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Statement of Original Authorship

The work contained in this these has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: _______________________________________

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Abstract

A diagnosis of cancer represents a significant crisis for the child and their family. As the treatment for childhood cancer has improved dramatically over the past three decades, most children diagnosed with cancer today survive this illness. However, it is still an illness which severely disrupts the lifestyle and typical functioning of the family unit. Most treatments for cancer involve lengthy hospital stays, the endurance of painful procedures and harsh side effects. Research has confirmed that to manage and adapt to such a crisis, families must undertake measures which assist their adjustment. Variables such as level of family support, quality of parents’ marital relationship, coping of other family members, lack of other concurrent stresses and open communication within the family have been identified as influences on how well families adjust to a diagnosis of childhood cancer. Theoretical frameworks such as the Resiliency Model of Family Adjustment and Adaptation (McCubbin and McCubbin, 1993, 1996) and the Stress and Coping Model by Lazarus and Folkman (1984) have been used to explain how families and individuals adapt to crises or adverse circumstances. Developmental theories have also been posed to account for how children come to understand and learn about the concept of illness. However more descriptive information about how families and children in particular, experience and manage a diagnosis of cancer is still needed. There are still many unanswered questions surrounding how a child adapts to, understands and makes meaning from having a life-threatening illness. As a result, developing an understanding of the impact that such a serious illness has on the child and their family is crucial. A new approach to examining childhood illness such as cancer is currently underway which allows for a greater understanding of the experience of childhood cancer to be achieved. This new approach invites a phenomenological
method to investigate the perspectives of those affected by childhood cancer. In the current study 9 families in which there was a diagnosis of childhood cancer were interviewed twice over a 12 month period. Using the qualitative methodology of Interpretative Phenomenological Analysis (IPA) a semi-structured interview was used to explicate the experience of childhood cancer from both the parent and child’s perspectives. A number of quantitative measures were also administered to gather specific information on the demographics of the sample population. The results of this study revealed a number of pertinent areas which need to be considered when treating such families. More importantly experiences were explicated which revealed vital phenomena that needs to be added to extend current theoretical frameworks. Parents identified the time of the diagnosis as the hardest part of their entire experience. Parents experienced an internal struggle when they were forced to come to the realization that they were not able to help their child get well. Families demonstrated an enormous ability to develop a new lifestyle which accommodated the needs of the sick child, as the sick child became the focus of their lives. Regarding the children, many of them accepted their diagnosis without complaint or question, and they were able to recognise and appreciate the support they received. Physical pain was definitely a component of the children’s experience however the emotional strain of loss of peer contact seemed just as severe. Changes over time were also noted as both parental and child experiences were often pertinent to the stage of treatment the child had reached. The approach used in this study allowed for rich and intimate detail about a sensitive issue to be revealed. Such an approach also allowed for the experience of childhood cancer on parents and the children to be more fully realised. Only now can a comprehensive and sensitive medical and psychosocial approach to the child and family be developed. For example, families may benefit from extra
support at the time of diagnosis as this was identified as one of the most difficult periods. Parents may also require counselling support in coming to terms with their lack of ability to help their child heal. Given the ease at which children accepted their diagnosis, we need to question whether children are more receptive to adversity. Yet the emotional struggle children battled as a result of their illness also needs to be addressed.
Introduction

Paediatric oncology is one of the greatest medical success stories of the last four decades (Izraeli and Rechavi, 2004). The cure rate of childhood cancer has increased from approximately 25% in the 1960’s to over 75% in the 1990’s. This astounding progress can be attributed to the malignancies causing childhood cancer being sensitive to chemotherapy treatment. A series of collaborative empirical clinical trials across Europe and the USA has also made significant contributions to the medical treatment of childhood cancer. However, whilst survival rates of childhood cancer have improved dramatically, approximately one in every 450 children will develop cancer and it is still the leading cause of death in children after the neonatal period (Izraeli and Rechavi, 2004). Furthermore for those children who survive, very little is known about how they, along with their families, actually experience the diagnosis and treatment.

Unlike cancers in adults, most cancers in children can not be prevented and are not receptive to early detection (Izraeli and Rechavi, 2004). Childhood cancers usually occur in tissues and organs that develop most rapidly during embryogenesis and the postnatal period. In contrast, many adult cancers form in the epithelial cells which cover the surface of body cavities that are exposed to environmental carcinogens for extended periods of time. Again unlike adult cancers, children diagnosed with cancer are expected to live many more years post cancer. Many adult cancers occur post-retirement age. It would seem reasonable to think then, that children faced with a life-threatening condition or serious disease such as cancer, have specific medical, psychosocial, emotional and spiritual needs, different to that of adults (Jones and Weisenfluh, 2003). Growing children are more vulnerable to the delayed effects of cancer such as fertility difficulties, effects on their growth,
neuropsychological functioning and the occurrence of secondary cancers. More importantly, because children tolerate chemotherapy better than adults they often receive a far greater “dosage” than their adult counterparts (Izraeli and Rechavi, 2004). Whilst there is some literature outlining the psychosocial care provided to adults who are seriously ill, these models haven’t been shown to be applicable to children (Jones et al. 2003). Thus, it has been established that there is a growing need for medical and allied health professionals to develop and implement interventions and models of support specific to the needs of children and their families. This is turn requires research.

Research involving children who are seriously ill in general (or who may be facing the prospect of death) has however, been traditionally considered as a highly sensitive and ethically challenging area to investigate. Clarke, Lawford, Sheppard and Eiser (2005) state that during and before the 1960’s medical staff rarely spoke to children directly regarding their illness. Staff were consulted on the assumption that such discussion with ill children would be unnecessarily worrying or anxiety provoking for the child. Health contexts have often focused on parents for information pertaining to a child’s health. At other times staff caring for a sick child, have been questioned on the child’s behalf as to how the child is managing (Clarke et al., 2005). However, differences have been noted between children and their parents in reports about the effects of the illness on the children. Work by Eiser and Morse (2001) indicated that parents reported much more negative consequences about the effect of the illness on the children, than the children themselves. This research indicated that parents were less able to judge accurately the impact of the illness on the child’s quality of life (QoL). For example, parents may not clearly be able to distinguish the internalisation of behaviours such as sadness or anxiety. Other explanations are also
prevalent regarding the difference of opinions between child and parent reports on the impact of illness. Firstly, parents have no direct experience of the child’s activities outside the immediate family environment (e.g. school). Secondly, parents may unwittingly bias their judgements based upon their own experiences and concerns (e.g. worry about future general health or employment prospects of child). Finally, parents’ perceptions may be biased due to their own mental health status. Due to the differences that can occur between children’s and parent’s reports about the effects of illness, information needs to be taken from the child’s perspective whenever possible. Relying on information from adults alone may result in incomplete assessments or fail to address the child’s subjective experiences and perceptions. As a result Eiser and Morse (2001) advocate that any assessment of QoL should include information from both the child and caregiver. As such it is important to develop an understanding of how children understand, interpret and make sense of their illness, medical treatment and care.

Recent research carried out through St. Jude’s Children’s Research Hospital and the Sydney Children’s Hospital is an excellent example of involving children directly to assess their understanding and idea’s on their own illness. Hinds et al. (2005) revealed that young cancer patients (aged 10-20 years) who were at the end-of-life stage of their illness were able to cognitively understand the nature of their illness and showed altruistic behaviours toward their families and other children with cancer. The findings from the research indicated that paediatric cancer patients as young as 10 years of age, were aware they had an incurable disease and were able to engage in discussions about their own end-of-life care with their family and health care team. Hinds et al. (2005) noted that one of the most important components of study was the involvement of the children, as it is typically parents and the clinicians who are
focused on, for the collection of data, to the neglect of the child. A significant finding of the study was the children’s wish to “benefit others” through their own experience even though they themselves would not benefit directly from participating in the study. This finding was unexpected as such behaviour is not reflected in existing theories of child development, which dictate that children typically expect to personally benefit, when they help someone else.

In considering the needs of children with cancer, research evidence to date confirms that children are cognitively aware of the nature of their illness and do not necessarily suffer additional distress by engaging in interviews where the interviewer is both sensitive to their needs and has the requisite interviewing skills (Hinds Burghen, Haase and Phillips, 2006). Research by Gray Deering and Jennings Cody (2002) indicated that even when not spoken to directly, children will unavoidably pick up information regarding their illness through visits to hospitals or other medical procedures. Children have also been known to show distress when presented with no information or not told the truth about their condition. Thus, issues about how children understand their illness and the medical treatment they are receiving are of great significance and necessary to understand, if we are to provide young patients with the best level of medical and psychosocial care.

The Current Study

Given my interest in learning about how children cope with adversity, the topic of childhood cancer was chosen for the current study as the diagnosis of cancer in a child represents a significant crisis for the child and their family. As noted above, the survival rates of childhood cancer have improved dramatically over the last 3 decades however, it is still an illness which has the potential to be life-threatening, its onset is still sudden and unexpected and treating cancer often involves a lengthy
period (up to several years) of invasive and intensive treatment. All of these factors affect not only the child but the whole of the family unit as they embark on a major life transition. Our understanding of the experiences children and their families undertake from the point of diagnosis through treatment to recovery, is still in its infancy. Therefore, the overall aim of the proposed research is to examine and explicate the experiences of children and their families in detail, where the child has a diagnosis of cancer.
The survival rates of children with cancer have increased dramatically over the last three decades. Today approximately two thirds of children with cancer survive their illness (Last, Grootenhuis and Eiser, 2005). However, in previous times when it was likely that the child would die from their cancer, the focus of clinicians was on helping the parents to cope with this ultimatum. Additionally, the child was protected from any information pertaining to the life-threatening nature of their disease as the general consensus was that the child should be protected from information about their disease, so as to limit the psychological distress they experienced (Eiser, 2004). Classic works such as “Who’s Afraid of Death on a Leukaemia ward” by Vernick and Karon (1965) captured the pessimistic attitude and outcome toward this population with such a poor prognosis.

Grief and Loss Model

With the focus being on providing support to the family in anticipation of the child’s impending death, the psychosocial perspective adopted across the 1960’s and
1970’s drew upon a grief and loss perspective (Lindemann, 1944). Kupst (1994) described that the grief and loss model assumed that the diagnosis of childhood leukaemia meant an inevitable death for the child whilst the family experienced a severe crisis. Thus, this paradigm focused on the parents’ stages of grieving as their role was perceived to be one where they would be required to prepare for the eventual death of their child. The initial stage of grieving was described as being shock or disbelief at having a child diagnosed with paediatric cancer. After this initial stage of shock or disbelief it was expected that the parents would begin to accept the probability of the child’s death on an intellectual level but not on an emotional level. Grief reactions such as denial were described as being common at this time. With the decline of the child’s condition, theorists at this time described emotional reactions displayed as being anger, blame and/or guilt. An optimal period for anticipatory mourning was considered to be 4 months prior to the child’s death (Kupst, 1994). The grief and loss paradigm assumed that the parents would experience the predictable stage of grief which if unresolved, would result in serious dysfunction. Families were thus expected to exhibit varying degrees of psychopathology. Because such difficulties were expected, intensive psychosocial intervention with the family would be necessary to assist them work through their grief. Research by Kaplan, Grobstein and Smith (1976) revealed that seventy percent of families who had experienced the death of a child then went on to suffer extreme marital, family and health problems.

Although research undertaken during this period made a considerable contribution to understanding how parents responded during times of crisis and during an experience such as childhood cancer, they did assume that the stages of grief were universal and predictable in nature. While most parents were bound to experience distress at having a child diagnosed with a critical illness such as cancer and then have
to witness the deterioration of their child’s health as the child moved closer to death, the grief and loss model led to an expectation of emotional problems and psychopathology occurring and left little room for potentially healthy forms of coping to develop.

Additionally, the typical methodology of research of this time depended upon observations and judgements made by staff, usually without the use of standardized instruments. Mothers were also the main participants of the studies rather than the actual child with cancer or other family members. Finally, examining psychosocial factors from a grief and loss perspective failed to monitor how families were managing after extensive periods of intensive treatment, nor did this perspective examine the late effects of treatment and coping in situations where the child survived (Kupst, 1994). Furthermore, the meanings or understandings which parents and children attributed to their experience were not explored.

**Recent Research on Childhood Cancer**

The progress that then occurred in medical care over the proceeding three decades from the 1960’s changed the focus of research in paediatric psycho-oncology from the impact of the inevitable death of a child, to the impact on the QoL of the child and family during and after treatment (Last et al. 2005; McCubbin, Balling, Possin, Friedreich and Bryne, 2002; Patterson, Holm and Gurney, 2004). Increased survival rates thus posed many new questions: What were the costs in terms of the effects on physical, cognitive, social and emotional functioning? How would the treatment for cancer impact upon the child’s functioning in society, relationships with peers and academic progress? How would families make sense of the experience when a child was diagnosed with cancer? Additional questions could now be asked about the level and type of care needed for the ongoing medical and psychosocial
needs of the child (Last et al. 2005). Also, with the increased survival rate children and their families were now enduring many challenges such as repeated invasive procedures, increased emotional and physical work and changes in family routine, roles, relationships and responsibilities. Symptom distress and the difficulty associated with containing symptoms in children was a significant cause of suffering and distress in not only their own, but also their family’s lives (Kim and Morrow, 2002).

Whilst a diagnosis of childhood cancer no longer meant a guaranteed death sentence it was and still is viewed as nothing less than a catastrophic crisis that rocks the stability and adaptive functioning of the entire family system (Carpenter and LeVant, 1994). It has been well documented that the diagnosis of cancer in a child puts the family into crisis (Noll et al. 1995, Stuber, 1995). As a result, developing an understanding of the impact that such a critical illness has on the child and their family was crucial to being able to provide a comprehensive and sensitive based care approach to the child and family (Woodgate, 2005).

With this move forward towards research with improved clinical knowledge and more systematically orientated outcomes, it began to emerge that families in this situation did not necessarily fit a pathological profile as previously identified (Kupst, 1994). Rather, these families appeared to be typical people who were experiencing significant stress and loss. In a recent study by Wijnberg-Williams, Kamps, Klip and Hoekstra-Weebers (2006) parents completed the same three self-report measures at four points in time across the 5 year period; diagnosis, 6 months, 12 months and 5 years post diagnosis. Parental psychological distress levels significantly decreased over a 5 year period from the initial time of the diagnosis. These results were consistent with those of Poder, Ljungman and von Essen (2008) who also undertook a
longitudinal study on parental mental health status following a diagnosis of cancer. In this study parents were assessed for post-traumatic symptoms at one week (T1), two months (T2) and four months (T3) post a diagnosis of childhood cancer. The results concluded that 33% of parents exhibited post-traumatic stress symptoms at T1, but there was a decline over time with 28% showing post-traumatic stress symptoms at T2 and 22% at T3. Thus research shifted from focusing on pathology to coping and adaptation in the context of a life-threatening illness.

*Family functioning.* Research utilising questionnaire based methodologies contributed to a number of interesting findings. For example, research by Kupst and Schulman (1988) indicated a number of variables that played a significant role regarding family coping which were: level of family support, quality of parents’ marital relationship, coping of other family members, lack of other concurrent stresses and open communication within the family. These results have supported other research. Spinetta, Swarner and Sheposh (1981) found that those whose families coped well with the death of a child had developed a positive philosophy about life, had good support systems and good communication within the family about the illness and death of the child. The variables reported by Kupst and Schulman (1988) to have an impact on coping and long-term adjustment of childhood cancer survivors also supported that of Koocher and O’Malley (1981) which include openness in family communication, emotional support, a positive outlook, satisfaction with the medical care provided, in addition to family income and socio-economic status. Kazak and Barakat (1997) also report strong associations between parental stress levels and parent rated child QoL. McCubbin, Balling, Possin, Frierdich, and Bryne (2002), identified that positive family recovery was predicted to result from strength based factors within the family from the perspective of the parents. The results of this
research indicated the following variables to be positive predictors of family coping and resilience in the context of childhood cancer; internal family strengths of rapid mobilization and reorganization, support from the healthcare team, support from the extended family, support from the community, support from the workplace and changes in family appraisal.

*The Resiliency Model of Family Adjustment and Adaptation.* With the findings of this recent research revealing the variables related to positive family functioning and recovery in the context of a diagnosis of childhood cancer, a number of theoretical frameworks were developed which attempted to explain how families and individuals cope in the context of adversity. One such framework is The Resiliency Model of Family Adjustment and Adaptation (McCubbin and McCubbin, 1993, 1996). This model essentially depicts how families are required to establish new patterns of family functioning, social support, community resources, coping and problem-solving to manage the crisis of having a child diagnosed with a critical illness such as cancer.

As determined by McCubbin (1996) resiliency can be defined as the positive behavioural patterns and competence individuals or the family unit demonstrate under stressful or aversive circumstances. This then determines the individual or family’s ability to recover as integrity is maintained, while restoring the well-being of family members and the family unit as a whole. An understanding of the psychosocial factors associated with resiliency looks at why some families are better able to adjust to crisis situations.

The Resiliency Model has been based on five fundamental assumptions about family life: (1) families face hardships and changes as a natural and predictable aspect of family life over the life cycle; (2) families develop basic competencies, patterns of
functioning and capabilities designed to foster the growth and development of family members and to protect the family from major disruptions in the face of transitions and changes; (3) families develop basic and unique competencies, patterns of functioning and capabilities designed to protect the family from unexpected or non-normative stressors and strains and to foster the family’s recovery following a family crisis or major transition or change; (4) families draw from and contribute to the network of relationships and resources in the community including its ethnic and cultural heritage at times of family stress and crises; (5) families faced with crisis situations which demand changes in the family’s functioning, work to restore order, harmony and balance in the midst of change.

The Resiliency Model of Family Adjustment and Adaptation hypothesises two phases which occur over time: the adjustment phase and the adaptation phase. In the adjustment phase the family relies on established patterns of functioning, resources, appraisal, problem solving and coping strategies with only minor changes being made. It is when these already established patterns of family functioning fail to support the family that the family is seen as being in crisis, and it is this that marks the beginning of the adaptation phase. In the adaptation phase the family is subject to significant vulnerability as the demands placed on the family due to the child’s diagnosis, in addition to the usual demands of work and family life, accumulate. In times of such crisis the family is then required to establish new patterns of family functioning, social support resources and actively engage in new coping and problem-solving strategies (McCubbin et al. 2002).

