanding of the adolescent HS' experience, how this is likely to change over the duration of the treatment and what factors influence their experience. The model illustrates how HS seem to experience stressors and negative outcomes as their life is changed by the diagnosis and the treatment phases. The way HS manage these stressors and negative outcomes is likely to depend on their temperament, their coping strategies and the support they receive, which are partly influenced by the relationships in their family. If HS are able to develop appropriate coping strategies and receive appropriate support from their family, friends, their school and the hospital, then they are likely to achieve positive impacts and outcomes along with the negatives. The developmental changes adolescents go through may serve as an additional protective factor, as HS acknowledged their maturity helped them through the process. This was particularly helpful when dealing with the loss of attention and taking on new responsibilities, but it also potentially reduced some support, as HS were concerned about adding to their parents' distress by expressing their concerns.

The model has clinical implications, as it suggests HS are likely to need greater levels of support between the diagnosis and the early phases of treatment. This was identified as the most challenging time, as HS try to come to terms with the diagnosis and cope with changes in the family. HCP can play an important role in ensuring HS receive appropriate support and have the required coping skills to reduce the chance of psychosocial problems developing. HS, who come from families with difficult relationships, may need additional support. This support for HS should include normalisation of the experiences, suggested ways of coping, psychological support being offered and the opportunity to make contact with other HS to support each other through the experience.

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Appendix D

Researcher's Perspective

To provide the researcher's perspective this section will be written in a first person account.

I am a male third year clinical psychology trainee who is working on a yearlong paediatric psychology placement at the John Radcliffe Hospital in Oxford. This role has included working with paediatric cancer patients and their families. I have also worked with children and young people with a variety of chronic health conditions in this and a previous placement. During my clinical psychology training I have gained experience in working with a range of client groups mainly using cognitive behavioural therapy, systemic therapy and narrative therapy.

I was aware that my own experiences might influence how I approached the data as I had a chronic illness as a child and was also the healthy sibling to a sister with a chronic illness during my adolescent years. I have spent time reflecting on these experiences before and during this study to ensure I am aware of any factors that may bias the analysis. I wanted to ensure that the siblings' voices were heard and that they had the opportunity to explore and explain their experiences freely away from potential influences that I might bring. The original interview transcripts were discussed between myself and my research supervisors to ensure potential biases were not influencing the study.

Appendix E

The Recruitment Process

The researcher carried out five presentations to the multidisciplinary paediatric oncology staff team at the John Radcliffe Hospital. The presentations explained the rationale for the study, what the study would involve and what the study was aiming to achieve. Each presentation ended with time for questions. The staff members were asked to consider whom they knew who would meet the inclusion criteria.



The inclusion and exclusion criteria were placed on the ward and given to the paediatric oncology outreach nurse specialists and the Clic Sergeant social workers.



Study information packs for potentially interested healthy siblings and their parents were put together and handed out to the paediatric oncology staff team members. The information packs included an invitation to participate in the study letter from the consultants in the oncology team (Appendix T), an information sheet for participants aged 12-15 (Appendix U), an information sheet for participants aged 16-19 (Appendix V), an information sheet for the parents of the participants (Appendix W), and an opt in form inviting them to participate in the study (Appendix X).



The oncology staff approached families who met the inclusion criteria, either on the oncology ward or at their follow up appointments, following completion of their treatment and gave them the information packs.



When the opt-in forms were received the researcher contacted the oncology team before calling the interested families to receive an update on the patient's health in case of a relapse. This was done to avoid causing the families any distress and to check that the sibling still met the inclusion criteria.



The researcher then called the families to discuss the project and arrangements were made to interview the siblings either at the hospital or in their homes.



Participants aged 16-19 were given the opportunity to ask any further questions or raise any concerns before they gave their informed verbal and written consent to participate. Participants aged 12-15 and their family were given the opportunity to ask any further questions or raise any concerns before they gave their informed verbal and written assent to participate and their parents gave their verbal and written consent for their child to participate.



The semi-structured interview was then completed with each participant on their own either in a clinic room in the paediatric psychology department or in the lounge or dining room of the participants' house whilst their family was in. Five participants chose to be interviewed in their homes and three chose to come to the hospital. Each sibling was given a £10 voucher as a thank you for his or her time.

Appendix F

The Participant Demographic Questionnaire

An exploratory study into the experience of healthy siblings of childhood cancer in the family.

Demographics sheet

Participant's details

Age _____

Gender:

Male ☐ Female ☐

Ethnicity: _____

Number of siblings _____

Age of sibling with cancer _____

Age of other siblings _____

Age of participant when sibling was diagnosed _____

Age of sibling when diagnosis was given _____

Age of parents _____

Parent's relationship:

Married ☐ Living together ☐ Separated ☐ Divorced ☐

Other ☐ (please specify) _____

Parents' occupations _____

Where they live _____

Does anyone else live with the participant _____

Details of extended family _____

_____

_____

_____

Details on the health of the sibling with cancer

Type of cancer _____

Current health status _____

Stage of treatment _____

Appendix G

The Interview Schedule

Interview Schedule

Questions about the family

1. Can you tell me about having a sibling with cancer?
   - Can you tell me about what happened when your brother/sister became ill?
   - What was going on in your life when they became ill?

2. Can you tell me about how you get on with your sibling?
   - Has this changed since they became ill?
   - What changes have you noticed?

3. How would you describe your relationship with your parents now?
   - What was it like before the illness?
   - (If there is a change) What do you think has contributed to this change?

4. Can you tell me about your family?
   - What is a typical day like at home with your family?
   - Have you noticed any changes in your family since the illness?
   - (If there is a change) What do you think has contributed to this change?

Questions about school and friends

5. Can you tell me about your school life now?
   - What is a typical day like at school?
   - Has your school life changed since the illness?
   - How are you getting on with the work?
   - (If there is a change) What do you think has contributed to this change?

6. Can you tell me about your friendships?
   - What do you like to do with your friends?
   - Have any of these friendships changed since the illness?
   - (If there is a change) What do you think has contributed to this change?

Questions about the self

7. Can you tell me a bit about yourself?
   - What were you like before your siblings illness?
   - What changes have you noticed?
   - What do you think has contributed to this change?

8. Have you learned anything about yourself from this experience?
   - Have you noticed any strengths that have developed over this time?
   - Have other people noticed any changes?
   - What do you think has helped you during this time?

   (for example: Age? Maturity? Experience? Acceptance of the illness? Hope? Updates on the illness?)

Questions about problems

9. What problems have you encountered whilst your sibling had cancer?
   - Have the type of problems changed over time?
   - What has contributed to these problems?

10. What do you do when you have a problem that you need help with?
    - What did you do before your brother/sister was ill?
    - (If there is a change) What has contributed to this change?
    - Who would you be most likely to tell about your problems?
    - Who did you tell before your sibling's illness?

Questions about help

11. Have you had help with any of your problems during this time?
    - Has it been the right sort of help for you?
    - Would other help have been more helpful?
    - What help did you get before your sibling's illness?
    - (If there is a change) What do you think has contributed to this change?

12. Who has been the most helpful to you during this time?
    - How has she/he been helpful?
    - Has school/ the hospital/ self help groups etc been helpful?

Final questions

13. After having these experiences, what advice would you give to someone whose brother or sister has cancer?

14. Is there anything else you think I should know to understand your experience better?

15. Is there anything you would like to ask me?

Appendix H

Ethical Approval Letter From the Oxford Research Ethics Committee

National Research Ethics Service
Oxfordshire REC B
Northwick Park Hospital
Level 7, Maternity Block
Watford Road
Harrow
Middx
HA1 3UJ

Telephone:
Facsimile:

25 November 2010

Mr Jonathan Gibbins
Trainee Clinical Psychologist
OBMH
The Isis Education Centre
Roosevelt Drive
Warneford Hospital, Headington
OX3 7JX

Dear Mr Gibbins

Study Title: **An exploratory study into the experience of healthy siblings of childhood cancer in the family.**

REC reference number: **10/H0605/60**

Thank you for your letter of 01 November 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

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

Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

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

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

Approved documents

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

Document	*Version*	*Date*
Protocol	2	01 September 2010
Response to Request for Further Information	By letter from Jonathan Gibbins	01 November 2010
Participant Information Sheet: Parents Information Sheet	2	26 October 2010
Participant Information Sheet: (aged 12-15)	1	26 October 2010
Letter of invitation to participant	1	01 September 2010
REC application		01 September 2010
CV Helen Beinart		17 August 2010
Young Person's Assent form	2	26 October 2010
Interview Schedules/Topic Guides	1	01 September 2010
Evidence of insurance or indemnity		01 September 2010
Referees or other scientific critique report		01 September 2010
Investigator CV		17 August 2010
Participant Information Sheet: (aged 16-19)	1	26 October 2010
Participant Consent Form: Young Person's (aged 16-19) Consent form	1	26 October 2010
Participant Consent Form: Parent Consent form	2	26 October 2010
Covering Letter		01 September 2010
Letter from Sponsor		01 September 2010
CV Karen Steinhardt		17 August 2010
Application checklist		
Opt in form	2	26 October 2010
Clinician's letter of Invitation	1	26 October 2010