The Resiliency Model of Family Adjustment and Adaptation has been applied to the field of childhood cancer as the diagnosis of cancer in a child is considered to be an event which places the family in such a crisis. Families need to adapt and
establish new patterns to assist them recover during active treatment phases and once treatment has terminated (McCubbin et al, 2002). These studies utilising mainly quantitative methodologies have identified variables such as internal family strengths of rapid mobilization and reorganization, support from the healthcare team, support from the extended family, support from the community, support from the workplace and changes in family appraisal are resiliency factors in the “adaptation phase” of the Resiliency Model. Obtaining information regarding family strengths and capabilities is important as it assists in identifying recovery factors relevant to managing the adversity of childhood cancer. One of the most recent studies using this model was that of Brody and Simmons (2007). These authors conducted a qualitative study investigating father’s experience of childhood cancer with a specific focus on resources and capabilities that contribute to resiliency and constructive coping. Four themes emerged with three of these themes playing a crucial role in father’s ability to adapt to their child’s illness; good social support, strong communications skills and being able to adjust to the necessary lifestyle changes bought on by the illness. These three themes together influenced the fourth theme; the effect of the cancer experience on fathers. By using the resiliency model as the framework, this study focused on parental adaptation to a diagnosis of childhood cancer.

**Stress and Coping Model.** Individual responses are also an important component of adaptation processes and have been conceptualised by means of a stress-coping model. The initial model developed by Lazarus and Folkman (1984) is the best known framework which accounts for how individuals cope with stress. The basic assumption of this model is that people who are confronted with a stressor (in this case, a life-threatening illness) evaluate the stressor, and this evaluation determines their emotional or behavioural reactions. In their early research Lazarus
and Folkman (1984) distinguish two kinds of evaluation or appraisal processes: primary and secondary appraisal. *Primary appraisal* assesses the personal meaning of an event and indicates whether the event has a positive, neutral or negative meaning for the individual. Negative emotions result if the event threatens the physical and/or psychological self (which would be expected in the case of a life-threatening illness such as cancer). Affective changes during the course of an illness may also result from *secondary appraisal*. This process refers to the thoughts or actions the person can explore and undertake which reduces the threat or loss determined by the event, thus the person’s coping capacity (Maes, Leventhal and De Ridder, 1996).

Lazarus and Folkman (1984) define coping as any effort to manage external or internal demands which are appraised as negative or challenging. In the original model they distinguish between two different forms of coping: problem-focused coping and emotion-focused coping. Problem-focused coping refers to coping responses which are directed at the external event itself (seeking social support). Emotion-focused coping refers to attempting to cope with the stressor through the individual’s emotional reactions or internal state (denial, avoidance). In this way coping is defined as a process rather than an event. The thoughts and actions directed at the stressor are thus likely to give rise to emotional and/or behavioural consequences. Additionally, coping behaviour may vary over time and from person to person which can explain why there can be differences in the effectiveness of coping behaviour and why some will adapt more quickly to stressors. How people cope with a stressor is likely to have important psychological, social and physical consequences.

Spinetta (1977) adapted Lazarus’s coping tasks for use with families and paediatric cancer patients. These coping tasks included the family learning to manage distress, maintaining a sense of personal worth, maintaining rewarding interpersonal
relationships and using available resources to meet specific situational tasks. Other longitudinal research by Kupst and Schulman (1988) indicated family coping with childhood cancer involved the adaptation to understanding the realities and implications of the disease and treatment, management of emotional reactions and use of available resources effectively.

Application of this model assumes the outcome is one of adaptation rather than psychopathology. However more descriptive information about coping strategies is still needed. Kupst (1994) argues that we need to know what strategies work, for whom, in what situations and at what times. Spinetta (1977) highlighted the importance of questions such as: what does a child with cancer experience from the point of diagnosis onwards? How does a child attempt to adjust to a potentially life-threatening illness? Can a child’s attempt to adjust be measured, predicted or modified? Can a child’s coping strategies be strengthened? It is crucial to determine the answers to these questions so that the critically ill child’s coping mechanisms can be maximized.

*The Experience of Illness*

*The new approach to childhood cancer.* The study of experiences of childhood cancer has long been dominated by approaches focused on the identification of psychological morbidities and the processes of adjustment, adaptation and coping, as stated above. These dominant frameworks in which the study of childhood illness and family functioning have been applied, have concretely conceptualized how children and their families function in the face of adversity. Research carried out recently has seen a change of focus and has utilised a variety of innovative methodologies. Narrative enquiry carried out by Woodgate (2005) indicated that the diagnosis of cancer was a turning point which forever changed the families’ life course. The results
of this particular study revealed that although the families retained many of their “old ways” of living, life was forever different. These results add support to Clarke-Steffen’s (1993) work which found that a childhood cancer diagnosis resulted in a fracturing of the reality of the lives of the children and families involved and forced the families to develop new strategies to cope with life in the context of the cancer. Research such as this confirmed that families had little choice but to embark on what was likely to be an unplanned, uncertain and potentially exhausting journey uncertain.

*The experience of parents.* As stated earlier in this document the way in which adults and families respond and adapt to stress has been conceptualised within frameworks which are characterized by family cohesiveness and other individual characteristics such as coping style and personality traits. As if these theoretical frameworks have provided a starting point, the complexity of the roles of parents as caregivers and their own experience of their child’s illness, needs to be further explored to again, gain that complete understanding (Dixon-Woods et al. 2005). For example, there is evidence to suggest that the initial period immediately after diagnosis is when parents experience most distress (Manne et al. 1995). Dixon-Woods et al.(2005) state that there is evidence which suggests that it is not only the child but also the parents who experience a “biographical disruption” as a result of having a children diagnosed and treated for cancer. Parents are thus required to redefine themselves. Young, Dixon-Woods, Findlay and Heney (2002) carried out a study examining mother and child perceptions and beliefs about childhood cancer. Whilst the results obtained from the parents were the only data published in this article, the results indicated that mothers experienced an obligation to be physically close to their child (obligation of proximity) at all times, as if to “keep watch” over their child. Mothers also reported experiencing an emotional interdependence with
their child which included managing the co-operation and treatment of their child. These results indicate that the mothers’ own quality of life was compromised by the sheer stress and strain of their obligations and their reduced ability to function in other roles e.g. parenting of their other children. Another study conducted by Young, Dixon-Woods, Windridge and Heney (2003) examined communication about cancer in childhood. Thirteen families (parent and child with the illness, aged 8-17 years) participated in semi-structured interviews. The authors concluded that parents often acted in an executive-like manner, controlling what and how their children were told about their illness. Parents took on this role for the purpose of protecting their child and in an effort to manage their own identity as strong and optimistic parents.

Finally, there is also evidence which suggests that cultural factors play an important role and have the ability to significantly change parental and lifestyle identity. A study by Yeh, Lee and Chen (2000) examined 32 Taiwanese parents’ responses to adapting to childhood cancer. Searching for spiritual meaning was an aspect many participants raised. The authors found that illusions caused by spirituality (e.g. it was fate that their child was diagnosed with cancer) could lead to drop out from treatment. Some parents also modified their behaviour and lifestyle significantly as they believed this would assist their child (e.g. becoming vegetarian).

**Limitations of Previous Research**

The research previously cited in this thesis has contributed significantly to our knowledge of how families cope in times of a crisis and in particular relation to the impact that a diagnosis of childhood cancer can have on a family. However, the studies cited have also presented with a number of limitations that have to some degree, impeded progress in a number of ways. Many of the studies noted have been retrospective in nature. Data have often been collected one to three years post
treatment being completed. Collecting data at such times is then required to rely on the memory of participants alone. This lapse in time since treatment was completed can influence participants’ recollections of the phenomena being studied, hence reliability of the data being collected. McCubbin et al. (2002) admit that the retrospective nature of their study (parents were interviewed on a single occasion that had had a child treated for cancer within the previous 3 years) is a limitation. They feel that further research based upon a longitudinal perspective is necessary to continue to develop the evidence on family resiliency in critical illnesses such as childhood cancer. A similar limitation was also noted in research by Patterson et al. (2004). Parents of a child who had completed cancer treatment at least 1 year beforehand were interviewed to examine aspects of the child’s cancer diagnosis, treatment and recovery that the parents perceived as difficult or helpful in managing the cancer experience. The author concluded that the year in which the child was diagnosed as well as the amount of time that had elapsed since the end of treatment, may have affected parental reports.

Previous research has also often only included data collected from parents alone with children being excluded. Thus, this type of methodology does not account for the biases that may occur from collecting information from parents alone. Added to this is the fact that parents’ involvement is usually for the purpose of finding out how the child is going, rather than focusing on their own actual experience of parenting a child with cancer. The unique status of parents as carer’s is overlooked, the complexity of their role is unable to be explored and the unique difficulties or experiences they encounter is unable to be captured (Dixon-Woods et al.2005).

Data have also often only been collected at a single point in time i.e. cross-sectional, and so in this way has assumed that variables such as parental stress levels
do not change over time. Finally, the majority of research undertaken to date in the area of childhood cancer has been undertaken from a quantitative perspective. The results of such research may then be potentially limited by the hypotheses posed and have not allowed for the detailed and in depth information on this particular phenomena, to be collected. The use of standardized instruments can predetermine what is important to children and their families. When the focus is on pathologizing parents’ experiences, coping, adjustment or identifying psychopathology and individual attributes, the scope of inquiry then becomes very limited. It doesn’t take into account the socio-cultural context of caring for a child with a life-threatening illness (Dixon-Woods et al. 2005). As the methodology employed for many of the previous studies cited was predominantly a priori in terms of using predefined categories, we still have a limited understanding of the experiences of the children and their parents.

Focusing on the Child

Having reviewed the literature from a predominantly parental perspective and the associated limitations, the following section of the literature review focuses on some of the fundamental theories around child development. The different views on these theories are also discussed. This section also explores some of the literature surrounding children’s experience of childhood cancer. A conclusive section is presented summarising the main arguments presented in the literature review and then finally an outline of the current study is proposed.

Theory of Cognitive Development

Jean Piaget is one of the fundamental theorists associated with the area of child development. Piaget’s theory about the way in which children develop and understand the topic of health and illness is well recognised as being fundamental in
contributing to the field of child development. Piaget proposed that children
developed and progressed into adulthood via a series of predetermined stages. It is a
theory which connects biological development with cognitive development, that is,
the biological development of a child is directly related to the child’s cognitive stage
of development (Piaget, 1954). The theory is based on the assumption that children
learn about illness in relation to their biological and cognitive level of development.
Piaget’s outline of cognitive development in the child has been recognised as a
valuable theoretical perspective in conceptualising the child’s ability to view illness in
a logical and structured way (Koopman, Baars, Chaplin and Zwinderman, 2008).
However, it has also received some criticism as outlined in a later section of this
thesis. The following is an outline of Piaget’s perception of the cognitive development
of illness in the child.

Sensorimotor Stage. This period is from 0 to 2 years of age and reflects the
time in which infants explore their world via their congenital reflexes. This stage
marks the development of spatial abilities and schemes about the world are initiated
through differentiation of the congenital reflexes.

Preoperational Stage. This period is from 2 to 7 years of age. This stage
marks the phase where the child learns language and thus, symbolic thinking. It is in
this stage that the child also has an inability to understand that others may have a
different viewpoint to themselves. Older children in this phase will start to develop
the skill of solving problems but will have difficulty following logical consequences.

Concrete Operational Stage. This period is from 7 to 11 years of age. It is the
period marked by the appropriate use of logic and thus the ability to solve problems
logically that apply to objects or events. The child may not be able to understand
abstract or hypothetical ideas. Other concepts such as reversibility are also understood within this phase.

Formal Operational Stage. The final period of this cognitive development theory commences at around the age of 12 and continues into adulthood. It is marked by an ability to think abstractly. The child is able to make decisions and problem solve on information that may or may not be available.

Whilst this was a brief review of Piaget’s theory, given the enormity of its impact as a fundamental child development theory, Piaget’s work has become the foundation for others such as Bibace and Walsh (1980) and Koopman et al. (2008) to build upon, adding further to the topic of children’s developmental knowledge about illness. These authors have undertaken work which has supported Piaget’s theory in that the development of illness concepts is consistent with cognitive development. That is, the progression of understanding illness follows the perceptual development of the child from that of personal causation to a symptom related view as they get older. Using Bibace and Walsh’s theory, Koopman et al. (2008) propose the “Through the Eyes of a Child” (TEC) Model.

Through the Eyes of a Child.

Koopman et al. (2008) term the first phase of the model the invisible. This phase refers to children’s inability to consider what, why or how they came to be sick or other aspects of the illness, it just is. This phase is similar to Piaget’s first phase of sensorimotor development and Bibace and Walsh’s first phase of incomprehension. Children in this category are usually aged 0-2 years.

The second phase is distance. This phase refers to the illness being defined by an activity external to the child (leaving the window opens makes you get a cold). Any association between the child and the external activity is usually coincidental.
This phase coincides with Piaget’s pre-operational phase and phenomenism phase. Children in this phase are usually aged 2-7 years.

The third phase is *proximity*. This phase is where the child is able to experience the illness in relation to other people, objects and event within the environment. The child develops an understanding that one can get sick from nearby contamination. The child may also view themselves as a victim of their environment that they have no control over. This phase is also with Piaget’s preoperational phase and is also consistent with Bibace and Walsh’s contagion phase. Children are still aged 2-7 years.

The fourth phase referred to as *contact*. Children in this phase are aware that bodily contact can cause illness and that medication can be used to cure illness. The child can not yet distinguish between the mind and the body but is aware of symptoms being associated with illness. This phase is consistent with Piagets concrete operational phase and Bibace and Walsh’s contamination phase. Children in this phase are aged 7-11 years.

The fifth stage which is also within Piaget’s concrete operational stage is *internalization*. This phase is characterised by an understanding that disease can be caused from within the body. It is understood that smoke, germs or other conditions such as obesity have an affect on the body. The child also develops an understanding that actions they take can help to prevent disease. This phase is consistent with Bibace and Walsh’s internalization phase and usually occurs in children aged 7-11 years.

The sixth and seventh stages correspond to Piaget’s highest developmental stage of thinking, the formal operational phase. Termed as the *body inside* phase the child is able to explain illness symptoms in relation to organs within the body, even though they are not directly visible structures. The awareness of having some control
over illness outcome continues. In the seventh stage, *body-mind inside*, the child has an awareness that thoughts and feelings can influence body functions and that physiological components can cause the development of disease. Children in these phases are aged 11 year and older.

All the models described above contribute to our understanding of children’s concepts of illness causation and this develops as the child develops and matures. With age, there is a shift from the identification and reliance on external cues to internal body cues. Thus when discussing illness with a child, it must be pitched at their level of development. For example, children below the age of 8 years do not normally have and understanding that the brain is involved in moving the arms and legs, as they think of them as being independent to the rest of the body in this way.

A study by Brewster (1982) examined the relationship between cognitive development and children’s understanding of illness. The results of this study confirmed that children’s understanding is determined largely by cognitive maturation. Concepts related to understanding the cause of illness, necessity of treatment and the role of medical staff were related to developmental ability. Another study by Carson, Gravley and Council (1992) had similar findings. These authors investigated the relationship between children’s age, cognitive-developmental level and conception of illness and how these variables may be related to adjustment. The results indicated that illness concepts are highly correlated with verbal receptive skills, conversation ability and age. Increased cognitive ability and understanding about illness was associated with better pre-hospital adjustment. These results are therefore, supportive of the theoretical models discussed above.

As Bibace and Walsh (1980) state, there are a number of benefits for health professionals in having an awareness of the above theories. When speaking with sick
children health professionals will be able to provided explanations or speak at a level that is more congruent with the child’s level of understanding. It is the clinical experience of these authors that when the child’s beliefs about illness are considered by the health professional, the child is reassured. Secondly, when providing education to children on illness, educators will be able to develop and provide educational strategies and material that are consistent with the child’s developmental status.

However, whilst the above theories contribute to our knowledge of how children come to make sense of illness and its causality, they do not explain the child’s perception or experience of their illness. Eiser (1989) adds that the validity of the “stage” approach described by Piaget and others should be queried. The stage approach to development has been criticised yet theoretically it has been unchallenged. It is not clear how the transition from one stage to another occurs and the theories provide little acknowledgement of experience, social or cultural factors. Eiser (1989) emphasises theories which place an importance on the role of experience and which do not assume such a structural restriction on a child’s cognitive level.

Dixon-Woods et al. (2005) argue that developmental approaches such as Piaget impose ideas as to what a “normal” child should be like and how a “normal” child should act. Such a developmentally orientated approach can be seen to infer that children are viewed as irrational, incompetent, immature and acultural (Dixon-Woods et al. 2005). In this way the traditional view of childhood development has been criticized as it is only one of many possible explanations, rather than the main account. If we consider the new and developing approach discussed earlier in this paper new perspectives and methodologies are required which view childhood development not simply as dependent on a biological construct, but which recognise it as also being socially constructed. Biology is not the sole determinant of the social
state. A socially constructed approach takes into account that people give meaning to the world via their actions and interactions. Childhood is then not viewed as a purely biological phrasing, but can be viewed as more of a cultural phrasing of the early part of the life cycle. Childhood is no longer viewed as a universal state with stable features, but is perceived and experienced differently across different contexts. A core component of this new view is that children are not necessarily passive victims but are active social agents who shape the childhood they experience. In this way children actively contribute to cultural production and change. Children need to be recognised as active and critical consumers of their health care as like adults, children have the ability to socialize and make sense and meaning from their experiences.

More recent work by Piaget (2008) does however, acknowledge that the rate at which a child progresses through development may vary between cultures. Piaget also acknowledges that the average age at which children move through each stage can vary from one social environment to another. Woodgate (2008) also feels that further research is required to facilitate children communicating about the thoughts and feelings associated with their illness, as discovering what children think and feel about their symptoms will assist healthcare professionals provide a more comprehensive treatment approach. The principles behind this new view and approach to childhood illness allow for a greater understanding of the experience of childhood illness to be achieved. Whilst the “dominant frameworks” noted earlier have formulated and informed our understanding of the impact of childhood cancer on the family, they have not necessarily presented a complete understanding of this phenomenon. These approaches have tended to depict children as passive victims of their predicament and have also not allowed for the exploration of the meaning that children may give to their experiences (Dixon-Woods et al. 2005). The need for a
phenomenological approach which investigates the perspectives of those affected by childhood cancer is crucial to developing a thorough understanding of childhood and childhood illness. Dixon-Woods, et al., (2005) proposed that such research into childhood illnesses could reveal a great deal of information about the theoretical development of childhood. While psychological approaches have much to offer it has been dominated by quantitative studies. There is now an emphasis on interpretative approaches to be used as there is now a need for a much more diverse range of research strategies. Woodgate (2008) also agrees that an interpretative approach is necessary as it is a method which informs clinical understanding related to human illness experiences. Thus, the development of a wider field of childhood studies should allow for a new and deeper understanding of the experience of childhood cancer. For example evidence from the “adult” literature in sociology indicates that the experience of illness goes well beyond the experience of physical symptoms. In a study conducted by Bury (1982) with adult rheumatoid arthritis patients, it was revealed that chronic illness can be viewed as a biographical disruption where a person’s biography and self-concept is altered. A small body of work has begun to address this problem and show some of the ways in which children function through their illness, yet this small body of literature stems mostly from a nursing perspective. In regards to this small body of work, it has also tended to focus on the physical symptoms of the disease.

*The Experience of Pain.* Physical symptoms such as pain are obvious features of the experience of childhood cancer (from the child’s perspective). The symptoms of the illness itself along with the aggressive treatment involved are the culprits of causing this pain. Again, there is a large amount of material discussing symptom distress in adults with cancer, but little literature on the symptoms children with
cancer experience. Yet as health care professionals, one of the most important goals in supporting these children and their families is to provide as much symptom relief as possible. Along with pain, sleep disturbance, fatigue, nausea, constipation, fear and anxiety, are all symptoms children can experience as a result of their illness or its treatment. Untreated or treated poorly, these symptoms can lead to a poor quality of life. The symptoms children experience have the ability to affect their emotional, cognitive, social and physical development (Woodgate and Degner, 2003). In their study of symptoms in children with cancer Woodgate and Degner (2003) found that the nursing staff were often unaware of the full range of symptoms the children were experiencing. They also found that the children along with their parents believed that experiencing distress from the symptoms was an inevitable and unavoidable component of the illness and so as a result, may not have attempted to relieve the symptoms. In another study by Hedstrom, Haglund, Skolin and Von Essen (2003) it was found that pain resulting for diagnostic procedures and treatments along with nausea and fatigue were the most difficult symptoms to manage. In another study by Enskar, Carlsson, Golsater and Hamrin (1997), they too found that the physical side effects of the treatment were seen to be the worst components of the disease. These results indicate that research on not only the pain children experience but also the severity and distress caused by the pain is important information to glean so that staff working with the children can respond accordingly. Finally, the qualitative study conducted by Woodgate (2008) noted a number of important themes. This study revealed that children were not only able to describe physical symptoms but how the cancer made them feel overall. The children were also able to describe how they felt via the use of “feeling states”. Determining explanations for their symptoms the
children were able to distinguish normal, everyday-type symptoms and were able to identify odd symptoms which seemed to occur for no reason.

*A disrupted life.* There is also evidence to suggest that the level of pain experienced by the children is congruent to the emotional difficulties experienced (Varni, Burwinkle, and Katz, 2004). There is still a need to identify the emotional responses to such a stressful life event. Previous research has indicated that the emotional difficulties children can experience pertain to confinement, feeling alienated and worrying about medical procedures (Hedstrom et al. 2003). Other emotional difficulties can pertain to the disruption of social relationships such as friendships and participating in normal activities. Returning and integrating back into school-life after extensive periods of time away can also be difficult. In a small qualitative study conducted by Fraser (2003) results varied. Some children reported that their friendships were maintained throughout the period of their illness while others reported that they felt isolated and lonely as they were rejected and stigmatized. Their appearance and the length of time that they had had away from school were factors influencing the isolation and loneliness they felt. Some of the older children who participated in the Hedstrom et al., (2003) study also expressed concern about the change in their appearance. Results such as these suggest that children may experience important changes in their identity as a result of their cancer experience. It is these changes in identity which appear to so far, threaten and have detrimental effects on their persona and self-image.

*Conclusion*

Prior to the 1970’s most children who were diagnosed with a form of childhood cancer died. As a result the psychosocial care of these children and their families was dominated by a grief and loss model which almost certainly predicted
parental psychopathology. With the significant advancement in medical treatment occurring over the last few decades the focus and type of psychosocial care provided to these children and their families has changed significantly to that of helping families cope in the midst of a life-changing crisis. Theoretical frameworks have been developed to explain how families and individuals cope with adversity with two of these being the The Resiliency Model of Family Adjustment and Adaptation (McCubbin and McCubbin, 1993, 1996) and the Stress and Coping Model (Lazarus and Folkman, 1984). Whilst these theories have provided great insight into how families and individuals cope in the face of adversity they have been formulated from research which has relied on the categorisation of responses and have relied on “adult” or parental data alone to document family coping.

To date a small body of research has been conducted which extends beyond the current boundaries defined by the theoretical frameworks noted above. Children have begun to be seen as individuals in their own right and are now viewed as being able to provide insight into their own experiences. Parents own experiences of caring for a child with cancer are now also being considered as they play a crucial role in coming to terms with their “new identity” as a parent of a sick child, developing a relationship with the staff and negotiating the care of their child. This research has also allowed for unique and individual experiences to be recorded and explored and has enabled an open-minded and interdisciplinary approach to examine in close-up, the experience of childhood cancer. As a result both the “altered identity” of the parent and the child has been revealed.

The Current Study

The current research encompasses several important components to overcome some of the limitations posed by previous research and add to the emerging body of
research examining childhood cancer. The current study will draw upon the models previously reviewed with a view to gaining an understanding of the experiences parents and children endure as they live through the vulnerabilities and life-threatening component of the illness. The study will explicate the ways in which both parents and children make sense of their experience. Using a semi-structured interview, transcripts will be derived from both parents and children. Experiential information will be collected at two points in time (T1 and T2) to capture changes across time. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) will be used. This particular methodology was chosen as it focuses on understanding the phenomena in question; the experience of having cancer from the perspective of the child and the experience of being a parent of a child with cancer. IPA is an approach which enables the fine-grained analysis of the phenomenon under investigation and so aims to understand the phenomenon from the participants’ unique frame of reference, hence, the individual’s lifeworld.

To clarify the demographics of the sample population, variables such as marital relationship satisfaction, family coping, family communication, parental stress, child coping and child quality of life will also be measured to determine their impact, if any, on the experiences of the child and family. Due to its descriptive nature and emphasis on following a qualitative methodology the proposed research does not contain a specific hypothesis but several aims which are to be investigated. These aims are:

1. Explicate the parent’s experience of having a child diagnosed with cancer, a potentially life-threatening illness.
2. Explicate the child’s experience of living with cancer.
3 Explicate any changes that may occur over time which influence the experience of either the parents or child participants, regarding their perspective on managing or living with cancer.

4 Examine the ways in which the findings support and contribute to current theories of family coping and the experience of childhood illness in the context of cancer.
Methodology

Development of Qualitative Research in Psychology

Since as early as the nineteenth century research psychologists have supported the notion of the objective measurement and identification of psychological variables with statistical associations as a primary research method (Murray and Chamberlain, 1999). This empirical approach is consistent with the biomedical model, to which modern medicine has attributed many of its successes. That is, improvements in health and longevity have been credited to the improvements in medical science. It is this achievement of biomedicine however, that some feel has also been somewhat overestimated (Yardley, 1997). An alternative model of understanding health and illness has been introduced through social medicine. In 1970’s the application of behavioural principles to health problems was introduced, which ultimately gave rise to the discipline of “behavioural medicine”. It is from here that health psychology emerged and the development of a new model, one which incorporated the biological, psychological and social aspects of illness was formed resulting in the “biopsychosocial model” (Yardley, 1997).

Health psychology initially followed the methods of mainstream psychology adhering to the emphasis of the measurement of persons, comparisons of groups and statistical analyses (Lyons and Chamberlain, 2006). Whilst qualitative methods had long been used in other forms of health research such as nursing and the social sciences, it has only been in the past 10 years or so that qualitative methods have gained acceptance within health psychology. Over this time the legitimacy and adequacy of quantitative methods within psychology has begun to be questioned. Health psychology as a discipline has included the individual in the health equation integrating biological, psychological and social aspects of health and illness. In this
way health psychology research has lent itself to a different type of research question. Rather than comparing groups and categorizing behaviours much of health psychology research has concerned itself with the meanings associated with health and illness and the lived experience of these constructs from the individual’s perspective. In this way insight can be gained into the individual’s lived experience of health and illness, a task not easily achieved via quantitative methods.

Benefits of Qualitative Research

The last decade has seen a shift in psychological research from what was once an almost exclusive use of an empirical research methodology of quantitative inquiry, to regularly using a qualitative inquiry or a mixed-methodology (e.g. both of these methods). Qualitative approaches reject predefined categories or hypothesis testing as reflected in questionnaire research as the focus is on trying to understand the lived experience of participants. In this way qualitative approaches are particularly useful when the topic of research is complex, novel or under-researched as it leaves the results open to the possibility of unexpected findings, rather than predicting an expected outcome as is often the case for quantitative research.

The use of qualitative approaches involves the detailed exploration and analysis of a particular topic whereas quantitative approaches more often then not, employ a number of measures to summarise specific and isolated variables at particular points in time. That is, quantitative research is concerned with counting occurrences or volumes whilst qualitative research attempts to provide rich descriptions of the particular phenomena under investigation via a small sample (Smith and Dunworth, 2003). In this way qualitative methodologies have a number of desirable attributes that are not prominent features of quantitative methods (Yardley, 2000). Quantitative research is also exploratory and pays close attention to unique
variation, interpersonal issues, meaning, context and culture and is carried out in order to answer scientific questions that differ from those of quantitative research. Nevertheless, qualitative methodologies genuinely offer a complimentary set of investigative approaches which can bring fresh insight into the research domain of health and illness (Yardley, 2000). Ultimately, the value of any scientific method must be evaluated in its ability to provide meaningful and useful answers to the questions that motivated the research in the beginning (Elliott, Fischer and Rennie, 1999).

Eiser and Morse (2001) note a number of contributing factors which favour the use of a qualitative methodology. Children, particularly young children, may not have the cognitive skills necessary to generate a response to a questionnaire which they then have to translate to fit into a category on a given response scale. This skill requires children to process the question or statement, retrieve the relevant information from memory and then provide an answer to fit into a particular format which may be difficult for young children. Secondly, research has shown that children commonly provide extreme responses when presented with response scale data as they are less likely to question items on the scale. As a result, quantitative data collected from children are more susceptible to response bias. Thirdly, the type of response scale used and the number of response items provided can influence the way in which a child self-reports. Thus, two questionnaires which have the same purpose may yield different responses dependent on their response scale. Fourth and finally, terminology in response scales such as “frequently” and “occasionally” can be interpreted differently between interviewees and for different types of behaviours (Eiser and Morse, 2001).
Other advantages of using qualitative methodologies include open, exploratory questions versus closed-ended hypotheses, unlimited and emergent descriptions versus predetermined choices or rating scales and the possibility of discovering new conditions or phenomena as opposed to confirming what was hypothesised (Elliott and Timulak, 2005). A qualitative inquiry is also useful when there is little known about a particular research area or when a research topic is highly complex. The current study fulfils both of these requirements.

*Choosing a Qualitative Methodology*

Qualitative research includes a diverse range of approaches. Some of these include phenomenology, grounded theory, discourse analysis, conversation analysis, ethnography and interpretative phenomenological analysis (IPA) to name just a few. Commonalities among these qualitative methodologies exist as the central purpose of all of them is to enrich our understanding of the phenomena in question, yet they have each developed their own theoretical and methodological approaches (Elliott et al. 1999). For example phenomenology is concerned with exploring the life-world of the participant or with understanding how participants make sense of particular experiences, whereas discourse analysis and conversational analysis are concerned with describing the linguistic resources participants use during conversations, the patterns these conversations take and the social interaction performed during them. When choosing a qualitative methodology it is thus important to consider a number of important issues. What is it that the researcher wants to discover about a particular phenomenon? What kind of data collection is required? Such questions as these are crucial to consider before choosing the particular qualitative analytical tool to be used (Shaw, 2001).
Phenomenology as a Qualitative Research Method

The aim of phenomenology is to “describe the experience as it is lived by the people” (Crotty, 1996). That is, phenomenology attempts to gain an understanding of the experience as understood from the individuals’ perspective, frame of reference or point of view. In research, the phenomenon is the topic studied by the researcher and is the topic described by the participants in the study. Phenomenology requires gaining access to the phenomena and achieving a thorough understanding and full elaboration of the phenomenon, to make its meaning or “essence” clear. The task of phenomenology is to identify the subjective experience, describe it and thus understand it. To achieve such a goal a phenomenological method of inquiry involves a mode of data collection and analysis that will present the participants’ experiences precisely from their particular perspective. Thus, a phenomenological philosophy lends itself to being a qualitative method of inquiry.

Husserl (1859 - 1938) is a central figure in developing phenomenology as a philosophical movement (Ashworth, 2003). The core philosophical basis of Husserl’s approach was a rejection that there is anything more fundamental than experience. In this way Husserl defined experience as a “system of interrelated meanings that are bound up in a totality of the “lifeworld”. Husserl argued that scientific approaches are inappropriate as human meanings are the key to studying lived experiences, as opposed to causal variables. Phenomenological psychology is consistent with this approach as it follows the belief that it is a whole set of factors that lead to differences in people’s perception of reality and so is committed to the exploration of individual lived experience (Smith and Dunworth, 2003). A number of qualitative approaches have since used phenomenology as a basis for their own development, and so are in debt to Husserl for his initial work.
Philosophical issues in phenomenology. The aim of phenomenological research is to understand and explicate the experiences of participants (the phenomena) as they are encountered, engaged and lived through their experience. The researcher works toward understanding the phenomena in question based as much as possible, on the perspective of the participants being studied. However it is impossible to put aside completely, one’s own perspective and interpretation. It is crucial that a researcher undertaking qualitative research minimises the affect that their own values and knowledge of the topic or existing theories has on participants’ responses. To allow participants to construct and give meaning to their own reality researchers attempt to put aside any prior knowledge or theories including their own preconceived ideas, beliefs and judgements. When researchers can avoid imposing preconceptions on the collection of data, only then can subjective data from the participant be more fully appreciated (Crotty, 1996). Bracketing is the term given then, to this “laying aside” of the researchers’ everyday perceptions or previous knowledge of the topic. Bracketing involves researchers’ reflecting on their past and current experiences so as to keep the meaning of their own personal experiences separate from those revealed by the participants. Fresh meaning can then be attributed to the phenomena being studied (Crotty, 1996) as the researcher is then able to understand and represent their informants’ experiences more adequately (Elliott et al. 1999).

Intentionality is another key notion of the phenomenological approach. Intentionality is the “essence of consciousness” (Giorgi and Giorgi, 2003). It means that our consciousness is always directed toward some other “world”. In this way intentionality does not have the same meaning as that which can be attributed to its everyday use being that of “deliberate” or “goal-orientated”, but refers to acts of
consciousness toward objects, which transcend the acts themselves. These “acts of consciousness” are then communicated to the world by description.

**Philosophical assumptions of IPA.** Smith (1996) notes that two very important theoretical touchstones form this particular qualitative methodology which are phenomenology and symbolic interactionism. These concepts stem from beliefs that human beings are not bystanders in an objective reality but are beings which formulate their own biographical stories by interpreting and understanding the world around them in a way that makes sense to them (Brocki and Wearden, 2006).

Phenomenological psychology is where an individual’s personal account of an object or event is used to produce a subjective view, as opposed to producing an objective statement of the object or event (Smith, Jarman and Osbourne, 1999). That is, it is phenomenological in the way that it is concerned with individual’s subjective experiences rather than formulation of objective accounts. Symbolic interactionism believes that the meanings individuals ascribe to events should be of central importance to the social scientist but also notes that these meanings are only obtained through a process of interpretation. That is, the way people perceive an experience is reflected directly in how they talk about and behave in relation to the event (Dean, Smith and Payne, 2006). It also implies that meanings occur and are made sense of as a result of social interactions (Smith, 1996). Meanings are said to occur as a result of social interaction. Therefore, the aim of IPA is to understand the participant’s view of the world and associated cognitions, to gain an “insider’s perspective” of the phenomena in question. With phenomenology as its basis IPA explores in detail how participants have made sense of their experiences, by examining their accounts of their experiences which assumes an existing inclination towards self-reflection. In this
way IPA focuses on the exploration of participant’s experiences, understandings, perceptions and views (Brocki and Wearden, 2006).

IPA notes that one can not get access to the participant’s personal world without the use of the researcher or interpreter. That is, access is dependent on the researcher’s ability to conceptualise and make sense of the participant’s personal world through a process of interpretative activity. Smith and Osborn (2003) state that the interpretative process can occur at different levels. The first level requires the participant to offer their interpretation of the phenomenon and associated cognitions and meanings via their language. The second level of interpretation occurs when the researcher attempts to understand the participant’s comments. Interpretation however, can be influenced by the participants’ abilities to verbalise and articulate their thoughts and experiences appropriately and thus, by the researcher’s ability to interpret and analyse. Access to the participants’ world is also influenced by the researcher’s own conceptions as the researcher attempts to “assess” the participants’ personal experiences. This process of “interpretative activity” is required in order to make sense of and understand the participants’ personal world (Brocki and Wearden, 2006).

*Description of IPA.* IPA essentially focuses on understanding an individual’s lived experience (Shaw, 2001) and how participants make sense of that personal experience (Smith, 2004). It is phenomenological as it is concerned with individuals’ perceptions of objects or events which as in the case of this study include participants’ responses to managing and living with a potentially life-threatening illness. It is interpretative as gaining access to the individual’s world depends on and is complicated by the researcher’s own preconceived ideas. Such interpretation is necessary however, to make sense of the “other’s personal world, and hence adds the
interpretive component to IPA (Smith, 2004). While the participant is trying to make sense of their personal world, the researcher is trying to make sense of the participant trying to make sense of their personal world. In this way IPA uses in-depth qualitative analyses and a process of explication to examine cognitive processes.

In order to produce a detailed account of the phenomenon in question, IPA may incorporate a variety of research designs. In terms of data collection IPA includes semi-structured interviews, focus groups, participant diaries and self-reporting tasks. Semi-structured interviews however, have been the exemplary method of conducting IPA and most of the research using IPA has indeed employed this method of data collection (Smith and Osborn, 2003). Employing semi-structured interviews as a data collection method maintains the aims of IPA as this method allows for the interviewees to be the “primary experts” on the material in question. Whilst semi-structured interviews still make use of an interview schedule, interview questions are open-ended and a non-directive style is used in the interview. In this way the interview schedule is used to facilitate participants to “tell their story” in their own way, a core component of IPA. Occasionally prompt questions may be used to facilitate further disclosure from the participant. However, in keeping with the principles of IPA minimal probes should be used and the effect that the interview has on the participant should be noted.

As noted earlier the primary researcher plays a significant role in the explication process. The researcher is required to make sense of the data by engaging in an interpretative relationship with the transcript. Through this process the researcher comes to understand the participant’s world. The researcher is able to identify the meaning/s behind the participants’ experiences and does so by dividing the text into “meaning units” (Smith and Osborn, 2003). By dividing the text into
meaning units the researcher is then able to identify commonalties, differences and contradictions not only for a single participant, but across a number of participants all describing the same phenomena. The researcher should then be able to reveal the main themes that have emerged from the meaning units identified. The final analysis of the participants’ experiences can then be constructed into a detailed interpretative analysis of themes.