Statement of compliance

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

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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

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

- Notifying substantial amendments

- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0605/60	**Please quote this number on all correspondence**

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

Yours sincerely

pp

Prof Margaret Rees
Chair

Email: michael.mullings@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR1 for CTIMPs, SL-AR2 for other studies]*

Copy to: *Ms Emma Stratful*
R&D Manager, R&D Department
Warneford Hospital
Headington, Oxford
OX3 7JX

Appendix I

The Sponsor and Indemnity Letter from Oxford Health NHS Foundation Trust

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Emma Stratful
R&D Manager
R&D Department
Warneford Hospital
Warneford Lane, Headington
Oxford, OX3 7JX
Tel 01865 738660
emma.stratful@obmh.nhs.uk

Mr Jonathan Gibbins
Trainee Clinical Psychologist
The Isis Education Centre
Warneford Hospital
Roosevelt Drive
Headington
Oxford, OX3 7JX

Our Ref: OBMH 821

1 September 2010

Dear Mr Gibbins

Research Study Name: An exploratory study into the experience of healthy siblings of childhood cancer in the family

I can confirm that Oxfordshire and Buckinghamshire Mental Health NHS Foundation Trust (OBMH) will act as research sponsor for the above study and will comply with the Department of Health Research Governance Framework guidelines. As sponsor, the Trust will also provide indemnity for the above study.

Sponsorship and indemnity is confirmed subject to formal approval from a Research Ethics Committee and any other relevant approving body and on the understanding that should any substantial amendments be submitted to the Ethics Committee and any other relevant approving body, these would also be copied to the Trust R&D office.

Please ensure that you provide the R&D Department with a copy of annual reports and your final report.

Please note that OBMH, as the sponsor, is responsible for the study and as such is required to monitor and audit a sample of sponsored studies.

Yours sincerely

Emma Stratful
R&D Manager



Appendix J

Letter of Approval From the Research Sub-Committee of the Oxford Doctoral Course in Clinical Psychology

Oxford Doctoral Course in Clinical Psychology

an NHS Course validated by the University of Oxford

Isis Education Centre, Warneford Hospital, Headington, Oxford OX3 7JX
Tel: +44 (0) 1865 226431 Fax: +44 (0) 1865 226364
Web-site www.hmc.ox.ac.uk/clinicalpsychology

27th July 2010

Mr Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology
Isis Education Centre
Warneford Hospital
Headington
Oxford
OX3 7JX

Dear Jonathan

I am pleased to say that you now have full approval for your Dissertation.

We wish you all the best with your project.

Yours sincerely,

Dr Myra Cooper
Chair, Research Sub-committee

c.c. Anna Randle
Helen Beinart
Karen Steinhardt

Appendix K

Letter of Approval from the John Radcliff Hospitals' Research and Development Department

Oxford Radcliffe Hospitals NHS

NHS Trust

HH/JF/6325

Mr Jonathan Gibbins
Trainee Clinical Psychologist
Isis Education Centre
Warneford Hospital
Roosevelt Drive
Oxford
OX3 7JX

From the R & D Lead
Research & Development
Room 13, Manor House
The John Radcliffe Hospital
Headley Way, Headington
Oxford OX3 9DZ

Tel: (01865) 221930
Fax: (01865) 222648
Email: jo.franklin@orh.nhs.uk

Dear Mr Gibbins

22 December 2010

Re: An exploratory study into the experiences of being a healthy sibling of a child treated for cancer

Research and Development Reference: 6325
Research Ethics Committee Reference: 10/H0605/60

Confirmation of Trust Management Approval

On behalf of the Oxford Radcliffe Hospitals NHS Trust, I am pleased to confirm Trust Management Approval and Indemnity for the above research on the basis described in the application, protocol and other supporting documents.

Conditions of Approval

Your attention is drawn to the attached conditions of approval. Breach of these conditions may result in Trust Management Approval being revoked.

Ethics Correspondence

In order to facilitate good communications and avoid unnecessary delays please copy all correspondence with the Research Ethics Committee (REC) to R&D, providing copies of all relevant documents.

Research Sponsorship

It is noted that OBMH Trust has agreed to undertake sponsorship for the study.

Site Specific Assessment

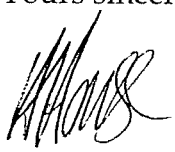
This Trust management Approval letter also incorporates site specific assessment for the Oxford Radcliffe Hospitals NHS Trust site

Approved Documents

Protocol – V2 – 01/09/10
REC Application Form
Signed SSI Form
Letter from Sponsor – 01/09/10
REC Approval Letter – 25/11/10
Clinician letter of invitation – V1 – 26/10/10
Study information letter – V1 – 01/09/10
Interview schedule – V1 – 01/09/10
Parents Information Sheet – V2 – 26/10/10
Information Sheet 12-15 yrs – V1 – 26/10/10
Information Sheet 16-19 yrs – V1 – 26/10/10
Parents Consent Form – V2 -26/10/10
Consent form 16-19 yrs – V1 – 26/10/10
Young person assent form – V2 – 26/10/10
Opt in Form – V2 – 26/10/10
Letter of support (Dr Myra Cooper) – 27/07/10
Email confirmation of funding – 20/12/10
Investigator CVs – Jonathan Gibbins
Helen Beinart
Karen Steinhardt

I wish you every success with the study.

Yours sincerely,



Ms Heather House
Research & Development Lead

Cc: Emma Stratful, R&D Manager, Warneford Hospital
Dr Helen Beinart, Clinical Psychologist, Isis Education Centre, Warneford Hospital

Standard Conditions of Approval by Oxford Radcliffe Hospitals NHS Trust for Research studies other than Clinical Trials of Investigational Medicinal Products or Medical Device Trials

Issued to Chief Investigators and Principal Investigators

Commencement of the Study

Before the study commences the Chief Investigator / Principal Investigator is responsible for the following:

- Ensuring that all members of the research team who have access to patients, their organs, tissues, data or access to NHS staff, information and facilities have ORH substantive/honorary contracts **or** appropriate research passports/honorary research contracts/letters of access in place prior to their involvement in the study.

- Ensuring that all members of the research team are appropriately qualified to undertake their role(s) through education, training and experience

- Establishing a Study Master File/Site File, which should be maintained throughout the study and be readily available to the study team.

- Ensuring that all investigators in the study are aware of and comply with the Regulatory Framework surrounding research practice, which includes but is not limited to:

- Research Governance Framework for Health and Social Care, 2005
- The Human Tissue Act, 2005
- The Mental Capacity Act, 2004
- The Human Rights Act, 1998
- The Data Protection Act, 1998
- The Declaration of Helsinki, 1996 and updates

- Registering any randomised trial on an appropriate Internet Database

- Ensuring that all appropriate approvals are in place and remain so for the duration of the study

Conduct of the Study

- The study will be conducted according to the all applicable regulations, principles of Good Clinical Practice and ORH Trust policies.
- The study will be conducted in accordance with the approved protocol
- Essential documents must be made available for audit/inspection purposes where required.
- The Trust must be made aware of any Intellectual Property that arises from the research study.

Protocol Amendments

- Where the ORH (NHS) Trust is the Sponsor, investigators must submit protocol amendments to R&D **prior** to submission the Research Ethics Committee and MHRA, to assess any implications for the Sponsor.
- All **substantial** amendments must be submitted to the appropriate Research Ethics Committee and the MHRA (if required) for approval. Documents should also be forwarded to the R&D Department for assessment as to whether the amendment affects Trust Management Approval.
- In order for the Trust to meet its responsibilities under the Research Governance Framework **all amendments, including non-substantial amendments** have to be submitted to R&D. You should include all supporting documents.
- Submission of non-substantial amendments will be acknowledged by e-mail and a letter confirming on-going Trust Management Approval will be sent for all substantial amendments.
- N0 substantial amendment, except those that relate to an urgent safety measure, should be implemented until all appropriate approvals, including R&D have been obtained.

REC Annual Progress Reports and Monitoring of the Study

- The Chief Investigator should ensure that the REC Annual Progress Reports are completed and submitted in a timely manner on each anniversary of the REC Approval, and copied to R&D

- The need for on-site monitoring of the study will be assessed according to risk to study participants and/or the Trust. Any special requirements will be communicated to the Chief Investigator in writing.

NHS Quality Accounts

- The Trust is obliged to submit data to the Department of Health annually. The Chief Investigator/Principal Investigator must provide to R&D, in a timely manner, such information about the study as to enable to Trust to meet its obligations.

Safety Reporting

- Appropriate safety reporting procedures will be agreed according to the perceived risks to study participants and/or the Trust. Any safety reporting requirements will be communicated in writing by the R&D Lead to the Chief/Principal Investigator.

Conclusion of the Trial

- The Trust R&D Department should be informed within 60 days of the close of the study and a final report provided.

- If the study is stopped early, the Trust R&D Department should be informed within 30 days outlining the reasons.

Termination of Trust Management Approval

- The Trust reserves the right to revoke Trust Management Approval or Sponsorship for any project that is not conducted according to Trust policy or the applicable regulatory or legal framework. However, any such action will not be taken without prior discussion with the R&D Lead and/or the Medical Director together with the Chief or Principal Investigator. Furthermore, all researchers undertaking research at the Trust are subject to the Misconduct and Fraud Policy.

All Trust policies for the conduct of research within the organisation can be found at www.oxfordradcliffe.nhs.uk/research

Appendix L

Consent Form for Healthy Siblings Aged 16-19

Oxford Doctoral Course in Clinical Psychology

An NHS Course validated by the University of Oxford

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Oxford Radcliffe Hospitals NHS
NHS Trust

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

Patient Identification Number for the Study:

Young Person's (aged 16-19) Consent Form

Name of Researcher: Jonathan Gibbins, Trainee Clinical Psychologist

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study. I have had the chance to think about the information, ask questions and have had these answered in a way I understand.	☐
2. I understand that I am taking part voluntarily and that I can change my mind up to two weeks after the interview without giving any reason, and without my medical care or legal rights being affected.	☐
3. I agree to the interview being audio taped and understand that the tape will be destroyed as soon as the interview has been typed onto a computer and stored securely.	☐
4. I agree to direct quotes of what I say in the interview being written up for the project and understand that I will not be able to be identified from these quotes.	☐
5. I understand that data collected during the study may be looked at by individuals from the Oxford Doctoral Course in Clinical Psychology, from regulatory authorities or from the NHS Trust, where this is relevant to the research. I give permission for these individuals to have access to my data.	☐
6. I agree to take part in this study.	☐

Name of young person	Date	Signature
Name of person taking consent	Date	Signature

Appendix M

The Parental Consent Form and the Assent Form for Healthy Siblings Aged 12-15

Oxford Doctoral Course in Clinical Psychology

An NHS Course validated by the University of Oxford

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Oxford Radcliffe Hospitals NHS
NHS Trust

An exploratory study into the experience of healthy siblings of childhood cancer in the family.

Patient Identification Number for the Study:

Parent Consent Form

Name of Researcher: Jonathan Gibbins, Trainee Clinical Psychologist

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study. I have had the chance to think about the information, ask questions and have had these answered in a way I understand.	☐
2. I understand that my child's participation is voluntary and that they are free to withdraw up to two weeks after the interview without giving any reason, without any medical care or legal rights being affected.	☐
3. I agree for my child's interview to be audio taped and understand that the tape will be destroyed as soon as the interview has been typed onto a computer and stored securely.	☐
4. I agree for my child to take part in the above study.	☐
5. I have discussed this project with my child and with the researcher and am happy to give my consent to their participation in the above study, which has been explained to me in full.	☐

Name of parent	Date	Signature
Name of person taking consent	Date	Signature

Oxford Doctoral Course in Clinical Psychology

An NHS Course validated by the University of Oxford

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Oxford Radcliffe Hospitals NHS
NHS Trust

An exploratory study into the experience of healthy siblings of childhood cancer in the family.

Patient Identification Number for the Study:

Young Person's Assent Form

Name of Researcher: Jonathan Gibbins, Trainee Clinical Psychologist

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study. I have had the chance to think about the information, ask questions and have had these answered in a way I understand.	☐
2. I understand that I am taking part voluntarily and that I can change my mind up to two weeks after the interview without giving any reason, without any medical care or legal rights being affected.	☐
3. I agree to the interview being audiotaped and understand that the tape will be destroyed as soon as the interview has been typed onto a computer and stored securely.	☐
4. I agree to take part in this study.	☐

Name of young person	Date	Signature
Name of person taking consent	Date	Signature

Appendix N

The Steps Taken to Ensure that Participants were Treated Ethically

An information sheet was provided to the siblings before they agreed to be contacted by the researcher. When the researcher discussed the study, the sibling and their family were given the opportunity to ask questions and raise any concerns they may have had before agreeing to take part. Verbal and written informed consent was obtained from the participants over 16 years old and verbal and written informed consent was obtained from parents and informed assent from participants under 17 years old to take part in the study, have their interviews taped, transcribed and direct quotes used in the write up and publication of the study. Participants were informed that the tapes would be destroyed as soon as they were transcribed, that their transcribed data would be made anonymous and stored securely. The data will be kept on a secure encrypted memory card and on a password protected computer during the writing of the project. Once the papers are completed the data and the notes will remain in locked cabinets in the Paediatric Psychology department at the John Radcliffe Hospital for at least five years. Participants were informed that their participation was voluntary and they could withdraw consent up to two weeks after the interview without this impacting on their family's treatment and their data would then be excluded from the study.

Before the interviews commenced, participants were assured of confidentiality, with the exceptions of any risks being indicated about harm to them or others. The participants were informed that the consent and assent forms were the only identifiable data and these were stored securely separately from the transcripts and demographic information. Numbers are used to identify the participants in the results section to ensure anonymity. Any potentially identifiable information that may have breached confidentiality has been omitted.

The researcher was aware that the participants would be discussing information that may have been upsetting for them. The participants were informed before the interview commenced that they did not have to answer all of the questions, they could have as many breaks as they needed and could stop the interview at any point. In accordance with the code of ethics and conduct (BPS, 2009) the viewpoint of the participants was considered during the interviews to help eliminate "potential risks to psychological well-being, physical health, personal values, or dignity" (p. 19). Factors that might put the siblings at risk of harm were considered; as no participants expressed any risks of harm during this study no suggestions were needed to help reduce such risks (BPS, 2009).

As a precaution, it was agreed that a clinical psychologist in the paediatric clinical psychology team at the hospital would immediately offer to see any siblings who were identified as being at risk. The participants were all debriefed at the end of the interviews and advised that they may feel upset later that day after processing their experience in the interview. They were all informed that they could be seen in the paediatric clinical psychology team, but no participants felt that this was needed.

Appendix O

Example of Initial Coding from a Section of a Transcript

			Coding
Timing	363	because my parents didn't want to talk about it. So I sort of	I didn't understand
	364	went along with it and I just didn't really understand. So I	
	365	suppose at the beginning, which was the worst bit I was,	Beginning was the worst bit but had less problems as didn't understand
	366	problem wise I was ok because I didn't really know what was	
Worried & upset Experiencing end of treatment	367	happening. But as things went on you know with chemo, I sort	Got more worried when chemo started
	368	of got a bit more worried and then I got more relaxed since it	More relaxed now.
	369	stopped.	
	370		
	371	**What help did you ask for or need?**	2 appointments with brothers psychologist
	372	I had one or two appointments with the therapy people in the	
	373	hospital, you know um with Kate Scarf. I didn't really ask for	I didn't ask for help.
	374	much help but sort of my mum said well your brother is having	
	375	one anyway so would you like to. I just said yeah, I didn't	Didn't want to worry anyone by having therapy.
Protecting parents	376	really feel that I wanted to worry anyone because it doesn't	
	377	sound good if someone is having weekly therapy sessions or	Didn't want to worry them by making them think I wasn't coping.
	378	anything. So I didn't want to worry anyone. I didn't want to	
	379	worry them that I was not coping well or doing something	
	380	especially badly or something. I sort of got one or two things	
Able to talk to parents Valuing talking	381	out but I just normally talk to my parents, so I think that was	Normally talk to parents that's the best help
	382	the best help and I didn't really have to ask I just said can we	Was good to have that.
	383	talk. It was good to have that.	
	384		
Able to talk to parents Getting on with it.	385	**What help would you get before your brother was ill?**	
	386	I would normally sort of talk to my mum because, well I wasn't	Normally talk to mum.
	387	really there most of the time. I would get on with things, but of	I get on with things
	388	course with something like this they are both quite	Parents both understanding so that is good.
	389	understanding, which is good.	
Able to talk to parents Valuing parents	390		
	391	**Did you receive any other help?**	
	392	No not really, I didn't want to branch out too much, it was	Mainly talked to parents
	393	mainly with my parents.	
	394		
	395	**Was it the right help for you?**	