Brocki and Wearden (2006) emphasise that this process of analysis is not merely the categorisation of data. Smith (1999) indicates that analysis requires close interaction between the researcher and the text as the researcher attempts to comprehend the presented account whilst at the same time, using their own “interpretative resources”. Smith (2004) goes on to say that the quality of the final analysis is determined by the level of personal analytic work done at each stage of the analytical process. In the current study I will refer to the analytic stage as explication to highlight that the process focuses upon making meaning explicit.

**Characteristics of IPA.** Smith (2004) describes three characteristic features of IPA: it is **idiographic, inductive and interrogative**. IPA is **idiographic** in the sense that it starts with the detailed examination of one case or participant until some degree of saturation has been achieved, before the analyst moves on to a second case. This process continues until all cases in the research have been examined. When all cases have been examined, only then can the researcher conduct cross-case analysis on the meaning-units and themes of each individual case for convergence and divergence. Smith (2004) recommends analysis of this type on a small sample size with a sample of 5-10 being a good example. The researcher should then have been able to achieve two important goals associated with IPA which is to allow the reader to see clearly the themes which have emerged which the participant’s share, in addition to learning
something about the life world of the particular participant’s who have told of their experience.

IPA is inductive (like many other qualitative methodologies) as it involves techniques which allow for unanticipated or unpredicted themes to emerge during analysis. Thus, IPA does not involve generating specific hypotheses based on the extant literature but rather generates broad research questions which then lend themselves to the collection of expansive data. Smith (2004) states that IPA can be most exciting to uncover the unexpected while engaged with the material.

IPA is interrogative as one of its central aims is to contribute to the existing body of literature, similar to mainstream psychology. Even though IPA involves in-depth analysis of small sample sizes, the results can be discussed in relation to the broader extant psychological literature.

Critique of IPA

One of the advantages of IPA is its ability to unveil phenomena that might not be expected. That is, quite often research projects commence with a predetermined set of hypotheses that the researchers wish to confirm or refute. However, as consistent with most qualitative methodologies, the data collection methods used in IPA often lend themselves to being more flexible and open-ended, with participants being able to discuss aspects of their experience that the researcher might not expect. As a result IPA has the ability to uncover phenomena that may not have been previously identified by researchers or present in the existing theories (Shaw, 2001). In this way IPA can be referred to as data-driven rather than theory-driven. If new data is unveiled then it can be added to pre-existing theories to extend them further or used as the basis of a new theory, which is highly beneficial as it has been established from those experiencing the phenomena. Added to this flexible, open-ended approach, IPA
allows the researcher to be more open-minded in addition to enabling the participants to tell their stories in their own way without being biased by any preconceived ideas by the research itself.

IPA also has the capacity to reveal experiences that are unique to the individual as well as reveal the shared experiences across a sample of participants. In this way IPA can pull out the subjective unshared aspects of experience in addition to those which are shared within the sub-culture of the sample being studied.

IPA does however involve the researcher playing an active role as they are required to make sense of the data collected. The researcher begins by reading over the information that has been provided by the participants, the accounts of their experiences, to identify the meaning units and themes. Reading over the data in this way can be time consuming. In identifying the themes and extending beyond this to code and explicate the data, the researcher must also constantly monitor themself. It is crucial that the researcher does not bias the data by interpreting more than what the participants have provided. The researcher must continually return to the original participants’ accounts to ensure they are themed and coded as the participants’ intended. Thus, this method of analysis involves careful and detailed analysis on behalf of the investigator.

Benefits of the Semi-Structured Interview

To gain an understanding of the meanings attributed to particular experiences in the real world qualitative researchers employ data collection methods conducive to collecting verbal data elicited through an interview. This is consistent with a phenomenological approach where the emphasis is on attempting to understand the psychological conceptions of participants (Smith, 1995). The use of the semi-structured interview is particularly useful to gain a detailed picture of participants’
beliefs, perceptions or accounts of a particular topic (Smith, 1995). The semi-structured interview provides the researcher with much greater flexibility than a questionnaire/survey or even a structured interview as it allows the researcher to follow up avenues presented by the participant that might not otherwise have emerged. In this way Smith (1995) describes a “natural fit” between the semi-structured interview and the purpose of qualitative analysis as a great amount of detail is provided via a verbatim interview.

In an interview it is assumed that the material a participant provides has some significance for them. The material they provide is a manifestation of their psychological world as the material provided is consistent with their world view. The researcher is interested in this psychological world and it is this approach that can be described as adopting a phenomenological perspective (Smith, 1995). Additionally, semi-structured interviews and qualitative analysis are particularly suited to research complex, controversial or personal issues.

Consistent with the phenomenological approach semi-structured interviews benefit from having an interview schedule but one which does not require to be strictly followed. This format then allows the interview to be guided by the participant rather than the schedule. The researcher is free to probe emerging areas that arise or follow the participants’ interests or concerns as following the order of the questions is less important. While the researcher has an idea of areas and questions they would like investigated, there is a desire to enter the psychological and social world of the respondent and as a result the participant will take part in guiding the direction of the interview as they discuss issues they feel are relevant or important to them.

The current study will make use of the qualitative data collection method of the semi-structured interview. However, in keeping with the general purpose of IPA it
will only be used as a guide to generate potential topics of interest. Participants will then have control over the direction of the interview and will be free to discuss issues they feel are important. As the topic of the current study concerns discussing very sensitive material, children being diagnosed with a potentially life-threatening illness, the use of the semi-structured interview will allow for such material to be collected and it is an approach which will allow participants to discuss their personal experiences in a way they are comfortable with.

*Rationale for IPA in Health Research.*

The vast majority of published work using IPA has been in the field of health psychology. This can be attributed to health psychologists becoming more aware of and wanting to be more informed about patients’ perceptions and interpretation of their health and illness experiences, and the meanings that are assigned to these experiences.

A fundamental premise of health psychology is the assumption that people think about their bodies and the experiences related to their bodies, and verbalise their thoughts about it. For example, if one were to give a diabetic patient a questionnaire about their illness, we could safely assume that the responses would be based on that patient’s cognitions about their physical condition and its impact on them. Thus, the methodology employed via IPA places it in a good position to understand a patient’s perception of their body and health status without being confined to the likert-scale categories often imposed by a questionnaire or survey. Another example may be to examine different accounts of the same physical process. That is, through the use of IPA an investigator would be able to focus on two patients’ perceptions and experience of the exact same illness. In this way IPA would prove very useful in gaining a detailed understanding of an individual’s response to dealing with a life-
threatening or chronic illness. IPA allows us to explore and understand these subjective experiences and thus, provides us with the invaluable insight into the participants’ experiences and how they have made sense of them.

In the past health psychology has typically made use of quantitative research approaches which simply do not allow for such detail and in depth information to be collected for research purposes. Research which is less concerned with “cause and effect” and more interested in exploring meaning and context would certainly benefit from an IPA approach. IPA is particularly relevant to health related research as it is a methodology which accentuates hearing about others’ illness narratives. This provides us with an exceptional method of learning about other people’s lives and experiences. Furthermore, as illnesses often occur and extend over periods of time (Brocki and Wearden, 2006) it is a methodology which allows for experiences over time to be captured. Qualitative research therefore has the potential to enrich the existing body of research in health psychology (Smith, 1996).

In relation to the current study the focus will be on drawing out the experiences of parents and children where the child has a diagnosis of cancer. Parents’ perceptions, understandings and views on what it is like to be the parent of a child with cancer and support their child whilst they undertake extensive and invasive treatment will be examined. How they have made sense of this experience and the meanings they ascribe to it will be explored. Children’s perceptions of their own illness will also be examined along with the associated meanings. As the researcher I will attempt to understand and interpret these experiences from both the parents and children, in an unbiased manner.
Validity of Qualitative Data

It is impossible to judge the validity and reliability of qualitative research within the traditional framework such as that of quantitative research. Yet it is still important to review the validity and quality of qualitative research but by specific criteria which are appropriate to it (Smith, and Dunworth, 2003). No single set of factors has yet been established as being definitive in evaluating qualitative research however, the suggestions that have been noted in the literature by various authors (Elliott., et al. 1999; Yardley, 2000) do contain a considerable amount of overlap. It is also important to remember that the suggestions that have been presented to assess the validity of qualitative data are in the form of guidelines only and so have not been designed to be used rigidly with a strict adherence to them. Slight variation in how the guidelines are followed is expected as they will fit differently with the different qualitative approaches. Before going any further it is important to clarify why documentation of the validity and rigour of qualitative research is necessary. Firstly, as qualitative research is still in its infancy stage it is important to legitimize it as a research tool to reassure traditional quantitative researchers that qualitative research is methodologically rigorous. Secondly, it is not uncommon for qualitative research to be evaluated via the standards of quantitative research and so in these cases criteria has been applied which does not do qualitative research justice. In the same way, qualitative criteria central to the qualitative research tradition may not be applied at times that it should be, making it difficult for qualitative research to be evaluated appropriately. Thus, it seems that guidelines which assist in not only the conduct but also the publishability of qualitative research would be very useful. Researchers should then be able to address how they have met the intentions of the guidelines or provide rationale for meeting alternative standards (Elliott et al. 1999).
Although the following set of guidelines are by no means all-inclusive or
definitive they can be used as a guide with which qualitative researchers can aim to reach:

1. Owning one’s perspective: The authors of the research are required to make clear their own personal beliefs and assumptions and theoretical orientation, both in advance and as they become apparent during the research. The authors recognise their own values, interests and assumptions and the role that these play in understanding the phenomenon. This disclosure then allows the reader to interpret the data with greater ease, and consider possible alternatives.

2. Situating the sample: The demographics of the sample are described along with the life circumstance or experience to which they are being investigated/interviewed, to allow the reader to understand who the findings of the research may be relevant to.

3. Grounding in examples: In writing up the results of the study it is necessary to provide examples of each theme or category that has formed. This allows the reader to see the fit between the data and the authors understanding of it, in addition to allowing the reader to conceptualise possible alternative meanings and understandings.

4. Providing credibility checks: To check the credibility of the categories or themes the author feels has evolved from the data, they could be checked with the original informants for clarity, multiple qualitative analysts could be used to review the data for discrepancies or errors, comparing two or more varied perspectives or “triangulation” with external factors or quantitative data.
5. Coherence: The data is integrated in such a way that it is easy for the reader to see how categories have been organised, titled and sub-titled. This structure allows the different aspects of the phenomenon in question to be easily seen.

6. Accomplishing general versus specific research tasks: The author needs to acknowledge the limitations of the findings. If a general understanding of a particular phenomenon is intended, then it has been based on a sufficient range of instances, where as if a specific instance or case is the goal, then it needs to have been studied and described comprehensively enough to provide the reader with a detailed analysis of the phenomenon in question.

7. Resonating with readers: The material is presented in such a way that once readers or reviewers have taken all other guidelines into account, they deem it to accurately represent the subject matter and that their understanding of the phenomenon in question has been clarified or expanded upon.

There has been some concern that codifying principles stipulating good qualitative research will impose restrictions on such an emerging and rich research methodology. Hence, it is important to remember that it is not the intent of the above guidelines to be used as a rigid checklist, but as a means of guiding qualitative approaches which then credits them as being rigorous and robust. Having some form of widely-recognised evaluative guidelines for qualitative research can then only add to its acceptability as a psychological inquiry.

In their critical evaluation of studies using IPA as the main methodology Brocki and Wearden (2006) note a number of different measures undertaken to ensure validity. Some papers had analyses checked and interpreted by other academics or
professionals either involved in the research or independent of it. In other cases transcripts were analysed by a number of researchers initially and then a joint thematic framework was agreed upon. Additionally, some researchers asked for feedback from the participants on the preliminary interpretations. Yardley (2000) argues however, that as the purpose of qualitative research is to produce just one of many possible interpretations, reliability may be an inappropriate criteria against which to measure qualitative research. This approach is consistent with IPA’s recognition of the interactive and dynamic role of the researcher. In this way the aim of validity checks is thus, not to produce a “singular true” account of the data presented but to ensure the credibility of the themes produced (Brocki and Wearden, 2006). It is also recognised that IPA is subjective as a qualitative research approach as it is unlikely that any two researchers analysing the same data will come up with the exact same codes and themes.

Whilst IPA assumes that there is no correct sample size, as an idiographic approach, this traditionally reflects a small sample size as being the norm. Large sample sets are associated with risk of potentially losing subtle reflections of meaning. The purpose of qualitative research in general is to produce in-depth analyses of a small group’s accounts rather than representative samples. With its idiographic approach IPA in particular focuses on establishing levels of analysis which enable us to see patterns emerging across the cases but which also allows us to note the particular intricacies of individual cases. Smith (1999) indicates that research of this nature should be judged in terms of how illuminating it is of the particular participant cases at the “micro-level” and should be richly informative of those particular participants as individuals. In this way qualitative research can advance research via the use of “a series of detailed, small-scale studies which acquire specific
and deep knowledge. Whilst broad generalizations to other populations may then not be possible, the data may still be useful in providing some insights to other phenomena. Conclusions drawn are then particular to that group and any generalisations made should proceed with caution. At the same time however, whilst IPA may not strive for generalisability it should not only consist of the retelling of participants’ accounts. The inductive nature of IPA must be used to discuss the analysis in the light of the already existing theories or knowledge on the phenomena in question.

Validating My Own Research

Any theoretical assumptions I may have had prior to commencing this study would have stemmed from the theoretical model’s noted in the literature review. The Resiliency Model of Family Adjustment and Adaptation (McCubbin and McCubbin, 1993, 1996) offers an explanation as to why some families recover and so appear to be resilient, when other families appear vulnerable and deteriorate under the same circumstances of adversity. This model has been developed from much of the pre-existing literature on family transitions, and adjustment in the context of a crisis. The assumptions which underpin this model dictate that it is natural for families to experience difficulties as part of family life and that family’s develop methods of living which enhance growth and development of the family unit. The assumptions also indicate that families have methods of coping which they draw upon to protect the family from stressors and that some of the protectors families use are drawn upon from the surrounding community and relationships with others e.g. family/friendships. Finally, the model also assumes that families work to restore order in the midst of a crisis.
The other theoretical orientation relevant to this research, which I am familiar with is the Lazarus and Folkman (1984) Stress and Coping Model which dictates two primary types of coping: problem-focused coping and emotion-focused coping. Problem-focused coping refers to physical acts individuals may do to improve their situation where as emotion-focused coping refers to the thoughts or cognitive processes individuals may experience related to the stressor that may impact upon their relationship with the crisis situation. This may then lead onto the process of making meaning and finding some sense out of the experience which is thought to aid adjustment to it.

From my own personal anticipations or assumptions, I would tend to think that those families who adjust “well” to having a child diagnosed with cancer would be those who demonstrate qualities such as clear communication, organisation and flexibility within the family unit. I feel that attributing meaning, even in a spiritual sense, to the event will also aid in coming to terms with such a crisis situation. I feel that having values and priorities related to family functioning and life purpose which are not materialistic in nature will also aid in understanding and managing the crisis. These beliefs have more then likely developed as a result of my own life experiences, as I am not yet a parent, let alone a parent of a child with cancer.

Conclusion

If the purpose of a research piece is to understand an individual’s experience, then IPA would certainly be one qualitative methodology to consider. Through the use of IPA in-depth accounts of an individual’s experience and gaining greater insight into the lived experience of that individual can be achieved. For example, when the focus of research surrounds a notion such as “quality of life”, then a method of psychological inquiry such as IPA which can delve into and gain access to such rich
and diverse data would be necessary (Shaw, 2001). In this way how one makes sense of their experience and attributes meaning to certain events in their life can be unveiled. IPA provides psychological research with a rich understanding of human experience and along with other qualitative methodologies, can then be used to inform health care policy and practice. More importantly, IPA may be able to enrich an area previously only studied through quantitative measures.
Method

Introduction

This chapter describes the process of conducting the study. The chapter commences by describing how ethical approval for the research to take place was sought. Participant criteria and demographics are described. The construction of the semi-structured interview is outlined along with how participants were recruited. The initial meeting with participants and the format of collecting data are also outlined. In view of the sensitive nature of the study, reference is made to the measures taken to ensure the welfare of the participants was protected at all times. This includes describing the measures undertaken in conducting the interview. An outline of both the quantitative and qualitative data administered is provided and finally a description of the process followed in explicating the qualitative data is also included.

Participants

Ethical approval. Ethical approval for this study to take place was sought in 2006. The process involved meeting with the then, Head Consultant Oncologist of the Paediatric Haematology Oncology Unit of the Mater Children’s Hospital, Brisbane, Australia. As a result of these discussions a submission was made to the Mater Health Services Human Research Ethics Committee (HREC) in June 2006. In August 2006 full approval for the study to commence was received by the Mater Health Services HREC. Upon gaining ethical approval from the Mater Children’s Hospital ethical approval was sought and gained from the Queensland University of Technology’s ethical committee.
Participant criteria. Participants were identified from the Paediatric Haematology Oncology Unit of the Mater Children’s Hospital. Potential participants were required to meet the following inclusion criteria:

1. Children were required to have received a formal diagnosis of cancer post January 2005.
2. The child with cancer and the parent/s of the child were required to provide informed consent and assent.
3. The child and parent participants were within the normal range of intelligence.
4. Child and parent participants were required to be English speaking.
5. Child participants were aged between 8-17 years.

Sample demographics. Data collection commenced in October 2006 and continued to January 2008. Nine families were recruited and agreed to participate. Diagnoses of the nine child participants included: Leukaemia (2); Hodgkin’s Lymphoma (2); Langerhans Cell Histiocytosis (1); Medulloblastoma (2); Non-Hodgkin’s Lymphoma (1) and a non-malignant brain tumour (1). Diagnoses dates ranged from January 2005 to May 2007. As the date of the diagnosis and type of cancer ranged considerably, there was also great variation regarding the treatment stage children were up to at the point of initial contact. At the point of initial contact 5 children were actively receiving treatment (usually chemotherapy), 3 children were undertaking maintenance measures and one child had not yet commenced any treatment but was being monitored only. Child participants were aged between 8 and 16 years of age with the average age being 11.89 years. Please see Table 1.
Table 1.

Child Participant Demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timothy</td>
<td>8</td>
</tr>
<tr>
<td>Chloe</td>
<td>8</td>
</tr>
<tr>
<td>Erica</td>
<td>9</td>
</tr>
<tr>
<td>Brian</td>
<td>10</td>
</tr>
<tr>
<td>Craig</td>
<td>12</td>
</tr>
<tr>
<td>Letitia</td>
<td>14</td>
</tr>
<tr>
<td>Annie</td>
<td>15</td>
</tr>
<tr>
<td>Jake</td>
<td>15</td>
</tr>
<tr>
<td>Jarrod</td>
<td>16</td>
</tr>
</tbody>
</table>

A total of 9 mothers and 2 fathers participated in the data collection. Parents ranged in age from 36 to 57 years with the average age being 44 years. One mother was a full-time stay at home parent whilst all other parents were employed. At the time of the initial data collection point 5 out of the 9 mothers who were employed had reduced their working hours to part-time as a result of their child’s diagnosis and treatment. One out of the 9 mothers had stopped working altogether and one out of the 8 mothers had transferred her employment from the family’s home town in the country to Brisbane city. One out of the 9 mother’s did not have her employment affected as she worked from home. One out of the 9 mother’s did not have her work status affected as she was a stay-at-home Mum. Both the 2 fathers who participated in
the study initially worked full-time but had to reduce their hours of work due to their
child’s illness. Please see Table 2.