Example of Focused Coding from a Section of a Transcript

Protecting parents

624 a little bit, but not too much, but obviously I would have been a
625 burden on mum and dad as they were looking after my sister,
626 so I think it kind of worked.
627
628 **So you worried you were a burden to your mum and dad?**

Protecting parents

629 I think it is because of knowing that they almost had more to
630 deal with as they were with my sister everyday for three and a
631 bit weeks in hospital, they couldn't really leave her, because
632 they didn't want to as well, she wanted them there and they
633 wanted to be there but they needed down time as well so I
634 don't want to go and share all of my troubles with them. They

Able to talk to parents

635 sort of were always there to listen if I wanted to regardless of
636 what the time was or how they were feeling, they were always
637 there, but I was conscious that when they were away from her
638 I didn't want to make them feel sad still, so, but yeah I kind of
639 dealt with it half and half really. We are close as a family and

Close family

640 we got each other through it I think.
641
642 **When you couldn't speak to your parents did you speak to**
643 **someone else?**

Protecting parents

644 I kind of just bottled things up and sorted it out and that was
645 then dealt with and if it wasn't I would speak to mum, because
646 yeah they were always there and they didn't ever say don't

Able to talk to parents

647 speak to us about it, it was just me being me and trying not to
648 upset them, even though they said don't worry if you do.
649
650 **What did you do when you had a problem before the**
651 **illness?**
652 Still spoke to mum.
653
654 **Who would you speak to now?**
655 Still mum.
656

Coding

Would have been a burden on parents if hadn't adjusted quickly

Parents had more to deal with as they were with sister everyday.

They needed downtime too, so didn't want to share my problems

Parents always there to listen regardless of time or how they were feeling.

Conscious not to make them feel sad when away from her.

Close family and got each other through it

Bottled things up and sorted it out. Would speak to mum if I couldn't deal with it.

They were always there to talk to

Just me trying not to upset them.

Appendix Q

Memos about the Collapsing and Merging of Categories and Codes and the Development of the Model

1. It was discussed with my supervisors how negative impact on physical distance from the family needed to be included in the relationship with their parents category, as it was too small on its own. The good relationship with parents was replaced with relationship with parents to accommodate the other variables that siblings discussed. It was then discussed how the parents separating and the family not being close before the diagnosis should also be collapsed into relationships with parents.

2. Following discussions with my supervisors it was also agreed that the sibling personality and sibling coping helped focus codes should be merged, as the quotes were overlapping as both were describing how the ill sibling's personality allowed them to cope, which helped the healthy siblings to manage the experience.

3. Whilst reviewing the focused codes, I realised that the life context and influencing variables (later became family relationships) were too similar to have as separate codes. I therefore collapsed the life context codes into the influencing variables. This will also make the model clearer.

4. I collapsed the other people noticing positive changes code into the positive gains code, as I realised they were explaining the same thing and the quotes were already in the positive gains code, so it was repetitive.

5. I collapsed the stable period in condition code from the positive impacts and outcome category and placed the one example in the wanting normality code (later became valuing normality, escapism and distraction) in the developmental category, as the quote talked about how the stable period allowed them to feel a sense of normality.

6. I collapsed the shared activities and interests code from the positive gains category and put it into the relationship with ill sibling code in the influencing variables category (later became family relationships). This again was due to the quotes already being in that code.

7. I collapsed the code feeling needed by the family, as it only had one quote in there. I realised that feeling needed would be a positive gain for the sibling, so collapsed it into that code.

8. I collapsed the external shock code into experiencing shock, as there was a strong overlap and having external shock, as an extra focused code did not contribute to the theory.

9. I collapsed the code relationship with healthy sibling as there was not sufficient data in the code and it fitted better with the close family code, as the reflections were about getting on well and that relationship becoming closer due to the

experience.

10. I collapsed the code impact of school transitions as there was only one example and that example did not really add anything other than to say they changed schools but it was fine.

11. I collapsed the support offered by the school counsellor and taking time off codes into the support from school staff code, as these were both related to that code.

12. I collapsed the valuing talking to people outside of the family, to valuing talking, as they really should be one category.

13. I collapsed not wanting to talk to other siblings into the choosing not to talk about it, as again it really belonged in one category.

14. I merged the able to talk to parents code into the valuing talking code, as I realised the codes overlapped and the talking to parents code was an aspect of valuing talking in general.

15. I decided to collapse the category supporting and protecting parents, as I realised these were factors that were actually causing a negative experience for the sibling and they also can be grouped together with the code of seeing their parents upset.

16. I collapsed the finding significant occasions harder code into the changes in family routine code, as this was a particular change in routine that was harder to face.

17. I merged the worrying and nerves and feeling angry codes into the feeling more emotional and stressed code, as this better sums up the emotions that the siblings faced in one category.

18. I collapsed the gained knowledge about cancer code, as it only had a few quotes in it, it was not really mentioned as a positive by the siblings and it did not add to an explanation of their experience.

19. I merged the positive gains for family members code into the positive gains category, as there was quite an overlap.

20. I collapsed the codes feeling understood, as the quotes taken were already used in the experiencing the end of treatment, valuing friends and support sections.

21. I collapsed the code uncertainty and fear from the end of treatment experience category and placed the one participants data into the more emotional and worried category due to this being more relevant. The code on its own was too small and in the wrong place, which I realised when I reread the quotes.

22. It was also discussed how the personality focused code needed to be changed to temperament as personality can have negative connotations due to personality disorders.

23. When trying to rework my model, I realised that some of my focused codes were within the wrong categories. "Temperament" needed to be moved to the coping strategies category and "regretting not taking support" was part of the end of treatment category as they were reflecting on their experience. The temperament was added to the coping category name, so that it was not lost in the model.

24. After reworking the model, I realised I did not know how to fit the developmental category into the model. On closer inspection I realised that the category was vague and that the wanting normality, was a coping aspect and should be tied in with valuing escapism and distraction, the not feeling understood was a stressor and a negative outcome, the fearing social judgement was merged in with the negative impact on social life focused code and the developmental issues was merged in with temperament as this was where the siblings were reflecting on how their temperament changed over time due to their developmental changes.

Appendix R

Reflective Diary

My Own Background

Between the ages of 4 and 10 I had nine operations for a bowel condition and I observed the impact it had on my family and especially my siblings. My two older sisters both had to contend with the stress of their younger brother being ill and the loss of attention as their parents rallied around to support me. A few years after I had recovered, my eldest sister became ill with glandular fever and then ME. This had a dramatic impact on our family as she had to drop out of school at the age of 14 and she became depressed. My other sister is two years older than me and dealt with the problems at home by going out, spending time at friends, in town and partying. I was too young to go out and we lived the other side of town to my school friends, this left me worried about my sister, the impact it was having on my parents and having to deal with these concerns plus the normal dilemmas of adolescents without much attention or support from both within the family or from friends who lived too far away.

These experiences have allowed me to gain insight into the impact of illness within a family both from being an ill child and being the sibling of an ill child. For this reason I realised I would be very interested in researching the impact of illness on siblings. I knew that the dissertation would be a very involved project and I wanted to choose a subject that would keep my interest throughout the lengthy process. I decided that researching the impact of ME or glandular fever would be too emotionally involved for me and this might have a detrimental impact on the research and potentially myself as well. Instead I decided that looking at the impact of childhood cancer would be a really interesting and rewarding piece of work that could provide important research in this valuable area.

Finding the Research Question

After deciding the area of interest I then had to find the research questions. This process was to be more challenging than I first envisaged. There is a lot of literature in this area and I was told that carrying out a thematic analysis of the literature would be the best way to find the gaps to find out how I could add to the knowledge base. I was apprehensive about this task, as I had never done this before. After conducting a literature search and printing off around 194 abstracts I then cut out each abstract and started to collate them into themes. This lengthy process allowed me to then subdivide every category into more categories and eventually I found the area of transitions needed further work. After more reading in this area I discovered that research needed to be conducted on the experiences of adolescent healthy siblings over the duration of their siblings treatment for childhood cancer. Further reading in this area also highlighted the lack of research investigating the impact that developmental stages has on the ability of a child to cope with siblings with cancer and how their coping and understanding changes as they develop.

Qualitative Research

To gain insight into the experiences of ill children I needed to carry out a qualitative analysis. This idea both excited and daunted me at the same time. I have always been interested in qualitative techniques, as they allow for richer data to be collected and analysed but I have not previously undertaken a qualitative piece of research before. After agreeing to have two supervisors, with one having a lot of experience of using grounded theory, I was pleased and reassured that everyone agreed that grounded theory

would be the most appropriate method to conduct my study. The advice I received also allowed me to further my understanding of the area and after reading books and articles I began to feel that grounded theory would offer a structure to the data collection and analyses and found myself looking forward to using such a dynamic process on my dissertation.

The Proposal

The proposal took form after much reading and research. When it began to take shape I felt pleased with how far it had come in such a short space of time and had a sense of accomplishment and anticipation as I handed it in. I was aware of how much work was ahead of me but felt pleased to have a project that I could start working on and one that I was interested in.

Gaining Ethical Approval

The process of gaining ethical approval was quite daunting for me. This was the first time that I have tried to gain ethical approval and I knew that my application would need to be thorough and well considered as I was requesting to interview children and young people. I found the application to be quite repetitive and tedious to complete and there appeared to be several hoops that needed to be jumped through before the work could begin. After finally gaining approval from the university, I was then given approval from the research and development department after some minor amendments. My study was then given its first setback, as I had to wait over a month for the next meeting to be held in Oxford.

The meeting itself was more daunting than I had expected, as there were around 23 people all sitting around a big table and they were all eating their lunch during my time slot, which I found slightly bizarre. There were a couple of people who raised some concerns and luckily I had asked my supervisor along to the meeting, as she was able to field some of the questions about the rationale for the study inclusion criteria. They respected her answers as she has years of experience in working in paediatric oncology. I felt that some of the questions were useful and I agreed with some of the amendments. I did, however, find it quite offensive when it was suggested I should not be allowed to interview adolescent girls due to my age and gender. Although I was able to give an appropriate answer I found the way the question was asked to be quite derogative and sexist, and I did wonder whether this question would have been asked about young males if I was female, or asked at all if I was older.

Despite some difficult questions, I felt that they were not challenging the overall study and only seemed concerned that some factors were addressed. This indeed turned out to be the case and I was able to get the conditions in quickly. Frustratingly it then took until past the New Year to gain full approval, as a member of staff breaking their arm held up my application and I was told it could not be sent out until they had approved it. This meant that I would only have from part way through January until July to recruit everyone, analyse all the data and write up the dissertation. This was quite anxiety provoking.

Recruitment

To aid the recruitment I carried out five presentations to the oncology team, which all went really well. As soon as ethical approval was given, the prepared information packs for the potential participants was given to the relevant staff in the oncology team and all of the staff were made aware of where to get the forms. I was pleased that the first

recruitment came quickly and I was able to do the first interview in January. I am now more confident that I will be able to complete the dissertation on time.

Following the initial three recruits I then had to wait over a month before my fourth interview. This was a nervy time as two families turned down the opportunity to participate. I found this disheartening, as previously everyone that was told about the study had reacted really positively to it. I am now a bit concerned that it is going to be harder to recruit than I thought it would be.

I am now feeling very appreciative for the support of the paediatric oncology outreach nurses and the Clic Sergeant social workers for their help in recruitment. I have now managed to recruit seven participants following the initial stumbling block of over a month without recruiting. This has highlighted to me the importance of engaging the staff members of the team where you are recruiting from, as they have been brilliant at identifying and approaching children. I am weary that they are very busy though, so I think it is a difficult balancing act between asking for help with recruitment and not being a nuisance to people.

I have now completed the seven interviews and although I feel that data saturation may have been reached, my supervisors felt that I was not certain enough and we had stated that a minimum of 8 should be recruited. Following these discussions, I stepped up the recruitment process but identifying siblings who met the inclusion criteria was proving harder than I thought it would. I had begun to contact Swindon and Milton Keynes hospital as some of their children were treated originally at the John Radcliffe hospital, luckily the clic sergeant social workers were able to identify two more families and one of them was happy to participate. I am so relieved to have recruited an eighth participant, as the deadline for the dissertation is fast approaching.

The First Interview

I was very surprised by how positive the first participant was. She appeared to have gained a new perspective in life and the experience has given her a drive to achieve and do things not only for herself but also for her sister. The account was balanced, as she also described the negatives including seeing her sister so ill, and the impact of the cancer on her sister, her family and herself. The reported positives appeared to come from having some coping strategies in place, such as being able to talk to her parents, being able to see and talk to her friends and using humour to help them see the funny side of difficult moments.

On a reflection in terms of the process of carrying out a qualitative interview I found it very hard to conduct the interview without slipping into a therapeutic style. When I listened back, some of my questions may have been slightly leading and my clarification questions sometimes resulted in yes or no answers. I need to be more careful in future interviews to ask more open and general questions and not put words into the participants' mouths. I think overall that the interview went very well and I was able to collect good data, which suggests that the interview questions were well selected. The participant fed back at the end that she had had the opportunity to discuss all that she wanted to and felt that she had been able to explain her experience well. I will make sure that I ask this question at the end of every interview to check that the participant feels that what we have talked about is a good reflection of their experience. This question may also provide the participant with the opportunity to discuss other matters that I may not have asked them to consider.

I think an avenue to explore in more detail in the next interview will be the experience of being in the hospital and seeing their sibling go through the treatments. I will also be interested to see if humour was found to be helpful.

Coding

After the first meeting about my coding with my supervisor, I realised that my initial coding was too interpretive and my coding needed to be more grounded to the participant's language. This was a very useful reflection to have after only coding one transcript. From then on I was much more focused on the actual language and more focused on the described actions in the transcripts.

Whilst discussing the categories and the related codes, it was suggested that the positives code looked quite full of examples compared to the others. Following a discussion about whether this was what had been found or whether this was what I was looking for, I realised that the code needed to be separated into positive gains and new perspectives. This turned out to be an important discussion as it will allow for richer data and the new perspectives is an interesting finding from this study that may have been lost within the positive code.

Using humour appears to be an important coping mechanism for the siblings in this study. They discussed how their family would joke about what felt to be inappropriate things to laugh at, but these were the things that helped them to get through difficult situations. It may have been a case of laugh or cry and the siblings explained that their ill brother or sister also joked about their health as a way to cope and help the family to stay positive in the face of difficult experiences.

It appears that families, who were described as close before the illness, were described as getting even closer for having been through the experience. Whereas one sibling, who described herself as quite independent from the family became more independent and reported less family shared activities. It may well be that going through the childhood cancer experience may exaggerate existing family identities, so that close families become closer and more independent siblings, become more independent.

Triangulation

I was pleased to see that there was in general a high level of agreement with the coding. This was done on S2's transcript with one supervisor and S6's transcript with my other supervisor. Both supervisors coding and focused coding was consistent with mine throughout. Through the triangulation process, it was discussed how one code may have been too vague. My supervisor recommended that I relook into "timing" code, as she felt one of the incidents in S2 was more about the initial reaction to the diagnosis, which is about timing and may be collapsed into timing later, but to just label it as timing could result in losing some of the richness of the data. I kept this in mind for the remaining interviews and the focused code ended up being called "diagnosis and initial treatment was the hardest time" and the discussions around timing were presented within this code.

Data Saturation

I felt that the data was saturating in the seventh interview and discussed this issue with my supervisor. It was agreed that I should try to recruit one more at least to ensure that the data is saturated and to use the final interview to test out the theory that was beginning to evolve from the transcripts. The final eight interviews confirmed the findings in the previous seven without highlighting anything new that would have added to the theory. This was agreed with my two supervisors and so the recruitment was finished at that point as it was unlikely that anything new would come out of a ninth interview.

Creating the Model

I presented my first attempt of the model to my supervisors feeling quite pleased with my initial efforts. After reviewing the model they suggested that it was not actually very clear how the different factors influenced each other and it was not very balanced or easy on the eye. It was discussed how factors and events needed to be differentiated clearly in the model and how it needed to be a clearer formulation of their experience.

I went home and tried to make it as simple as I could. I added a section in the middle labeled "the siblings' experience" and had all of the categories pointing into this section, with the positives and negatives then coming out. The influencing variables category was changed to mediating factors (later became family relationships), as this resembled predisposing factors better. The mediating factors, support, developmental and coping categories were, therefore, shown to influence the siblings' experience. These factors then combined to impact on the positives and negatives that they experience, which will also be influencing their experience. I took the model to my next meeting and both supervisors felt the model was now too simplistic and was at danger of resembling a spider diagram. We agreed that I would look again at the Wallander and Varni's (1992) and Clarke-Steffen's (1993, 1997) models to see how my findings fit with the existing literature.

Although I was disappointed to have got the model wrong again, I completely agreed with my supervisors, who also recommended that I took a break from the model for a day or two, as I was probably finding it hard to see the woods for the trees. After having first gone too complicated and then too simplistic, I set about trying to develop the model with a fresh mind. I reviewed the suggested models and then read through my results section again, I also kept in mind the advice to try to tell the story in a linear fashion.