Table 2
Parent Participant Demographics

<table>
<thead>
<tr>
<th>Wife</th>
<th>Husband</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sonia, 36 years</td>
<td>Alex, 37 years</td>
<td>Timothy</td>
</tr>
<tr>
<td>Julie, 37 years</td>
<td>-</td>
<td>Chloe</td>
</tr>
<tr>
<td>Carol, 42 years</td>
<td>-</td>
<td>Erica</td>
</tr>
<tr>
<td>Belinda, 44 years</td>
<td>-</td>
<td>Brian</td>
</tr>
<tr>
<td>Pamela, 50 years</td>
<td>-</td>
<td>Craig</td>
</tr>
<tr>
<td>Sylvia, 45 years</td>
<td>-</td>
<td>Letitia</td>
</tr>
<tr>
<td>Doris, 40 years</td>
<td>Jack, 57 years</td>
<td>Annie</td>
</tr>
<tr>
<td>Sandra, 44 years</td>
<td>-</td>
<td>Jake</td>
</tr>
<tr>
<td>Leanne, 52 years</td>
<td>-</td>
<td>Jarrod</td>
</tr>
</tbody>
</table>

All mothers who participated in the research did so at both T1 and T2. One out
of the 2 father’s who participated only one father was able to participate at the follow-
up data collection point, T2.

Procedure

Constructing the semi-structured interview. Although the interview is co-
determined, as stated earlier in this chapter, it is still important to develop an
interview schedule in advance. Producing a schedule prior to the interview allows the
researcher to think-over the areas to be covered in each interview. In addition, the
interview process allows the researcher to think about problem areas such as the
wording of sensitive questions (Smith, 1995). This philosophy was adopted for the current study:

1. The first part of the process involved determining the general area to be investigated via the interview. This consisted of clarifying the experience of having a child with cancer (a potentially life-threatening disease) from the perspective of the parent and the experience of having cancer from the perspective of the child. The primary investigator identified areas to be covered in the interview which consisted of investigating parents’ experience with the healthcare team, if parents had experienced anything particularly helpful or positive about having a child with cancer and the difficulties associated with having a child with cancer. Regarding the child interview schedule, the focus was on experiences identified as being some of the most significant changes that had occurred since the diagnosis, if there were any positive parts about being unwell and what were the most difficult or challenging parts about being unwell.

2. The second part of the process involved clarifying the most appropriate sequence for the questions. The current study followed Smith’s (1995) recommendations which involved considering the most logical order of the questions and their respective sensitivity. Whilst all the interview questions could be identified as sensitive in some way simply as they are associated with a sensitive topic (having a child with a life-threatening illness), those that involved greater sensitivity were placed toward the middle or latter of the interview, so as to build rapport with the participant prior.

3. Thirdly, appropriate questions related to each area being addressed (noted in point 1) were devised.
4. Finally, the literature relating to childhood cancer and families facing adversity was reviewed to inform the development of the interview schedule (McCubbin et al. 2002; Patterson et al. 2005). Brocki and Wearden (2006) state that whilst care needs to be taken when working with a pre-existing theoretical framework so as not to impose too much of this pre-existing theory onto new material, IPA is not a methodology which prohibits the use of pre-existing knowledge. It is unlikely any researcher would embark upon a project without having some knowledge of the current literature surrounding the topic.

**Recruitment process.** The recruitment of potential participants involved sending an information letter (please see Appendix A) out to all families who fitted the above inclusion criteria. The information letter briefly described the purpose of the study and informed potential participants that they would be required to meet with the researcher to complete questionnaire material and respond to a set of interview questions. The letter also informed participants that they would be required to meet with the researcher on two occasions to carry out the same data collection procedure. Families were provided with a reply paid envelope addressed to the Clinical Trials Unit within the Paediatric Haematology Oncology Unit. If families expressed an interest in participating in the study they were required to indicate this in the “tear-off” section which formed part of the information letter and return it to the Clinical Trials Unit. Upon receiving the responses, the Clinical Trial Co-ordinator forwarded the positive responses to the researcher. The researcher then made contact with the respective families, initiating contact by phone. This initial phone call consisted of the researcher introducing themselves formally, informing the families of the study and its purpose in greater detail, answering any questions the families may have had and
organising an initial time to meet. Families were provided with the option of choosing where to meet the researcher, which usually consisted of either their home or the hospital. This was to ensure that families were as comfortable as possible and reduced any feeling of having to go “out of their way” to meet with the researcher. For example, if the child was in the midst of a treatment protocol and actively receiving chemotherapy the family may have preferred to meet at the hospital (where often parents spent many hours sitting by their child’s bedside) or if the child was on a break from receiving treatment or in the process of returning to school, the family may have preferred the researcher to meet them in their home environment (as some families preferred to attend the hospital as little as possible). Please see Table 3.

Table 3
Data Collection Venue

<table>
<thead>
<tr>
<th></th>
<th>Initial Interview</th>
<th>Follow-up Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Home</td>
<td>Hospital</td>
</tr>
<tr>
<td>Timothy</td>
<td>✓</td>
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Organising the time of the initial meeting to occur was also left to the families to decide, as this ensured that data was collected at a convenient time. All families were interviewed within several weeks to two months from making the initial phone contact. The process followed, ensured that families were not interviewed or approached at a stressful or inappropriate time.

*Initial meeting.* Families were provided with a detailed Information Sheet, a Consent Form and Assent Form at the initial meeting (please see Appendix B). Parents and children read this information, any further questions were answered and if both parents and children were happy to participate in the research, they signed their respective forms. (All participants who agreed to attend the initial interview went on to participate in the study and attended both interviews). Families were reminded that they were free to withdraw from participating in the research if they so chose, at any point in time they desired, without penalty. To minimise any distress participants were also informed that if they preferred not to answer particular questions asked by the researcher or fill in any of the questionnaire material, they were free to decline at any time. Consistent with an IPA approach, participants were reminded that there were no right or wrong answers but that the researcher was simply interested in learning about their experience that is, of parents having a child with cancer or the child having a diagnosis of cancer. Finally, participants were informed that whilst responses would be recorded and transcribed (at a later date), all information gathered from them would be maintained as confidential. To ensure this confidentiality occurred participants were informed that all identifying information provided would be coded so as to de-identify the data. All families confirmed their agreement to participate and were happy to commence the first interview at this initial meeting.
The format. Parents commenced by completing a brief demographic information sheet (please see Appendix C). Both parents and children were then provided with their respective questionnaires and given time to fill them in. Completing the questionnaires was undertaken prior to the semi-structured interview as this provided an opportunity for participants to ease themselves into the study, ask any questions or chat with the researcher. Upon completion of the questionnaires the semi-structured interview commenced. Parents were typically interviewed first. As adults are usually more conversant and relaxed when speaking with a person they’ve just met, I felt this provided an opportunity for the child to relax and again become familiar with myself as the researcher. When both interviews were complete I thanked the families and reminded them that I would contact them in 6 months to meet with them again, T2.

Conducting the semi-structured interview. Individual interviews are recommended by (Smith, 1995) although he does provide some exceptions where this would not be suitable. Given the sensitivity of the topic of research and given that some of the children interviewed were quite young, families were asked whether they preferred to be interviewed alone or together. On all occasions families preferred to be interviewed together, that is, child participants preferred Mum and/or Dad to be in the room with them and parents were happy to be interviewed with their child present. However, on most occasions when interviews took place in the home it was very common for Mum and/or Dad to get up on various occasions (when their child was being interviewed) and attend to other household demands and return to the interview intermittently. Then when the parents were interviewed children often preferred to return to various play activities rather then be present for the parent interview. In the hospital environment also, once the child had completed their interview and it was the
When children and parents were interviewed every attempt was given to provide participants with as much time as necessary to complete answering a question before I asked them another question. Wording of all questions, particularly those in the child interviews, were framed using terminology familiar to the interviewee’s own level and understanding. Open questions were also identified as being essential to encourage more information from the interviewee. Closed questions were only used to clarify or summarise what the participant had verbalised and to ensure a thorough understanding of the information provided. Closed questions were also occasionally used during child interviews where rapport was difficult to build. Closed questioning was useful for children who were shy or who had difficulty explaining their ideas.

It did however, require consistent effort on my behalf to refrain from moving forward too fast in the interview, rather then allowing participants time to think their answers through. To reduce any chance of any awkwardness I occasionally felt as though I “jumped in” too soon with the next question to try and keep the interview “moving” or to give the impression I was competent as an interviewer and not struggling to understand the information which provided by the participant. At other times I didn’t want to appear as though I was taking too long to process participants’ answers. I noticed I also had a tendency to summarise participants’ responses which is possibly a result of my training as a psychologist where in Cognitive Behaviour Therapy for example, an important component involves engaging in some of those micro-counselling skills such as paraphrasing and summarising. The summarising of
participants’ responses is not necessarily negative as it does provide the interviewee with reassurance that the interviewer has heard and understood them. I also felt it necessary to show empathy and sympathize with what was sometimes difficult and sensitive information being conveyed by the participant and so would offer encouraging support and confirmation on these occasions. This may have influenced participants’ responses. Finally, there was also the occasion when either the child and/or parent became upset during the interview as of course, sensitive information was being discussed. As Smith (1995) notes, the interviewer has certain ethical responsibilities toward the participants to respond to their distress. On these occasions I responded in an empathetic manner checking in with the interviewee that they were okay, whether it was acceptable to continue the interview, they needed some time to themselves for a few minutes before resuming the interview. On these occasions I also checked if it was okay to continue talking to the interviewee about the particular topic in question or whether they preferred to move on at that point and perhaps come back to that topic at a later time.

Probes were used throughout the interviews to assist participants expand and provide more detail on the information they had provided and to allow the interviewer gain a greater understanding of the participants “psychological world”. At these times questions such as “What was that like for you?” or “What did that mean to you?” were asked. It should be noted here however, that in reading the transcripts of the interviews at a later time, there were often times when I as the interviewer noted points in the transcripts where additional probing would have been useful to explore concepts further. Having noted this though, regardless of how good an interviewer I might be or how effective I am at probing, I feel that there would always have been areas that in retrospect, I could improve upon.
**Materials**

_Quantitative materials._ The quantitative materials administered comprised of the following questionnaires (please see Appendix D):

Parent questionnaires:

1. _Family Crisis Oriented Personal Evaluation Scales (F-COPES),_ (McCubbin and McCubbin, 1996). The F-COPES measures family coping patterns and consists of the scales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help and passive appraisal. Test-retest reliability on all scales ranges from .75 - .95. Validity – factor structure breaks down into 5 scales consistently.

2. _Family Problem Solving Communication (FPSC),_ (McCubbin and McCubbin, 1996). The FPSC measures family communication style in families undergoing hardships with two subscales being: affirmative and incendiary (inflammatory). Overall test-retest reliability is .86. FPSC has been validated in a number of large scale studies of families under stress.

3. _Abbreviated Spanier Dyadic Adjustment Scale (ADAS),_ (Spanier, 1976). This scale measures relationship satisfaction via a number of items which address: philosophy, aims, time, ideas, discussion, working together and happiness. The ADAS has a moderate internal consistency of .34 - .71. Regarding validity, people who scored low were those who were separated or divorced.

4. _Parent form of the Paediatric Cancer Quality of Life Inventory (PCQL-32)_ (Varni, Katz, Seid, Quiggins and Friedman-Bender, 1998). The PCQL-32 assesses disease and treatment-related symptoms, physical functioning, psychological functioning, social functioning and cognitive functioning.
For both parent and patient forms, internal consistency reliability was high at .91 and .92 respectively. Validity – predicated “on” and “off” treatment of paediatric cancer patients.

5. *The Kessler Psychological Distress Scale (K10)* (Kessler and Mroczek 1994; Kessler et al., 2002). The K10 is a scale which measures non-specific psychological distress along the depression and anxiety spectrums. The K10 has been found to be comparative to the General Health Questionnaire (GHQ) and the SF-12 regarding diagnosing anxiety and depressive disorders (Andrews and Slade, 2001).

Child questionnaires:

1. *Kidcope* (Spirito, Sark and Williams, 1988). The Kidcope assesses distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support and resignation. It has moderate test-retest reliability over short intervals (.41 - .83) and moderate to high validity when compared to another coping tool (.33-.77).

2. *PCQL-32* (Varni et al. 1998). This questionnaire has the same scales and properties as the parent form and is a measure of the child’s perception of their own quality of life.

*Qualitative materials.* Once parents and children had completed the quantitative measures the following semi-structured interviews were administered:

Parent Interview 1

1. *Tell me about your life now, as compared to before the diagnosis?*

2. *What have been the difficulties you and your family have had to deal with since the time of your child’s diagnosis?*

3. *What have you found to be most helpful to you or your family since the time of*
your child’s diagnosis, if anything?

4. What is important to you in your everyday life?

5. Tell me about your experience with the health care team?

6. How has the way you look at yourself, others and the world around you changed as a result of this experience?

Child Interview 1

1. Please tell me a little about your life right now?

2. What have been the biggest changes in your life from when you were not sick to now?

3. What are the hardest parts about being sick?

4. What are the easier or nicer parts about being sick?

5. What is the most important thing to you in your life? Has this always been the most important thing?

6. If there was just one thing that you could tell other kids going through the same experience as you that would help them, what might it be?

The following semi-structured interviews were administered on the second meeting with families:

Parent Interview 2

1a. Please describe what your life is like now (e.g. same as prior to diagnosis or any remaining changes)?

1b. Looking back now, how has the diagnosis and treatment of your child affected your life, if it has at all?

2. What has been most helpful during this experience?

3. What has been most difficult during this experience?

4. What is important to you in your everyday life?
5. Tell me about your experience with the healthcare team.

6. How has the way you look at yourself, others, and the world around you changed as a result of this experience?

Child Interview 2

1. Please tell me a little about your life right now?

2. What have been the biggest changes since we last met?

3. What has changed most in your life since you were sick/diagnosed?

4. Looking back were there any good parts about being sick? If so, what were they?

5. Were there any bad parts and if so, what were they?

6. If there was just one thing that you could tell other kids going through the same experience as you that would help them, what might it be?

Analysis

Preliminary coding. Every interview was taped using a digital voice recorder. Parent interviews ran from forty-five minutes to one and a half hours in length and child interviews were approximately twenty minutes to forty minutes in length. All interviews were transcribed verbatim. The primary researcher undertook the following process in relation to the analysis of the data.

1. The primary researcher read the first transcript in its entirety. At this stage any preliminary themes or ideas which stood out were noted in the margin of the transcript. (For more lengthy or complex transcriptions, they were read several times to get an overview or general sense of the information being explained).

2. After a general understanding of the transcript as a whole was achieved, the transcript was then read again and the emerging themes
were divided into meaning units. Each meaning unit referred to a
different topic of the participant’s experience of the phenomena in
question. To demarcate each meaning unit, suitable marks (slashes)
were made at the beginning and end of each meaning unit on the
transcript.

3. Each meaning unit was then given a code. Each code described the
essence of each meaning unit (e.g. impact of the diagnosis). To code
the entire transcript each meaning unit was provided with a number,
also recorded in the margin of the transcript. On a separate sheet of
paper all the numbers from the transcript were recorded and the
corresponding code for each meaning unit was recorded against its
respective number. (This particular strategy was devised and used by
the primary investigator to avoid recording the codes on the transcript
itself, making it difficult to read.) This process of coding each meaning
unit is the interpretative component as the primary investigator tries to
make sense of what the participant was experiencing via their verbal
response (Smith and Dunworth, 2003).

4. It is also important to note that the analysis of a single transcription
was completed before moving on to another. This process was
followed for each transcription until the analysis of all interviews was
complete. This method of analysis follows an idiographic approach,
consistent with the IPA methodology (Smith and Dunworth, 2003).

*Final coding for explication phase.* To assist with further explication of the
data, the computer software program Atlas.ti was used.
1. Once each transcript was coded by hand it was “assigned” into Atlas.ti. Each transcript was then re-coded using the preliminary coding as a guide.

2. Once all transcripts were coded onto Atlas.ti, the codes were grouped into “clusters” or “families” of codes. Each cluster or family of codes represented a similar topic or theme, hence the name sub-theme was used to describe each cluster or family of codes. Sub-themes were then grouped further into similar topics to provide an overarching thematic essence referred to as master themes (Smith and Dunworth, 2003).

3. As soon as two or more transcriptions were assigned to the Atlas.ti program and coded, it became very easy to see any connections and similarities among the codes (e.g. “desire for normality” and “desire for return of everyday life”) and “clusters” or “families” of codes (e.g. support from partner, support from staff, support from school). All codes were grouped into sub-themes and then sub-themes were grouped into master themes.

4. As similar codes were identified or as master themes emerged the transcripts were continually re-checked to ensure that the original code or sub-theme still matched the corresponding meaning unit. This process of analysis involved a close and lengthy interaction between the text and the primary investigator with total immersion in the data being the unavoidable result (please see Appendix E for Audit Trail).
Inter-rater agreement on coding. At various points in time throughout the coding process I often met with my primary supervisor, who acted as an independent researcher and so was able to assist in the verification and confirmation of code names and themes. This often involved the scrutiny of transcripts to verify my evaluations of the data in addition to noting the quality of the material collected. Inter-rater agreement occurred on approximately 90% of master themes and sub-themes between my primary supervisor and myself. Independent coders were not utilised, however this is consistent with the methodology chosen, as this is not an integral process of IPA. I am aware that collaboration does allow for reflection on the analytical processes and ensures the credibility of identified themes, however, due to the nature of qualitative research and as outlined earlier in this document, any assessment on qualitative data is subjective.
Social and Demographic Profile

A number of questionnaires were administered to both parents and children. Due to the small sample size descriptive statistical analysis was used to describe the sample study however significance testing was unable to be completed. All questionnaires were still scored and the following is an outline of the results.

Parent Questionnaires

Relationship satisfaction as measured by the Abbreviated Dyadic Adjustment Scale (ADAS). Nine out of 11 parents (82%) who participated at T1 scored within the “high” range of relationship satisfaction. The two remaining parents scored within the “low” range of marital satisfaction (18%). At T2 all parents who initially scored within the high range, remained in the high range for marital satisfaction. Out of the two parents who initially scored within the low range at T2, one of these parents’ score improved as they scored within the high range (91%). The second parent had separated from her husband at this time and so did not complete this particular questionnaire. Please see Appendix F.