This process really helped me to see my results in a different and less jumbled way, so I presented the linear story of the cancer journey down the left side of the model, which every child who has finished treatment will have gone through; life before the diagnosis, the diagnosis, the treatment, and end of treatment. I was then able to demonstrate clearly how the diagnosis and treatment phases caused the stressors and negative outcomes. I then had to think about how to illustrate the fact that the siblings were able to achieve some positives despite these problems. I realised that I could present the variables that helped them to cope all down the right hand side of the model. This then showed how the support received, the siblings' temperament and coping strategies and their family relationships all combined to help them to also achieve the positive aspects from their experience. This then helped to clearly demonstrate the clinical implications from the model, as these are the factors that will require the attention of health care professionals to ensure that healthy siblings are given the best chance of avoiding psychosocial problems.

I was surprised by how many different models I got through before coming to the final one. The model has changed a great deal from arrows everywhere in a haphazard and confused way, to eventually following a linear story, with the causes of stress, the negatives and stress and how these are managed to create some positives being quite clear. I am very pleased with the final model and feel that it fits nicely with the existing literature, such as Wallander and Varnis' (1992) and Clarke-Steffen's (1993, 1997) models.

Appendix S

Table 2.
The Categories, focused codes and quote references

Categories	Focused codes
Life Before the Diagnosis	**Life normal before diagnosis** S1: 30-31, 35-42*, 134-138. S2: 64-66. S3: 155-167, 290-295 S4: 58, 61-62.S5: 12, 59-62. S6: 32-38*, 294-297. S7: 127-138. S8: 19 **No problems before the diagnosis** S1: 38-40*. S3: 155-157. S4: 544-545.
The Diagnosis	**Experiencing illness before diagnosis** S1: 7-8, 12. S2: 31-39. S3: 25-27, 29-38, 44-45, 56-58. S4: 31-43 S5: 23-27, 30-39. S6: 23-29, 40-46. S7: 63-85* S8: 15-16. **Being told of the diagnosis** S1: 12-15, 22-28, 568-571, 579-585. S2: 42-54. S3: 31-38, 47-59, 61. S4: 46-52, 196-200, 213-215. S5: 18-19, 22-26*. S6: 49-57. S7: 51-60*. S8: 5, 10-11, 5-11, 97-98. **Experiencing shock and disbelief** S1: 5, 7, 24-25, 250, 315-317, 570-571, 707. S2: 25-26. S3: 4-7, 31-33, 36-38, 88, 97, 110-113, 157-162, 372-374 S4: 193-196, 420-422, 471-475. S5: 375-378. S6: 52-57*. S7: 52-55, 337-339. S8: 5, 10-11. **Diagnosis and initial treatment was the hardest time** S1: 6, 253-254. 276-279, 301, 497-498 S2: 5-9, 12-16, 20-23, 31, 36, 65-66, 229-230, 278-284, 367-369. S3: 9-14, 19-20, 100-103, 114-116, 132-133, 136, 330-333, 350-356, 359-361, 364-370, 376-377, 574-577. S4: 348-354. S5: 382. S6: 364-369.
Stressors and Negative Outcomes	**Changed family routine due to illness** S1: 100-102, 108-109, 139-143, 148-150, 253-254, 275-279, 287-288, 456-470, 478-479, 490, 498-501, 507. S2: 6-7, 12-19*, 128-130, 130-135, 373, 377-381. S3: 8-9, 118-131, 138-151.

S4: 20-24, 146-148, 404-408, 458-464, 587-589.
S5: 104-107.
S7: 43-47, 58-60*, 248-254, 87-89
S8: 22-25*, 37-40*, 106, 110-111.

Negative impact on the ill siblings

S1: 108-109, 204-209, 221-225, 311-316, 322-323, 707-714, 730-734.
S2: 14-16, 19-23, 25-26, 31-39, 138-140, 143-145, 158-167, 170-171, 210-211, 260-265, 367-369, 377-381, 395.
S3: 14-20, 7-9, 62-66, 133-134, 498-504, 542-549.
S4: 9-13, 21-28*, 32-43, 70-77, 82-87, 93-98, 146-148, 242-249, 402-408, 414-426, 430-437.
S5: 173-176, 194-198.
S6: 17, 187-192, 195-209.
S7: 5-6, 12-15, 22-23*, 89-90*, 93-96*, 612-613.
S8: 28-30, 65-72, 299-302*.

Negative impact on other healthy sibling

S4: 429-43, 464-480.
S5: 42-44, 333-336.

Negative impact on academic performance

S1: 217-219, 225-229.
S2: 309-310.
S3: 350-356.
S4: 267-271, 599-603.
S6: 220-223*, 236-243*.
S7: 5-15*, 400-413.

Taking on new responsibilities

S1: 216-218, 228-229, 235, 247-250*, 258-261, 275-279, 301-304, 380-383.
S2: 64-66, 141-147, 157-161, 251-253, 258-260.
S4: 9-11, 348-354, 484-495, 499-500*.
S5: 104-107, 122-130, 201-202, 239-242.
S7: 260-262*, 346-353*.
S8: 37-43.

Seeing parents upset

S1: 72-81, 104-105, 258, 457-469, 463-465*, 472-479, 492-495, 517-518, 595-596, 644-648*.
S2: 18, 358-361, 364-366, 374, 378-381.
S3: 125-126, 418-422*, 461-465*
S4: 51-55, 310-313*, 337-344, 505-509, 527-531, 566-569, 611-612.
S5: 201-202, 308-313*.
S6: 168-173*, 375-380*.
S7: 93-97, 286-294*, 297-301*, 332-335*, 484-489, 623-626*, 629-640*, 629-634*, 644-648*.
S8: 222, 300-305, 309.

Not liking being in the hospital

S1: 310-312, 322-323.
S2: 53-54, 147-153.
S3: 77-83, 108-109, 127-131, 134-136, 487-496*, 501-507*
S4: 80, 89-98*
S5: 175-176.
S6: 176-184*.
S8: 55-62*.

Negative impact on social life

S1: 198-199, 281-288, 589-591, 603-606, 607-610, 697-698.
S2: 199-203, 308-310, 314-317.
S3: 103-107, 138-141.
S5: 104-107.
S6:258-264.
S7: 390-396
S8: 117-118.

Not feeling understood

S1: 285-286, 661-668*.
S6: 229-231.

	S7: 5-12, 37-42*, 305-310*, 365-370*.
	More emotional and worried
	S1: 707-713.
	S3: 18-20, 68-69, 436, 542-543, 598-600.
	S4: 5-6, 59-61, 242-249, 348-349, 351-354.
	S6: 5, 10-11, 16-18, 354-358*, 364-369, 487-488.
	S7: 87-89, 102-103*, 346-357*, 410-413*, 432-434*, 437-450*, 467-474*, 476-487*, 485-487*, 523-529.
	S8: 5-7, 283*.
	Los of attention
	S1: 456-470, 481-483, 490-501*.
	S4: 13-17*, 127-130*, 133-136*, 310-321*, 324-328*, 371-373*, 383-387, 458-464, 474-477, 527, 587-589.
	S5: 93-96.
	S6: 157-159, 164-173*.
	S7: 258-269.
	S8: 50-52*, 198-200.
	Losing their faith
	S3: 441-452.
	S6: 333-351*.
Family Relationships	**Close family**
	S1: 18-20, 40-42, 108-110, 113, 117-119, 130, 134-137, 685-686.
	S2: 84, 87-89, 93-94, 94-96, 104-108, 114-120, 439, 451.
	S3: 201-217, 248-249, 275-289, 298-309, 316-318.
	S4: 115-120, 144-162, 166-171.
	S5: 80-81, 122-126, 343-344*.
	S6: 103-106.
	S7: 32-33, 189-194*, 461-464*, 639-640*.
	S8: 88-94.
	Relationships with parents
	S1: 59-84*, 88-95*.
	S2: 47-48, 57-61, 87-89*, 125-128, 223-225, 269-270.
	S3: 207-217, 221-230, 248-249, 252-259.
	S4: 125-130, 136.
	S5: 75-76*, 84-89*.
	S6: 86-96.
	S7: 174-184, 263-269.
	S8: 83-84.
	Relationship with ill sibling
	S1: 35-42, 40-42*, 45-56*, 127-131, 137-138, 156-160, 345-348, 426-428.
	S2: 71-73, 76-80, 390-391, 451-456.
	S3: 170-184
	S4: 69-72, 101-110, 376-377, 380-390.
	S5: 51-52, 59-62*.
	S6: 68-70, 74-75, 78-82*.
	S7: 31-33, 141-153*.
	S8: 75-80.
	Sibling coping helped
	S1: 419-424, 430-439.
	S3: 629-646, 644-646*
	S4: 249-252, 408-410, 415-416.
	S5: 37-39, 352-354.
	S6: 203-209, 212-217.
	Difficult relationships in families
	S1: 503-504.
	S3: 230-232, 263-275.
	S6: 116-120, 130-133.
	S7: 209-216, 222-224.
	Close family
	S1: 18-20, 40-42, 108-110, 113, 117-119, 130, 134-137, 685-686.