Parental mental health status as measured by the Kessler Psychological Distress Scale (K10). This measure of psychological distress places parents within one of three categories: low risk; medium risk; and high risk. Nine out of the 11 parents who participated at T1 scored within the medium range of risk for an anxiety or depressive disorder (81%). Two out of the 11 parents scored within the low range of risk (18%) and no parents scored within the high range of risk of a mental health status. At T2 two parents’ mental health status’ improved over time with their risk improving from the medium range to the low range of risk (36%). No other changes occurred across T1 and T2 regarding parental mental health status. It is only those who perform within the high range of risk who are required to seek professional
assistance for their mental health status, while those who perform within the medium range should seek self-help information (Kessler et al., 2002). Please see Appendix F.

*Communication style as measured by The Family Problem Solving Communication Scale (FPSC).* The FPSC measures the problem solving and coping component of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, Thompson and McCubbin, 2001). All families demonstrated an “affirming” communication pattern. This result was consistent across T1 and T2 which suggests that a positive communication style was dominant across the sample. Please see Appendix F.

*Family coping style as measured by the Family Crisis Orientated Personal Evaluation Scales (F-COPES).* The F-COPES identifies the problem solving and behavioural strategies families use to resolve difficult situations (McCubbin et al. 2001). The results indicated that families relied on and used all the subscales (social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help and passive appraisal) as strategies to cope, with no one particular subscale appearing any stronger than any other and again. This result was consistent across Time 1 and 2. Please see Appendix F.

*Parent and Child Questionnaire*

*Paediatric QoL as measured by the Paediatric Cancer Quality of Life Inventory (PCQL-32).* In four out of the nine families who participated, children reported their QoL to be better than their parents’ perception of their QoL. Four families reported minimal difference between parental and child perception of the child’s QoL. One family reported a better parental perception of the child’s QoL than the child reported. These results were consistent across T1 and T2. These results are
similar to that of Eiser and Morse (2001) who indicate that it is common for parents and children to have different perceptions on the child’s QoL.

**Child Questionnaire**

*Child coping as measured by the Kidcope.* Children demonstrated the use of a range of coping strategies (distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support and resignation). No particular coping strategy appeared to be used more than any other coping strategy. However, social withdrawal, self-criticism and blaming others were noted as coping strategies that the children did not frequently rely upon. Minimal changes were noted across T1 and T2.

**Summary**

With the exception of one married couple who separated over the course of their child’s cancer experience, most parents reported good relationship satisfaction, good mental health and positive or helpful family communication patterns. Parents also demonstrated the use of a number of different behavioural and emotional coping strategies. Discrepancy was noted between some of the parental and child responses regarding child QoL with many parents perceiving their child had a lower QoL than the child’s own perception. Children demonstrated the use of a range of adaptive cognitive and behavioural coping strategies. No maladaptive responses from either parents or children were noted.
Results

Explication of the Parent Interviews

Nine master themes were explicated from the qualitative data collected via the semi-structured interviews: *a pivotal moment in time* (1), *the experience of living with a seriously ill child* (2), *on being a parent of a child with cancer* (3), *the experience of adaptation in relation to having a sick child* (4), *the nature of support* (5), *feeling safe within the system* (6), *re-evaluation of values during a critical life experience* (7), *experience of future health concerns in the present* (8) and *the experience of optimism and altruism* (9). While most sub-themes which made up the master themes were consistent across the interviews, a small number of sub-themes were unique to either the first (T1) or follow-up interviews (T2). Where this has occurred it has been noted in the document to fully inform the reader.

To protect the identity of those who participated in this research pseudo names have been used throughout this document. All quotes transcribed in this document have been taken directly from the raw data. Changes to the quotes have only occurred when it has been necessary to clarify the participant’s experiences. For the sake of simplicity all participants aged eight to 17 who participated in this study are referred to as “children”.

*A Pivotal Moment in Time*

The experience of hearing that a child whom the parent thought had a mild illness, was in fact suffering from cancer, a life-threatening illness, was experienced by each of the participants as profound and personal. Parents responded in unique ways which varied from shock and deep sadness to denial and adjusting to the diagnosis over time. A common response was a lack of understanding why their child had been diagnosed with what was often perceived as a fatal condition. Almost all
participants described a period during which their worlds were “turned upside down” after which they experienced coming to terms with the diagnosis.

This master theme consisted of one sub-theme only being learning of your child’s potential immortality. No other sub-theme correlated with the experiences parents described in this theme, the process associated with realising and coming to terms with the severity of their child’s illness and its life-threatening component.

Learning of your child’s potential immortality. Sandra described how she felt at the time of diagnosis. Upon hearing of her son’s diagnosis she went into shock and felt that it was the end of her child’s life:

“I never thought I’d have a child with cancer, you go into total shock when you’re told I tell you… I was always anxious because with cancer you think “Oh God, this is going to be a death sentence.” (Sandra 44 years, mother of 15 year old son Jake, Int.1)

Carol confirmed that one of her immediate thoughts upon learning of her child’s diagnosis was its potentially life-threatening component. Carol also inferred that their lives changed dramatically as a result of her daughter’s diagnosis:

“...at first you think, oh our child could have a life-threatening illness and your life just sort of goes upside down.” (Carol, 42 years mother of 8 year old daughter Erica, Int. 2)

Sylvia used the same expression, indicating that their lives turned “upside down”. Such an expression gives an indication that life changed dramatically, unexpectedly and instantly. The predictability of life was challenged:

“Well Letitia was quite sick and had been home from school, only a couple of days though and basically I just took her to the doctor’s, got a blood test that afternoon and then got a phone call that night... [we] ended up in Accident and Emergency and were ambulanced here [to the hospital] the next day so really within 24 hours the world had turned upside down...” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

In addition to experiencing shock, learning of their child’s potential mortality and experiencing an instant life-changing event, parents also expressed learning of
their child’s diagnosis as being the most demanding and difficult part of their total illness experience. Being unexpectedly forced to come to terms with an unimaginable situation was overwhelming:

“Well the difficulty [for the hardest part] going through was the diagnosis for a start…you never ever envisage ending up in hospital with this sort of stuff do you?” (Jack 57 years, father of 15 year old daughter Annie, Int. 1)

Pamela confirms that hearing of her child’s diagnosis was also the hardest part for her in the way that having a child diagnosed with cancer is simply unfathomable:

“I think the hardest part was actually the diagnosis, to actually get those words coming out of someone’s mouth, that your child has Hodgkinsons Lymphoma…it’s just not even in your scope of thought that that would happen…” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

In conjunction with some of the other parents’ experiences’, Sonia experienced denial, feeling that her son’s diagnosis could not be true and that out of all the possible explanations for his initial symptoms, he could not possibly have had a life-threatening illness:

“Well with Timothy he was just complaining about dizziness, I never would’ve thought that this is the outcome of those dizzy spells he had which lasted for 5 seconds, it’s the last thing in your mind that would happen, and then it is what it is, so you just think, it can’t be true, it took a while for us to absorb it…never in your wildest dreams would you think you’d have to go through this, amongst everything else it had to be a brain tumour…” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Finally, Leanne reported experiencing grief and a sense of helplessness as she was unable to help her son. She was unable to control the situation:

“At first I think it was shock and then grief of not knowing how to fix this or get him better…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Overall, there were both common experiences as parents dealt with the unexpected nature of the diagnosis and common outcomes in coming to terms with the health status of their child. All parents admitted to experiencing something which
was incomprehensible and challenged every assumption a parent would have about their child’s health status.

The Experience of Living with a Seriously Ill Child

The impact of having a child diagnosed with cancer meant that families experienced significant changes to their daily routine and family lifestyle. One cause of this change was the fact that the child with the diagnosis was often required to spend several months at a time in hospital receiving the appropriate treatment and so was accompanied by a parent. Parents’ time and attention was often centred solely on the sick child whilst they were receiving treatment accentuating the isolation other children in the family felt. The other parent and remaining children in the family often felt abandoned. Parents reported feeling alone and isolated from one another and from the patients’ siblings. One family was even required to temporarily move to Brisbane from a country town for their child to receive treatment.

Parents reported that the sick child’s response to their own illness affected their response as a parent, so optimistic and positive responses from the sick child were perceived as helpful. Parents’ responses to having a child with cancer were also influenced by the experience of previous family illnesses. Regardless of all of the above, life changed irrevocably for participating families and so maintaining a sense of normality and routine was a struggle.

Within this master theme there were seven sub-themes: impact on siblings, child becomes the focus, surviving the ordeal, experience of child’s response to illness, the impact of previous family illness, experience of lifestyle change and desire for return to former life. All sub-themes reflected the significant and inevitable impact that having a child with cancer had on the family.
Impact on siblings. The impact the child’s illness had on siblings was a common theme experienced by most families. This impact emerged as a result of parents admitting their attention was centred on the child with cancer. This sub-theme was explicated from T1 only.

Carol commented on life revolving around her daughter with an illness and she realised this fully when her son made comments about his sibling’s illness also. At this time it dawned on Carol that Erica (her daughter) really was the centre of attention.

“...so life has tended to revolve around Erica...we took a video camera with us to Coffs Harbour and her brother Mark did some of the commentary and said “we’re here for Erica’s holiday, it’s all about Erica”, and I thought we don’t realise from his perspective that everything is all about Erica.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Carol went on to say:

“...and even now I guess we’re still so...Erica has to be careful, siblings fight and wrestle and chase each other around the house and often Mark gets reprimanded [with us saying] “don’t you hurt your sister” sort of stuff, when she might have provoked the incident in the first place...”

Carol experienced herself as being over-protective and favouring Erica over Erica’s brother even on occasions when Erica may not have been deserving of this motherly concern.

A similar theme experienced by Doris confirmed that her son also felt left out, lonely and isolated while her and her husband focused on Annie in response to her vulnerability. Doris recalls her son feeling as though he had to draw attention to himself:

“Because sometimes he [sibling] feels neglected and so says “can’t you talk to me”, because you’ve got to worry about Annie’s medication or you’ve got to do something for her and [so he says] “what about me”, you know...” (Doris 40 years, mother of 15 year old daughter Annie, Int. 1)
A single child in the family with a life-threatening illness such as cancer inevitably impacts all family members, as further illustrated by the following example. Pamela not only commented on the time and attention her son missed out on by her having to stay with Craig (her sick child) at the hospital, but also what she missed out on as a mother. Pamela realised that she was unable to fulfil her usual role as a mother and struggled with this impact:

“Craig wouldn’t let anyone else stay with him [at hospital] but me so that meant James [his younger brother] suffered, he was either put out somewhere, so he missed out on a lot of time with us and I missed out on time at home to be able to do anything with him so that was very difficult.” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

Sonia discussed how she felt it was important to maintain the family’s routine and maintain a normal life as much as possible, as if to shield William away from the intensity and focus on Timothy and his illness:

“Probably just making sure things are as normal as possible with William [sibling] because he started high school this year so that is another change, we didn’t want all of this to have pressure on him. We just wanted him to concentrate on what he had to do...” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

In the final example Sandra discussed a different type of sibling experience she noticed in her daughter Tammy. Tammy was just about to commence her first year of university when her brother Jake was diagnosed with cancer. The content of her course involved learning about the different types of cancers so she was not only provided with information relevant to her education but to her brother’s illness. Her education suddenly became very personal:

“I think...it was hard for Tammy [sibling] because she had just started uni [her first year], she hadn’t even started when he [Jake] was diagnosed and the first semester she was doing radiography and it was all cancer, tumours, stuff like that...so that was difficult for her and being the first semester of uni.” (Sandra 44 years, mother of 15 year old son Jake, Int. 1)

In summary, this sub-theme brings to light how the siblings of the sick children were affected as parents were required to focus on the sick child. Siblings
often felt left-out and alone, they may have been cared for by friends or family members when their parents weren’t available and parents tried hard to shield siblings from the pressure associated with caring for a seriously ill child, doing their best to maintain some sense of a normal life.

Child becomes the focus. Parents experienced a transition towards their life revolving around their sick child and an increasing sense of isolation from previous involvements, resulting in the child becoming the focus of their lives. This sub-theme was explicated from T1 only.

Leanne noted the isolation which she and her husband experienced as their whole lives revolved increasingly around Jarrod and his emotional and physical needs.

“But at the moment compared to before it’s fairly isolating, before the illness we were sort of involved with lots of activities, the parish and the community and now we’re just focusing on Jarrod and his illness and getting him through as best as possible, keeping him emotionally connected to the goal of getting well…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

In another example Sonia noted how their lives were scheduled entirely around Timothy and his needs, right down to daily needs:

“Well I’ve had to arrange timetables with work obviously, cause we’ve got schedules for Timothy, our life is scheduled around what he has to do and having to have someone always here [at home] with him...” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Both of these experiences provide evidence of the transition parents undertook to support their child’s needs. Parents had no choice but were forced to adapt and modify their lifestyle accordingly, to support the needs of their sick child, whether they were emotional or practical needs.

Surviving the ordeal. With parents all of a sudden being required to come to terms with their child’s diagnosis and being required to attend the hospital on a regular basis, often for lengthy periods of time, it was inevitable that the lifestyle and
typical functioning and structure of the family was going to change. The impact of living with a child being treated for cancer was colossal and in some cases catastrophic.

The following examples indicate the many changes families endured. Pamela discussed the impact her son’s illness and treatment had on her husband, Jim. While Pamela and Craig (her son) lived at the hospital Jim felt helpless as he could only stand by and watch the process:

“My husband out of all of us probably felt the major impact because after it was all over he couldn’t work for 3 months…it really hit him hard…for us [Craig and I] because we were in it and doing it and having the sleepless nights and the ‘whatever’s’, we just rolled with the punches but because Jim couldn’t be here [at the hospital]…he was working through that time I think that he fell over after the event.” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

Sandra also made note of this semi-permanent life where again she lived at the hospital with Jake and her husband remained at home with the rest of the children. Whilst she and her husband maintained constant daily contact there was still a sense of the family unit being split a part:

“I mean we would talk daily, constantly and he [my husband] would come up to the hospital daily but basically it was him and the kids, they kept the household running and I just probably dealt with Jake day-to-day [at the hospital].” (Sandra 44 years, mother of 15 year old son Jake, Int. 1)

In these two examples the husbands were seen as peripheral and in the first instance, husband Jim was unable to “stand on the side-lines and watch” and so struggled to survive the ordeal.

Jarrod and his family felt a significant impact as he and his family were from a Queensland country town, and thus they were required to attend Brisbane for treatment of Jarrod’s condition. Not only was this impact unexpected but the family were then required to find employment in Brisbane so they were able to survive financially:
“...it was a shock to hear that we couldn’t go back home [country town] after so many weeks, we were hoping that the initial treatment would be here, but initial treatment for 6 weeks not 6 months and then the rest of treatment be delivered from home...the other difficulty is being tired, not sleeping as much or only sometimes or at different times...but the routine of working as well, we have to get up earlier, catch trains, that sort of thing, we didn’t have to do that before, in a small country town...”

(Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

For Carol and her family the diagnosis and treatment of her daughter’s (Erica) condition, had an overflow effect onto other family members, including the extended family. The demands associated with having a sick child were enough to cause pressure, not just in the immediate family, but all those who had a vested interest in Erica’s health status, as if there was a “domino-effect”:

“Everybody was stressed, the whole nuclear family group, the brother’s and sister’s, aunts and uncles, grand-dad’s and grand-ma’s, everybody was stressed about it... the fact that we were stressed, they were stressed.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 2)

One of the most salient experiences for Sonia regarding her son’s treatment was the rate at which it took place. For Sonia and her husband it was as though the treatment occurred too fast for them to keep up and feel as though they had some control. The treatment period felt like a whirlwind. It was not until after the treatment was finished that they actually had time to reflect on everything that had happened and adjust:

“With us it just happened so quickly...as soon as Theo was diagnosed, we saw the surgeon, then one week later he had surgery and then you know after his diagnosis everything just went bang, bang, bang...we didn’t even have time to sit back and go hang on, no time, just yes let’s do that, yes let’s do that and then now we’re finished it’s like hang on, did we do the right thing?” (Sonia 36 years, mother of 8 year old son Timothy, Int. 2)

The above examples bring attention to the demands families faced as they tried to meet the practical needs of their child’s illness. Families were divided and stress levels increased while all those around the child were affected. Parents were
taken for a whirlwind ride and everything they once knew about the predictability and stability of their lives, changed instantly.

**Experience of child’s acceptance of the illness.** Parents also commonly commented on their child’s response to having cancer and how this affected their own management and attitude toward their child’s experience. Many parents described their child as accepting and came to terms easily with their illness which they in turn, found helpful.

Sonia described how she felt her son’s obliging nature made it easier for her to manage his treatment:

“I guess the other thing [that has been helpful] too is that Timothy is just a really good patient, like if you explain to him why you have to do stuff and why he can’t do some stuff, he just listens and even though sometimes it is difficult for him he tries to do what you tell him…so I feel that is half of our battle, like if he was a difficult child and just stubborn it would have been more difficult but because he has just been so good and never complained about going to radiation…” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Parents also expressed their admiration for their children and commended them on what they had to endure:

“I look at Jake and say because he went through shit and he did so well, he’s such a happy kid, and I just think we haven’t done any of that, we should be happy, I haven’t had to go through what he’s had to go through and he’s done so well, I admire him for that, I think he’s just done so well, so I do remind myself of that…” (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

Like Sandra, Pamela also admired the strength she saw in her son Craig as he endured the treatment, although Pamela also questioned whether less life experience equated to an increased ability to cope with difficult situations. Does a child’s ignorance place them in an advantageous position?

“I admire his strength and his courage because I think part of that is their naivety, although they’re aware that those things hurt, they’re not pleasant, they’re probably a lot less concerned about them then we are, my sister-in-law had breast cancer and she only did two rounds of chemo and she couldn’t do anymore so she was pretty amazed that Craig got right through…” (Pamela 50 years, mother of 10 year old son Craig, Int. 2)
Whilst Julie also experienced admiration for her daughter Chloe, this admiration was of a different nature. Julie admired her daughter’s capacity to negotiate her own treatment:

“I can remember one time she argued with them [the staff], she had one of the chemo drugs give her really bad jaw pain, it’s a really rare reaction but it happens, so the next time she had to have it, they gave it really slowly over 24 hours so it didn’t produce the same reaction, well the time after that they went to give the drug to her in her central line again, and she just flipped her lid, and said “no no no, I don’t get that drug in there, I get it in an infusion over 24 hours...” she put it back at them.” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Whilst the majority of families reported that their children were accepting of the illness experience, there was one family who experienced difficulty in relation to their child’s response to having cancer. This led to difficulties in managing their child’s illness. Leanne (52 years) mother of Jarrod (16 years) described the following (Int. 1):

“...dealing with a child who was fiercely independent or wanted to be and was finally setting goals for his future and now he’ll say things such as “oh cancer stops everything”, that’s his response to it all...”

“...and [he] has rejected going to school [and] doing his school work, you can’t get him to do his school work at the moment at home, prior to the diagnosis he was coming along with his schoolwork very well, and even the school was happy with how he had settled, we’d been through turmoil in Yr 9 but Yr 10 he was more focused and Yr 11 he was setting goals but now those goals have been taken away so he has had to adjust to that...”

Here Leanne described the experience of her son, Jarrod having difficulty coming to terms with his diagnosis. Jarrod reacted in a defiant manner and he carried this defiance across to other area’s of his life. Having their child respond in this manner to his illness, added to an already stressful situation.

This sub-theme reflects parents’ experiences in relation to how their children managed their illness and the impact that this in turn had on them, as parents. Some parents experienced their child as accepting of the illness and its treatment
requirements as their child endured it without protest or reaction. Other parents admired the resilience, strength and “care-free nature” their children demonstrated as they ceased to tire of the treatment requirements. While most families attributed positive attributes to the way in which their children managed their diagnoses one family did experience their child as being threatened by his diagnosis of cancer. For this family, they felt as though their son had lost all hope of continuing on and living as a result of his diagnosis.

Impact of previous family illness. A number of families mentioned they had experienced previous family illnesses and indicated that they felt these experiences had affected the way they managed their child’s illness. Whilst some parents felt a previous family illness had affected them in a positive way, others’ also felt it had had a negative impact. This sub-theme was explicated from T1 only.

Carol felt that the diagnosis of her daughter’s illness was almost “easier to deal with” as a result of her husband’s health status. That is, Carol and her family had already adjusted to a lifestyle in which they appreciated every single day and had a pre-existing belief that life sometimes throws unexpected things their way:

“I mean with Derek [my husband] having MS, we’ve always sort of taken life day by day anyway because of his illness...” (Carol 42 years, mother of 8 year old Erica, Int. 1)

Carol continued to say:

“...and I think that was something that we carried through with Derek so I think in that way, Erica’s diagnosis, because we had already been through that [with Derek] was a little bit easier to deal with because we had accepted [that] sometimes life isn’t fair and sometimes things happen...”

Leanne also found that she benefited from knowing other people who had experienced illnesses such as cancer or just other adverse events. By knowing that other people had experienced difficult circumstances and survived, this provided a
sense of hope and confidence that their own family could survive the current circumstances:

“We’ve had a wide experience of knowing other people...so from all circumstances of life, old and young, illness, health, careers, we have known people with cancer, we’ve known people who have had terrible things happen to them, people have had to adapt to life for all sorts of reasons, so I think the way we look at the world is, we know that people can get through these things and that hope is never lost.” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Belinda’s experience with her son Brian, was unique in the sense that she felt frustrated and exasperated by the previous family illnesses she had had to contend with, to the point of feeling sorry for herself:

“I have had a bit of a run with [previous family illnesses] so I’ve sort of stayed a little bit within that grief period...because I had lost my brother to a brain tumour two and a half years before [Brian’s diagnosis]...my mother had a hip replacement, she was in hospital for a long time, then she had a fall, then she had breast cancer and we had a lot of running to hospitals...the last 8 years has been a lot of hospital time for me...and then my brother was sick for 18 months before he died so you know there were more hospitals again...and then three weeks after Brian my eldest cousin was diagnosed with a brain tumour as well...so I went though a lot of “what is happening to my family?” (Belinda 44 years, mother of 10 year old Brian, Int. 1)

Belinda continued to say:

“I know it was that shock factor like “what else am I going to have to deal with” and probably felt a bit sorry for myself sometimes...I don’t like to but I think “oh my God, why do I have to deal with all this, why have I been given so many things to deal with?”

The experience of having a previous family member with an illness varied across participants. For one family it meant that their daughter’s illness was easier to grasp as they had already come to an understanding and acceptance that unexpected events can happen which might not seem fair. Another family found hope and strength in their previous experiences as it provided them with the knowledge that others had experienced difficult situations and survived, physically and emotionally. Finally, for one parent, her previous experiences of family illness left her wondering why she had had to endure so much hardship and felt sorry for herself.
Experience of lifestyle change. Whether parents had experienced a previous family illness or whether a child responded well and was accepting of their illness, families still seemed to experience a significant change to their lifestyle. As noted by the following parents this change often incurred practical implications that affected the functioning of the entire family on a day to day basis.

Carol noted the significant impact her daughter’s illness had on her working life:

“Prior to Erica being diagnosed I was working full time, you know a forty hour week, now obviously once Erica started having chemo every week I dropped to four days a week...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Doris described her experience of her lifestyle change bluntly when she implied that her life simply "was" the hospital. This creates a clear image of what lifestyle this family lived and breathed every second of the day and how vastly different it was from their usual lifestyle:

“Life is more living at the hospital rather than the normal day to day running and going to work...whereas before Jack was working... he was working full-time with our business but now that has had to be culled down to 3 days and then I contribute 2 days a week to our work...and of course our income is different because of that as well...” (Doris 40 years, mother of 15 year old daughter Annie, Int. 1)

Having a child diagnosed with cancer and who was actively receiving treatment also meant that it was difficult to plan ahead. For Sonia and her family, life became very much about living in the present:

“We just don’t plan too far ahead I guess, because we don’t know [what might happen], a lot of things affect our schedule whereas before I could schedule everything in advance and organise things, whereas now we just take it one week at a time.” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Sonia also mentioned the practical changes that had occurred in their lives, not just for herself but for her son Timothy, which then required adapting to new boundaries for a period of time (Int. 2):
“I guess just not being able to do normal things, like for Theo not being able to swim or play sports or be as rough with the other kids as he wants, things like that, just being out of the normal routine was a little bit difficult...

For parents the practical changes to their lifestyle often meant that they were unable to engage in their own pastime activities. These changes were usually major changes in the sense that they occurred for significant periods of time:

“And some things I’ve given up like I’d go to the gym 4-5 times a week and I think I’ve been twice in the last 6 months...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Julie went on to provide a good example of the chaos and unpredictability associated with her daughter’s illness and the impact this had on her working life. Due to the severity of her daughter’s illness, caring for her was a serious matter and so required careful management:

“[I] went back to work for a little while and then she got the pancreatitis [so] it was off for [a number of weeks] because she was in ICU for a bit and then eventually [I went back] to two days a week...and because she can’t go to school she needs constant care and my Mum still works and her father’s Mum is not really capable of taking care of her...and if she gets a temperature it could be really serious and giving drugs [may be necessary]... so it’s either been him [my husband] or me...so he works three days a week and I work two days a week...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

For many parents the practical implications of having a child diagnosed with cancer meant a reduced ability to engage in employment as it was necessary to spend more time caring for the child, often in hospital. It was almost as if parents had no choice but to develop a new life, a new existence focused solely on their sick child where they could live in the present moment only.

Desire for return to former life. Finally, whilst parents battled to come to terms with their child’s diagnosis and manage the demands and chaotic life often associated with tending to their sick child, they also attempted to maintain some sense of normality and control throughout their experience.
Sonia expressed the importance of maintaining the same expectations and standards as she did pre-diagnosis. She felt it was important to have a normal life as much as possible but with a focus on enjoying life:

“The discipline is still the same at home, he still has to do school work, he still has to get along with his brother, we try to keep things as normal as possible, we still try to encourage him to be challenged and not just think “oh I’m sick, I can’t do that”, we don’t try to get into the mentality that our son is sick so people should feel sorry for us so I think it’s just trying to keep it as normal as possible and trying to just enjoy the little things in life, not to dramatize everything…” (Sonia 36 years, mother of 8 year old son Timothy, Int. 2)

Similarly, Julie’s focus was on leading a normal life as much as possible which meant continuing to have interests outside the focus of her child’s illness:

“...like me personally, I need an out, I don’t want to live leukemia 24/7, I don’t think it’s really healthy, I want to cope with the illness when we have to but when we don’t we want to have some normality in our life and do things we always did…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Jarrod’s mother emphasized the importance of participating in activities he previously did and viewed this as fundamental to providing some relief from his illness and to give him the feeling that his illness wasn’t consuming every part of him and his life:

“Hope, that’s important...Jarrod is planning on going to a concert on the 27th September but that’s the week he is in hospital and we’ve bought the tickets but there may be some adjustment to his protocol so he may be able to [attend the concert]. just knowing he can do that is good, [the illness isn’t] taking everything out of his life...” (Leanne52 years, mother of 16 year old son Jarrod, Int. 1)

Finally, for some families there was a sense of desperation to return to their former lifestyle, the one which we all take for granted and complain about, thinking that it is boring or full of chores. Suddenly when you have a child diagnosed with a life-threatening illness, a boring, dull life doesn’t appear so bad after all:

“Well I guess the less intrusive the treatment is, the more you regain your life back...and the more milestones you hit, the more you just want to keep on keeping on, the more you want to just look forward to the things that I think people always probably tend to think [is] the routine or the drudgery of life…and it’s just like, give me back the routine, give me back the drudgery, I think you probably appreciate
everything a hell of a lot more then you ever did before, but it’s to get back into school, get back into doing things that you could do, take a holiday and go swimming...things that have just been completely out of our lives for 12 months, it’s just getting back into life...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

This sub-theme represents families desire to return to and retain as much of their former life as possible. Families attempted to achieve this by having social outlets and retaining the same expectations as much as possible, which existed prior to the diagnosis. The experience of having a child diagnosed with cancer also led parents to develop a new appreciation of what once may have been considered as mundane and insignificant.

*On Being a Parent of a Child with Cancer*

Caring for a child with cancer and whom required such extensive medical treatment was often challenging for parents. Parents managed their experiences differently with some opting to spend time away from their sick child while others appreciated spending as much quality time with their child as possible. Having a child with an illness as serious as cancer also seemed to accentuate differences between couple’s parenting expectations and style’s and in one particular case highlighted pre-existing marital difficulties. A common experience was parents’ difficulty in coming to terms with the notion that their child’s health was not in their control. Parents felt helpless and a lack of control as they were unable to control the outcome of the condition affecting their child. Finally, it was common for parents to continue to worry, be anxious and over-protective of their child post-treatment. Parents struggled to let their children go, back into the world they came from.

This master theme incorporated the experiences associated with being a parent of a child with cancer. Within this master theme three sub-themes were identified:
Experience of parenting a vulnerable child, experience of conflict around parenting and feeling powerless to protect.

Experience of parenting a vulnerable child. The experience of parenting a child with cancer which involved undertaking extensive and invasive treatment, often placed pressure on parents’ relationships with each other and also the relationship with their child. Parents managed their experiences differently, depending on what they thought would provide a better outcome for them and their child.

Leanne felt that her son’s illness placed pressure on the relationship between her and her husband. To manage this and rejuvenate themselves Leanne and her husband took time-out from caring for Jarrod, to ensure their lives weren’t consumed by his illness.

“[It has placed] pressure on our relationship in terms of who is going to care for Jarrod, who is going to work, do we have time for each other...sometimes we just toddle off and go and have dinner together or go to a movie and leave Jarrod, “it’s okay Jarrod, no one is going to sleep here tonight [at the hospital], we’ll be back tomorrow morning for breakfast just to make a break”, [he needs] to realise that sometimes Mum and Dad just need time...it gives us a chance to talk to each other rather than about Jarrod or medication all the time.” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Sonia and her husband exemplify two different approaches to managing their son’s illness. Sonia described her denial upon hearing of her son’s diagnosis and her need to remain calm whilst the diagnosis was confirmed, whereas her husband demonstrated a much more action-orientated approach. Sonia and her husband were aware of each other’s differences but did not influence each other’s approach:

“I didn’t think it [the diagnosis] was real, like it wasn’t happening to you, my husband had already started searching for what to do [on the net], for me it was like ‘just stay calm, I’ll see what the doctor says first before I start thinking of what it could be, so that was how I coped whereas with my husband he was wanting to know what was happening around the world so he could ask the doctor about it, whereas for me I couldn’t believe [what] was happening and I was wanting to believe that it was going to be benign.” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)
Julie also recognised the difference between herself and her husband’s approach to their daughter’s illness. In this instance Julie demonstrated an action-orientated approach whereas her husband felt hopeless:

“... and this is the great difference between her father and I, when she got diagnosed her father was dealing with a dying child, whereas I can still remember looking at the oncologist and saying what’s next, what do we do, what happens now, where do we go...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

Belinda felt it was important to be physically present for her children when they needed her, even if it was just to talk about the day’s events. Belinda also felt it was important to prioritise her children above her domestic responsibilities:

“I like just being there, being there for them [children] and mainly for when they want to talk and whatever...like probably the least important thing is whether the house is clean, I like mine to be clean though but I don’t kind of go “ooh gosh I can’t talk to you because I’ve got to vacuum or whatever you know”, you’re sort of there for them to talk to...” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Carol experienced guilt following the instructions the Doctor had placed on her daughter Erica, regarding the physical limitations he had recommended for her. Carol faced an internal struggle and was caught between following the Doctor’s instructions and having a distressed child or disregarding the Doctor’s instructions and allowing her daughter to experience some joy:

“You feel guilty because you knew Doctor P was taking it to the extreme [when he said] don’t ride your bike, don’t ride your scooter, don’t climb trees, so he was taking it to the extreme...like we’d always run things by him like “oh, can Erica do this” and he’d be ‘I’d rather she didn’t’...so then there’d be times when you’d think okay you can’t live your life being wrapped in a cocoon so I’d see a glimpse of Erica riding the bike flat-out down the drive way and just have to [pretend] I didn’t see it, and let her because otherwise she’d just sit on her bed and cry and you’d be feeling “oh look, we just won’t tell Doctor P that we did this or we did that” and just hope that nothing happens, [that] I don’t have to explain to him [why we are here now] with Erica being injured...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 2)

Parents incurred a number of different experiences along the path of parenting a vulnerable child and so managed this in different ways. Some parents felt their relationship with each other incurred a pressure that they would not have felt
previously and so dealt with this by spending time together, away from their sick child. Others felt it was important to prioritise their children (well and unwell) above all other demands to ensure that their children felt heard and loved. Among the pressures parents felt regarding their relationship with their spouses, they also experienced new pressures concerning their child’s health and so were required to learn how to deal with these effectively.

Experience of conflict around parenting. Whilst individual parenting styles may have been challenged as a result of having a child with cancer, as already suggested in the previous sub-theme, it often highlighted the differences in partners’ expectations, which sometimes led to conflict.

For Carol and Derek managing their daughter’s illness was sometimes the catalyst for disagreement or conflict to occur. The difference in their parenting styles were pre-existing to Erica’s diagnosis, yet were accentuated by the diagnosis.

“Derek and I have very different ways we cope with stuff, Derek is not very expressive whereas if I’m upset about something you could just look at my face and tell that I’m upset...I will tell you that I’m upset and that we need to deal with this and sort it out...whereas Derek will get to a point where “talk to the hand” and then I tend to maybe get cross and say “interact with me”, otherwise you feel like you’re having a fight with yourself sort of thing...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Belinda was aware of the difference between her and her husband in approaching the requirements of tending to their son, Brian’s needs. Belinda’s approach of remaining calm and comparing herself to those around her was a way she found helpful in dealing with Brian’s illness. Excluding Brian’s father from some of the requirements of caring for Brian was another method Belinda used to reduce conflict or distress:

“In hospital you’ve got to be calm for starters because sometimes you’re here for such a long time...you’ve got to be calm, you’ve got to be patient...I mean I come up here and I look around and I see so many children...they’re way worse then Brian and I just think for the time being we’re fine, we don’t have to cope with a lot of stuff
people must cope with…and Brian’s father just doesn’t handle that so I don’t involve him.” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Julie experienced a complicated parenting issue as she not only had to manage a daughter with cancer but decided to separate from her husband during the time her daughter was receiving treatment in hospital. Julie felt that separating from her husband during this time was the best decision:

“Why not take on the kid with cancer and leaving the husband at the same time? What do you do? You’ve got two major things going on in your life, do you introduce your kid back as they’re recovering into a home environment that is volatile, or do you make the break now [while she’s in hospital] and deal with some of the consequences later…and it [the divorce] was just about to happen before she got diagnosed…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

This sub-theme highlights the different approaches couples demonstrated throughout the process of caring for a seriously sick child. For some couples their different approaches resulted in conflict whereas others managed to avoid conflict by accepting the different approach between them and their spouse. For one family the impact of having a seriously ill child also accentuated pre-existing marital difficulties as the demands on the parents relationship increased and so the parents separated whilst their child was being treated.

Feeling powerless to protect. Parents also regularly commented on the difficulty they experienced in not being able to help their child “get better” as such. Parents often felt restricted and helpless while watching their child suffer a life-threatening illness and undergo treatment which itself, was often invasive.

Leanne expressed the difficulty she and her husband experienced as a result of having to hand over the care of their son to the health professionals and all they could do as parents was trust that their son was receiving the best medical care available:

“We know some of the side-effects of some of the medications, the positives and negatives, we know that there are a variety of treatments out there but at the moment this is the treatment that was recommended for our son, but we wouldn’t know any other treatment to access…so you have to trust the professionals which is huge and
my husband even said the other day, “we’ve just allowed people to insert something into our child’s chest [porta cath] which could be there quite a long time” and it’s quite a big thing to allow, to give permission for that to happen...so all we think of is that we’ve had the best advice possible so we will give permission for anything to help our son get better, to perform to his most optimal level, physically [and] emotionally.” (Leanne52 years, mother of 16 year old son Jarrod, Int. 1)

Leanne also stated:

“It’s been up and down, at times it’s been confronting and as my husband says “oh you can’t fix your child and that is confronting for parents” you know you want to be able to help your child get better, [you want] to do as much as you can and there is only so much you can do and the rest is just...as the doctor said, you get on a train and you go on the train and there are people on the way who will help you on the journey and you don’t know when you’re getting off, so she’s right, so you just take the advice of others and you go with it...”

This excerpt provides a good example of how challenging it was for Leanne and her husband to admit to the lack of control they had over their child’s health status and how they had no choice but to let go and let others help.