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Note. *Key quotes

Appendix T

Letter of Invitation to Participate from the Consultants in the Oncology Team

Dr C D Mitchell, PhD, FRCP
Dr K A Wheeler, MRCP, FRCPCH
Dr G W Hall, PhD, FRCP, FRCPath, FRCPCH
Dr S M Lane, PhD, MRCP, MRCPCH
Dr A Qureshi, MRCP, FRCPath

Paediatric Haematology/Oncology Unit
Oxford Children's Hospital
Level 2
The John Radcliffe
Headley Way
Headington
Oxford
OX3 9DU

Tel: 01865 234199
Fax: 01865 234211

Our Ref:

Date 30th November 2010

Dear

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

Invitation letter

The purpose of this letter is to introduce Jonathan Gibbins who is training in the Clinical Psychology Department at the University of Oxford. His clinical supervisor is Karen Steinhardt, who is the psychologist in our unit. Part of his Doctoral Course is a study looking at the experience of being a healthy sibling of a child treated for cancer.

Jonathan would like to invite siblings of our patients to participate in this study. It would involve an interview to talk about their experiences. The interviews will remain confidential, unless there are concerns about risk to your child or others. If such concerns should arise, Jonathan will talk with your child first before discussing the matter with you and relevant professionals. The doctors and nurses looking after your child would not be made aware of what was said.

We are fully supportive of this study, but there is no obligation to participate and your child's medical care would not be affected if you decide not to participate

This study has been reviewed and given a favourable opinion by Oxford Research Ethics Committee B and is sponsored and indemnified by Oxford and Buckinghamshire Mental Health NHS Foundation Trust.

There are comprehensive information sheets available which explain the study. If you are interested in finding out more please complete and hand in the opt in letter and Jonathan will contact you.

Yours faithfully,

Dr Kate Wheeler
Consultant Paediatric Oncologist

Dr Sheila Lane
Consultant Paediatric Oncologist

Dr Chris Mitchell
Consultant Paediatric Oncologist

Dr Georgina Hall
Consultant Paediatric Haematologist

Dr Amrana Qureshi
Consultant Paediatric Haematologist

Appendix U

Information Sheet for Participants Aged 12-15

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Oxford Radcliffe Hospitals NHS
NHS Trust

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

Young Person's (aged 12-15) Information Sheet

We are asking if you would join in a research project to explore how young people are affected by having a brother or sister who has been treated for cancer. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. So please consider this information carefully. Talk to your family and friends if you want to.

What is the purpose of the study?
Growing up brings its own challenges and stresses as people develop from being children into young adults. When a sibling is diagnosed with cancer, young people have to try to adapt and cope with this news and the resulting changes to family life, on top of the normal challenges that every young person faces. Having a brother or sister being treated for cancer can be a stressful experience. Some young people find they cope well in this situation and may even find benefits from the experience, whilst others find it more difficult.

Why have I been invited to participate?
We are looking at the impact that having a sibling being treated for cancer has on the healthy developing sibling such as yourself. Learning more about your experiences during this difficult time and about the ways in which you managed these, will help us to help other young people in the same situation.

In particular, we are hoping to find out about both positive and negative changes you have experienced since the diagnosis and whether you feel your experience has changed as you have grown older. We are asking young people who were aged between the ages of 12 and 16 years of age whilst their sibling was receiving treatment for cancer to take part in this research study. It is an educational project being written up as a thesis at Oxford University as part of the Oxford Doctoral Course in Clinical Psychology.

What will happen if I take part?
You will be interviewed once and the interview will last up to approximately one and a half hours. The interview will ask questions about the experience of having a sibling being treated for cancer, how this changed over the duration of the treatment, and how it has impacted on your life. You will be interviewed on your own to give you the chance to talk about your experiences without worrying about what your family might think. We appreciate that you would be giving up free time to talk to us and you will be given a £10 HMV voucher as a thank you for your time.

Where and when will the interview take place?
If you chose to take part then you will be interviewed in the Children's Hospital at the John Radcliffe Hospital, or if you prefer you can be interviewed at your home if this is more convenient.

Do I have to take part?
You do not have to take part and the research study is separate from your sibling's medical care. You can also withdraw from the study any time up to two weeks after the interview, for any reason and you do not need to explain why. We would like you to think carefully about the study, and you do not have to decide right now if you want to help with the research. You may find it helpful to talk to friends or family about the study or to us if there is anything that is not clear or if you would like further information.

What are the advantages and disadvantages of taking part?
The information will be used to help improve the care of future young people whose siblings are treated for cancer. You may find it helpful to have the space to talk about this experience but it is also possible that thinking about your feelings and experiences may be upsetting.

Is the study confidential?
All the information collected about you during the course of the research will be kept strictly confidential. The data will be coded so that your name can be removed and the information will only be accessed by the researchers on this project. The interview will be digitally recorded on a hospital owned Dictaphone and typed up by myself to ensure confidentiality and to ensure that what you say is not lost. The recording will then be destroyed as soon as it is typed up and your name will not appear on the typed interviews.
What you say in the interview will remain confidential, unless there are concerns about risk to yourself or others. If such concerns should arise then I will talk with you first before discussing the matter with your parents and relevant professionals.

The use of quotations
Some direct quotes from what you have said may be used in the write up but no one will be able to tell that it was you who said them. For example the write up may say that one young person commented that "It was hard to concentrate at school because I was so worried about my brother".

Who has reviewed this 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. This study has been reviewed and given a favourable opinion by Oxford Research Ethics Committee B and is sponsored and indemnified by Oxford and Buckinghamshire Mental Health NHS Foundation Trust.

Any questions?
If you have any questions or concerns, either now or during the study, do not hesitate to ask us about them. I can be contacted on the number at the top of the opt in letter you were sent with this information sheet. If you would like to talk to someone independent of the study then feel free to contact PALS, the Patient Advisory Liaison Service on 01865 221473.

What do I do if I decide to take part?
If after reading this and discussing it with your parents you would like to take part then please complete the opt in letter and fill out your contact details and I will telephone you to arrange a time to meet you and your parents. I will then ask you to complete an assent form and ask your parents to complete a consent form before the interview commences. You are welcome to have your own copy of the assent form to keep.

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

Yours sincerely,

Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology.

Appendix V

Information Sheet for Participants Aged 16-19

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

Young Person's (aged 16-19) Information Sheet

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?
Growing up brings its own challenges and stresses as people develop from being children into young adults. When a sibling is diagnosed with cancer, young people have to try to adapt and cope with this news and the resulting changes to family life, on top of the normal challenges that every young person faces. Having a brother or sister being treated for cancer can be a stressful experience. Some young people find they cope well in this situation and may even find benefits from the experience, whilst others find it more difficult.

Why have I been invited to participate?
We are looking at the impact that having a sibling being treated for cancer has on the healthy developing sibling such as yourself. Learning more about your experiences during this difficult time and about the ways in which you managed these, will help us to help other young people in the same situation. In particular, we are hoping to find out about both positive and negative changes you have experienced since the diagnosis and whether you feel your experience has changed as you have grown older. We are asking young people who were aged between the ages of 12 and 16 years of age whilst their sibling was receiving treatment for cancer to take part in this research study. It is an educational project being written up as a thesis at Oxford University as part of the Oxford Doctoral Course in Clinical Psychology.

What will happen if I take part?
You will be interviewed once and the interview will last up to approximately one and a half hours. The interview will ask questions about the experience of having a sibling being treated for cancer, how this changed over the duration of the treatment, and how it has impacted on your life. You will be interviewed on your own to give you the chance to talk about your experiences without worrying about what your family might think. We appreciate that you would be giving up free time to talk to us and you will be given a £10 HMV voucher as a thank you for your time.

Where and when will the interview take place?
If you chose to take part then you will be interviewed in the Children's Hospital at the John Radcliffe Hospital, or if you prefer you can be interviewed at your home if this is more convenient.

Do I have to take part?
You do not have to take part and the research study is separate from your sibling's medical care. You can also withdraw from the study any time up to two weeks after the interview, for any reason and you do not need to explain why. We would like you to think carefully about the study, and you do not have to decide right now if you want to help with the research. You may find it helpful to talk to friends or family about the study or to us if there is anything that is not clear or if you would like further information.

What are the advantages and disadvantages of taking part?
The information will be used to help improve the care of future young people whose siblings are treated for cancer. You may find it helpful to have the space to talk about this experience but it is also possible that thinking about your feelings and experiences may be upsetting.

Is the study confidential?
All the information collected about you during the course of the research will be kept strictly confidential. The data will be coded so that your name can be removed and the information will only be accessed by the researchers on this project. The interview will be digitally recorded on a hospital owned Dictaphone and typed up by myself to ensure confidentiality and to ensure that what you say is not lost. The recording will then be destroyed as soon as it is typed up and your name will not appear on the typed interviews.
What you say in the interview will remain confidential, unless there are concerns about risk to yourself or others. If such concerns should arise then I will talk with you first before discussing the matter with your parents and relevant professionals.

The use of quotations
Some direct quotes from what you have said may be used in the write up but no one will be able to tell that it was you who said them. For example the write up may say that one young person commented that "It was hard to concentrate at school because I was so worried about my brother".

Who has reviewed this 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. This study has been reviewed and given a favourable opinion by Oxford Research Ethics Committee B and is sponsored and indemnified by Oxford and Buckinghamshire Mental Health NHS Foundation Trust.

Any questions?
If you have any questions or concerns, either now or during the study, do not hesitate to ask us about them. I can be contacted on the number at the top of the opt in letter you were sent with this information sheet. If you would like to talk to someone independent of the study then feel free to contact PALS, the Patient Advisory Liaison Service on 01865 221473.

What do I do if I decide to take part?
If after reading this and discussing it with your parents you would like to take part then please complete the opt in letter and fill out your contact details and I will telephone you to arrange a time to meet you and your parents. I will ask you for your consent before the interview takes place. You are welcome to have your own copy of the consent form to keep.

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

Yours sincerely,

Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology.

Appendix W

Information Sheet for the Parents of the Participants

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

Parents Information Sheet

We would like to invite your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for your child.

What is the purpose of the study?
Growing up brings its own challenges and stresses as people develop from being children into young adults. When a sibling is diagnosed with cancer, young people have to try to adapt and cope with the news and the resulting changes in the family life, on top of the normal challenges that every young person faces. Having a brother or sister being treated for cancer can be a very stressful experience for young people. Some young people find they cope well in this situation and may even find benefits from the experience, whilst others find it more difficult.

Why has my child been invited to participate?
We are looking at the impact that having a sibling being treated for cancer has on the healthy developing sibling. Learning more about their experiences during this difficult time and how they cope and adjust to the cancer and the resulting changes in family dynamics, will help us to help other young people in the same situation. In particular, we are hoping to find out about both positive and negative changes following this experience and whether their experiences have changed as they got older. We are inviting young people who were aged between the ages of 12 and 16 years of age at some point during their sibling's treatment for cancer to take part in this research study. It is an educational project being written up as a thesis at Oxford University as part of the Oxford Doctoral Course in Clinical Psychology.

What will happen if my child takes part?
Your child will be interviewed once and the interview will last up to approximately one and a half hours. The interview will ask questions about the experience of having a sibling being treated for cancer, how this changed over the duration of the treatment and how it has impacted on their lives. Your child will be interviewed on their own to provide them the space to talk freely about their experiences without having to worry about upsetting other family members. If during or after the interview your child feels distressed and thinks it might be helpful to talk in more detail about some of their experiences then please contact me and we can consider how best we might be able to help your child. We appreciate that your child would be giving up free time to talk to us and they will be given a £10 HMV voucher as a thank you for their time.

Where and when will the interview take place?
If your child chooses to take part then they will be interviewed in the Children's Hospital at the John Radcliffe Hospital, or if they prefer they can be interviewed at your home if this is more convenient.

Do they have to take part?
Your child does not have to take part and the research study is separate from their sibling's medical care. They can also withdraw from the study for any reason at any point up until two weeks after their interview. We would like you to think carefully about the study and talk it through with your child. They do not have to decide right now if they want to help with the research. You and your child may find it helpful to talk to friends or family about the study or to us if there is anything that is not clear or if you or your child would like further information.

What are the advantages and disadvantages of taking part?
The information will be used to help improve the care of future young people whose siblings are treated for cancer. Your child may find it helpful to have the space to talk about this experience but it is also possible that thinking about their feelings and experiences may be upsetting. If at any time during or after your interview you feel distressed and think that it might be helpful to talk in more detail about some of your experiences then please contact me and we can consider how best we might be able to help you.

Is the study confidential?
All the information collected about your child during the course of the research will be kept strictly confidential. The data will be coded so that your child's name can be removed and the information will only be accessed by the researchers on this project. The interview will be digitally recorded on a hospital owned Dictaphone and typed up by myself to ensure confidentiality and to ensure that what your child says is not lost. The recording will then be destroyed as soon as it is typed up and your child's name will not appear on the typed interviews. What your child says in the interview will remain confidential, unless there are concerns about risk to themselves or others. If such concerns should arise then I will talk with your child first before discussing the matter with you and relevant professionals.

The use of quotations
Some direct quotes from what your child has said may be used in the write up but no one will be able to tell who said them. For example the write up may say that one young person commented that "It was hard to concentrate at school because I was so worried about my brother".

Who has reviewed this 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. This study has been reviewed and given a favourable opinion by

Oxford Research Ethics Committee B and is sponsored and indemnified by Oxford and Buckinghamshire Mental Health NHS Foundation Trust.

Any questions?
If you or your child has any questions or concerns, either now or during the study, do not hesitate to ask us about them. I can be contacted on the number at the top of the opt in letter you were sent with this information sheet. If you would like to talk to someone independent of the study then feel free to contact PALS, the Patient Advisory Liaison Service on 01865 221473.

What do to do if we decide to take part?
If after reading this your child would like to take part then please complete the opt in letter and fill out your contact details and I will telephone you to arrange a time to meet you and your child. I will ask you for your consent and your child's assent if they are under 16 years old, or consent if they are aged 16 or older. You are welcome to have a copy of these forms for you to keep.

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

Yours sincerely,

Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology.

Appendix X

The Opt in Form

Oxford Doctoral Course in Clinical Psychology
An NHS Course validated by the University of Oxford

Oxfordshire and Buckinghamshire Mental Health NHS
NHS Foundation Trust

Oxford Radcliffe Hospitals NHS
NHS Trust

Opt in Form

Jonathan Gibbins
Department of Paediatric Psychology,
Children's Hospital,
John Radcliffe,
Headley Way,
Oxford,
OX3 9DU
Telephone:01865 234187

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

We are inviting young people whose sibling has been receiving treatment for cancer to take part in this research study. The study aims to look at the impact of having a sibling being treated for cancer and in particular on the impact during adolescence. We are therefore seeking to recruit young people who were aged between 12 and 16 at some stage of their sibling's treatment. Learning more about their experiences during this difficult time and how they cope and adjust to the cancer and the resulting changes in family dynamics, will help us to help other young people in the same situation. In particular, we are hoping to find out about both positive and negative changes following this experience and whether their perception of these experiences has changed as they have grown older. The study is an educational project being written up as a thesis at Oxford University as part of the Oxford Doctoral Course in Clinical Psychology.

I have enclosed two information sheets which explain a bit more about the study, one of them is for you as parents and the other is for the young person themselves. If you would like the researcher to contact you to discuss the possibility of your child participating in the study then please complete your contact details on page 2 and sign your consent to be contacted. Once you have completed this form please either hand it in at reception of the Oncology ward addressed to Jonathan Gibbins or post it to the address on the top of this letter.

If you would like to receive a letter summarising the study's findings once the project has been completed then please tick the relevant box on the opt in form. If you indicate that you would like to receive the summary letter then your name and address will be stored securely and confidentially and will be destroyed as soon as the letter is sent out to you.

Thank you for taking the time to read this letter.

Yours sincerely

Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology.

An exploratory study into the experiences of being a healthy sibling of a child treated for cancer.

I confirm that I have read and understand the information sheet for the above study and I give consent for the researcher (Jonathan Gibbins) to contact me to discuss the possibility of my child participating in the study. I understand that this does not constitute an agreement to take part in the study at this stage.

_____	_____	_____
Name of parent	Date	Signature

Contact details

Name of parent/parents:_____
Name of child who may participate:_____
Home telephone number:_____
Mobile number:_____
Address:_____
_____
_____
_____
Post code:_____
Preferred contact time/method:_____
_____
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_____

By ticking this box you are indicating that you would like to receive a letter summarising the study's findings once the project has been completed. ☐

Thank you for replying to my letter and I will contact you as soon as possible.

Yours sincerely

Jonathan Gibbins
Trainee Clinical Psychologist
Oxford Doctoral Course in Clinical Psychology.