Sonia described the profound loss of control and fear of the unknown she felt when she had no choice but “surrender” the care of her son to the health professionals:

“I think it’s just the unknown, of just having to leave everything to your doctors, cause you don’t know, you don’t know how to treat it, you don’t know what to do and it’s totally just...surrendering everything to the doctors and not knowing how effective their treatment is going to be...are they deciding the correct things for your son...is there something better and they just don’t know about it, so it’s just the fear of the unknown and leaving it up to them completely...” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Not only did parents discuss the difficulty they experienced in handing the control of their child’s health over to the health system but they also described what it was like to be helpless and watch their child suffer in pain. Sylvia described the experience of not being able to assist when her daughter Letitia was in pain, all she could do was stand by and watch:

“[It was hard] just even two days ago when she had to have the cannula...and that made Letitia upset, which I understand because she didn’t want it, and so that’s upsetting for me...it’s horrible, the night in ICU was [also] awful...so when
unexpected obstacles occur which cause Letitia anguish, pain and upset...that’s probably the worst thing without a doubt...because there’s nothing I can do to change it.” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Even when children had finished treatment for their condition parents still struggled and felt the desire to protect them. Sandra admitted to wanting to keep Jake protected and so struggled with herself over this matter as she knew she would not always be able to keep him from returning to his former life and pursuits.

“I think you just want to keep them wrapped up in cotton wool, and you can’t do that, it is hard, I think once you’ve gone through something like that with a child it is hard, I can’t explain it, my head tells me that I’ve got to [let go] but the heart doesn’t want to...you just want to keep them locked up forever...so that would be basically the thing that I am finding hard to do...” (Sandra 44 years, mother of 15 year old son Jake, Int. 1)

Carol felt a similar pressure to Sandra as she was unsure of how much she should let her daughter go back to her typical life and activities. It is a fine line between being safe and sustaining a serious injury:

“I feel Erica’s life for the last 2 years has been put on hold and she was in this bubble and that now finally she is starting to regain the freedom of having a normal life, like playing netball but at the same time with letting her go to the pony riding party, that was a really difficult decision and [I] stressed, to let her go because her doctor has always emphasised it would be a bit like humpty dumpty, if she falls and does anything to that hip, it’s not going to be impossible, but extremely difficult for him to put her back together again...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 2)

As can be seen from the above, parents struggled to protect their child in many different ways as a result of the child’s illness. Parents were required to hand the care of their child over to health professionals and a health system they were not familiar with and so found this challenging and confronting. Parents then felt helpless as they often watched their child suffer in pain, not only as a result of the illness but also the medical procedures which were often unpleasant. Finally parents struggled with the on-going desire to protect their child, even once their child had finished treatment.
Parents were reluctant to let their child return to activities they engaged in pre-diagnosis, in fear of re-injury.

*The Experiences of Adaptation in Relation to Having a Sick Child*

The experience of having a sick child can best be understood from a phenomenological viewpoint as having a vulnerable child. Once parents had adjusted to their child’s illness and overcome some of the initial shock, they were able to carry out their parenting role in supporting and monitoring their child’s progress to a much greater degree. Parents discussed what this process was like along with their personal approaches which assisted them in supporting their child. One parent discussed the experience of what it was like to have her child almost die. A common experience among parents was viewing their circumstances in comparison to others and feeling as though they were better off, which they experienced as helpful. Parents also minimized the severity of their child’s illness by comparing the time it took from their lives, against the whole of their lifespan. Several parents also discussed their religious beliefs as fundamental to who they were as human beings and how they found comfort in these beliefs.

This master theme portrays the experiences parents had which assisted them manage and respond to their child with cancer. There were five sub-themes which contributed to this master theme: *experience of managing child’s illness, maintaining a sense of groundedness, acceptance of lifestyle change, responding to challenges and the experience of faith as being the key to survival.*

*Experience of managing child’s illness.* Parents managed the demands of their child’s illness in various ways which included continual visits to the hospital, closely observing and monitoring their child’s progress and coming to terms with the medical language and processes their child was required to undertake.
Belinda found it helpful to approach her son’s treatment requirements in a prepared manner and so was able to accommodate for any delays or gaps in between appointments. More than this she described an attitude of openness and acceptance of her situation which helped her remain calm and manage Brian’s treatment requirements:

*I don’t stress out about having to come to the hospital at all. I usually bring Brian and he brings his game and I bring magazines and food if we know we’re going to be here for a while… and if I’ve got gaps between appointments I know the Starlight room is there, there is a food place downstairs and yeah, we just roll with the flow… so I come prepared… so that’s how I deal with it…*” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

For parents, part of being able to manage their child’s illness involved understanding the medical terminology used by staff. Pamela experienced a period of adjustment to this use of a new language, but once this adjustment was made, she managed well:

“So after a while you get your head around the lingo and then you can speak back in the terminology and you start making your little charts of all your blood tests and how things are going and we did a diary, so that helped us each day…” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

It was also an adjustment for Sonia, not so much in understanding the medical terminology but understanding the process of events and what some of the treatment involved. Once she had an understanding of the treatment involved, she relaxed and felt more comfortable moving forward through the treatment regime:

“It was hard at first because I don’t like not knowing what to do… but with me as soon as I know what it is going to be like then I’m alright, like for example because we hadn’t gone through this with Timothy or anyone before, we didn’t know what it was going to be like to have radiation but once we got the hang of it, we were okay and with his chemo for example, we didn’t know what to do but once I got the hang of it, I was okay for the next cycle.” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Being informed and understanding the treatment requirements of their children’s illnesses resolved some of the helplessness parents felt and provided
parents with a renewed sense of control over their child’s illness. Leanne found it helpful being informed about all aspects of their son’s treatment. Leanne and her husband used this new information to teach their son about his own illness so that he had a greater understanding of his progress:

“I think being informed about processes, medication, so that we can go on the internet...we look up research papers, we try to understand some of the terminology and get a grasp of it, which has been good, we’ve been able to understand the blood counts and being given that information has been helpful as we can see progress and we can also get Jarrod to look at them too and together we can say “well this is when you weren’t well, now look back here, your blood counts weren’t very good were they, how long were they down for, well that was a long time wasn’t it, and then oh they’re coming up now, so this is why you’re feeling better because of this and this...so it’s been informative and helpful because then we can go back to Jarrod and give him factual information...” (Leanne 52 years, mother of 16 year old Jarrod, Int. 1)

Julie’s daughter Chloe experienced a number of serious side-effects from the chemotherapy she received for her illness. As a result her daughter almost died a number of times throughout the course of treatment. Julie described having to move at the pace of the illness, regardless of whether her daughter had almost died or not because she has no other choice. Julie just had to take what came and “keep moving” even when her daughter experienced a life-threatening reaction.

“Again it was a strange situation, she nearly died and 6 hours later it was just like over that, forgetting that and moving on to the next thing which was treating the shingles and you look back on it 6 weeks later and think, “Oh my God, she was almost not here again”, but yeah you’ve just got to strangely enough, take it as it comes, get over it... she’s okay now except for now you’ve got [something else] to deal with.” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

Julie went on to describe the extraordinary situation she found herself in and the fine line between life and death. It was difficult to comprehend the complex reality involved in helping her child live:

“...it (the chemotherapy) is just like this absolute evil necessary, it almost kills her on the way, it’s that close to killing her on the way but it’s also getting her better it’s just a really bizarre circumstance, a really bizarre thing to know that your basically feeding your kid enough poison that it’s killing something bad off but it could just be...almost taking her life as well, so it’s a bit of a bizarre situation...it’s not a matter of giving her medicine and saying “oh well, this is going to make you better”, it’s a
matter of giving medicine and saying “well you’re going to die if you don’t have this but along the way you can die if you do have it because there’s just so many side effects to it…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

Maintaining a sense of groundedness. Another method parents used to manage their child’s illness was “comparing themselves to others” and feeling as though others were worse off than them. This method provided parents with a feeling of groundedness. Developing future goals, valuing family or putting their child’s illness into perspective against the grander scale of life was also helpful.

Carol felt that on the scale of things that could go wrong, Erica’s diagnosis was minor. This thought provided some comfort and assurance to her. This sub-theme was explicated from T1 only.

“We wished that we didn’t have LCH [Langerhans Cell Histiocytosis] but on the scale of things that Erica could have had this is a much better thing to have…and the aggressive treatment that she would have had to have for [a different form of cancer] ” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

A similar theme was expressed by Belinda who also felt that her situation with her son Brian was miniscule in severity in comparison to some of the other families she had seen in the hospital. Again, realising that others were worse off had a way of making participants feel better themselves:

“I mean I come up here and I look around and I see so many children…they’re way worse then Brian and I just think that you know, for the time being we’re fine, we don’t have to cope with a lot of the stuff people must cope with…” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Sylvia found comfort by thinking about her daughter’s illness against the bigger scheme of life and had specific aims and goals which then seemed to make the illness look small and unimportant. This assisted her in achieving a sense of groundedness:

“…but generally it [my daughter’s illness] hasn’t been too much of an issue because it’s not forever, so there is light at the end of the tunnel, it’s just another couple of months in the big picture of life… as I keep saying to Letitia, we’ll look back at this
year and go oh 2007, we just won’t worry about it…” (Sylvia 45 years, mother of 14
year old daughter Letitia, Int. 1)

Sylvia went on to say:

“Obviously, my fitness has been affected, but we’ve got a plan, when this is over
we’re going to do our own swimming, jogging, beach plan…you’ve got to have these
aims and targets is what I feel…” (Sylvia 45 years, mother of 14 year old daughter
Letitia, Int. 1)

The theme of groundedness was also expressed by Leanne who found support
in her family which helped in keeping her stable. She saw her family as a grounding
tool which was always there in both good times and bad and which reinforced
everything you believe in, whether they are beliefs and values or a family gathering:

“I think it’s grounding you as a person, I think when you have a time of crisis or
some event in your life to celebrate then family can come together and be there for
you, so I think it’s a good thing, it’s support for values, lifestyle and faith…”
(Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Families undertook different measures as a means of maintaining a sense of
groundedness. For some this involved comparing themselves to others and feeling as
though they were better off, that their situation was not one of dire straits. Having
goals to work towards was also viewed as helpful as this allowed parents to feel that
there would be a time when the illness was over, when they wouldn’t have to deal
with it. The support of family was also seen as an important tool in maintaining
groundedness as they provided a sense of stability and reinforcement. Regardless of
how this sense of groundedness was achieved, being grounded allowed parents to feel
as they were not so “hard done by”, that they were okay and managing well.

Acceptance of lifestyle change. Parents also demonstrated what can almost be
called an experience of a “resignation to a new life”. That is, their lifestyle had
changed as a result of their child’s illness and they had adapted accordingly.

Jack described some of the practical or day-to-day changes in a very “matter-
of-fact” fashion:
“You just get up and basically the first job was school...now it’s straight to hospital...and we always try and get there early, by 8 in the morning...tomorrow is another day...got to go and get a canula put in tomorrow morning at the Mater and then from the Mater straight over to the Royal Brisbane Hospital (RBH) and from the RBH back to the Mater and then [get] bloods [taken] every hour on the hour for 3 hours...then see Doctor X...so that takes care of tomorrow...” (Jack 57 years, father of 15 year old daughter Annie, Int. 1)

Annie’s mother had a philosophical approach where she felt that people can not control everything that happens to them, which she found some satisfaction in:

“You can’t help what life brings before you, I think everyone has to learn that at some stage in your life...because you never know.” (Doris 40 years, mother of 15 year old daughter Annie, Int. 2)

Leanne felt that the routine and focus of their life was simply different to what it was pre-diagnosis, it was a new normal:

“Our normal has changed to what our normal was before, life is centred around hospital and appointments and treatment and medication and Jarrod without hair...” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

When asked what this “new but normal” life was like, Leanne replied:

“Exhausting...[but] this is life, just a different sort of normal for a time.”

The above examples show how parents adapted to their “new life”. Whilst it may have been different from their life pre-diagnosis and a little more exhausting, they slid into a new routine and simply did what they had to do

Responding to challenges. Parents demonstrated personal attributes that supported them in managing their child’s illness and therefore, emerged as an important theme. Parents found that there was a tendency to respond to their child’s illness in the same manner in which they would typically respond to other difficulties or scenarios.

For example Julie felt that she approached many facets of life in the same way, regardless of what it was. In this way she compared having a child diagnosed with cancer to moving house or getting a new job:
“I guess it all comes down to what sort of person you are, I’ll take things on, if they happen just take things on and deal with them and get through it, I don’t often fall down in a heap, but that’s just me personally, I attack work like that, I generally attack life like that as in if there’s something you’ve got to deal with, get on with it, whether it is a life threatening disease or change in jobs, or moving house or other things that crop up in your life…and that’s just pretty much my personality…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

Belinda felt that always showing a strong and positive front to her children was important. If she was not able to present at being strong at all time, she would manage her feelings away from her son, Brian:

“Even though I feel [down] sometimes in myself, I try not to let that come out with everyone. I might have some moments when I’m on my own, or with my partner when Brian is in bed…we might be sitting up having a drink or something and I’ll just say you know “I don’t feel like I’m coping at the moment and whatever” and we’ll talk…” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Sylvia described that part of how she coped was by expressing her feelings. She felt that this assisted her emotionally as she was then able to move on and deal effectively with the situation at hand:

“I’m one to express my emotions, let them out and then I’m able to move on and I don’t dwell on them but I need to release them, and that works fine, I don’t go around feeling awful about what’s happened to Letitia.” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Pamela found it easier to cope with each dilemma or situation as it arose and preferred this option, as opposed to being aware of what lay ahead and what future treatment may involve. This approach of managing what she was required to and not have to think ahead too far is similar to the idea of living in the present:

“I don’t know that sometimes knowing [what is ahead of you in regards to treatment is good], I don’t know that that helps, sometimes it is better not to know too much and just face it as you get to it rather than jumping ahead too far.” (Pamela 50 years, mother of 10 year old son Craig, Int. 2)

Julie also preferred this approach of living in the present but in a slightly different way to Pamela. Julie had no need to remember the past, once it was over, it
was over and her focus was on what lay ahead in front of her and only moving forward:

“I know this seems really odd but it’s like I don’t remember things that I don’t need to anymore, like I keep moving forward and whatever happens then has gone…which is probably a bit weird because I think some people would probably remember the journey day by day, where as I keep just wanting to move forward, it’s not that I want to forget, it’s just that I don’t see any need to keep [remembering]….I guess it is funny that you don’t remember big milestones but I keep looking for the next milestone, rather then tracking when the last one was because it’s not important anymore.” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

Parents described a number of personal attributes which can be viewed as either problem-focused or emotion-focused strategies, which supported them in caring for their vulnerable child. Regardless of the approach parents used, this theme reflected that the personal attributes people exhibit, are often consistent across different situations.

Experience of faith as being the key to survival. The final sub-theme which reflected how parents responded to having a vulnerable child was the faith families demonstrated in their religious or spiritual beliefs. Whilst not all families experienced a relationship with God, the families that did have a strong faith in God found this to be a very supportive experience. Families felt that their beliefs assisted them in finding meaning in their experience and it also provided them with a sense of assurance that their child would get well.

Leanne felt that the religious beliefs she and her family had, helped them to manage the different situations that were thrown their way. She felt it was important o have faith in God as this helped her to make sense of the world and eased the tough times when things went wrong:

“...and faith is really important through it all and we find people who don’t have faith in the future, in God, find life very difficult to deal with, [they] make no sense of the world around them, when things go wrong...” (Leanne52 years, mother of 16 year old son Jarrod, Int. 1)
Leanne had a fundamental belief that God wanted her son to get better and that God has given her family the strength to survive this experience. Leanne felt that this experience with her vulnerable child was all part of “God’s plan” and that by the end of the experience with her vulnerable child, she would be a better person:

“We know that God has a plan for us and we know that he would like to see us well and able to manage and that we have a strength inside us to manage whatever comes, not that we won’t react or have terrible thoughts or have terrible reactions or get angry, of course we will, that’s all there in the mix of everything but despite all that we will come out a different person and probably a better person as a result and being able to understand others and relate to other people, support them too as a result of this…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Pamela expressed a similar sentiment to Leanne regarding the faith and trust she had in God. Pamela described God as being unlike any human being as God has an unmatched power to heal. Pamela described a relationship with God that provided her with the assurance she needed to know that everything was going to be okay:

“Because you only have limited tools in yourself and you don’t really have all the knowledge that a doctor has and a doctor only has the knowledge that he’s learnt from a textbook and you get an assurance when you pray that everything is going to be okay, you can [then] move quite competently to the next step.” (Pamela 50 years, mother of 10 year old son Craig, Int. 2)

Pamela demonstrated her utmost faith in her religious beliefs with the statement:

“I just pray and God will answer me.”

This sub-theme reflected a particular approach that some parents demonstrated which supported them in supporting their child. Those parents who demonstrated a strong faith and trust in a higher power such as God felt an underlying assurance that they would be able to survive this experience that had been thrust their way and in the end, everything would be okay. Parents felt a sense of security via their relationship with God which was not reflected through any other support mechanism. Hence, it was only these parents which expressed the importance of their faith and belief in God, who demonstrated a “knowing” that their child would survive.
The Nature of Support

Parents commented on the support they received as being a salient part of their experience. Within this master theme many different types of support were mentioned, including the extended family, parent’s place of work and the education system supporting the child. The notion of support also emerged as being highly complex as it resulted in having both positive and negative connotations. In this way support was not only mentioned as being helpful but also unhelpful or potentially intrusive. Some parents even experienced a lack of support. Many parents commented on the positive response they received from their workplaces and the school their child was attending. One parent who was of Pilipino origin had a unique support experience which altered her perception of herself and how she felt others related to her.

The master theme of support contained 4 sub-themes: experience of family support, supportive workplace, experience of the education system and the experience of being accepted.

Experience of family support. The experience of family support was a theme experienced by all parents but in unusually different ways. While many parents reported that their extended family responded in positive ways, not all parents welcomed the support on offer. This sub-theme was explicated from T1 only.

As a parent with a vulnerable child Sylvia wanted all those around her to be informed of her family’s situation. She also felt it was important to maximize the support on offer from her and husband’s family:

“…when Letitia was diagnosed I wanted people to know so that they understood what was going on for us. I mean particularly my parents and my husband’s parents, they wanted to come straight away, but we held them off because I wanted to be able to pick when they came so they could be most physically and emotionally helpful for us, and we’ve been able to do that which has been great…as I said [to them] “we’d really like you guys to come at this time and you at this time”, to maximise and
Julie recalled that while she found the support offered by her family and friends as good, she was also overwhelmed by the support she received as it was an extraordinary and novel experience for her:

“Definitely the network of friends and family that just swung into action was just quite amazing, just being somebody that has never had anything happen to them...before this the kids may have just been to the doctor for their immunization, they hadn’t had anything so ever and so all of a sudden there’s just this huge network of family and friends that are just offering all this support and it was good but it was quite overwhelming as well...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Although families recounted support from their extended families as helpful and useful, for Carol it was important for the nuclear family to maintain as much independence as possible, as this was a means of maintaining the family’s usual routine and way of life. This meant being ambivalent to and resisting the support and attention provided by Erica’s school and their extended family, to the point of being rude if she had to be. The support on offer was not part of their normal routine:

“...as I said when we got home we had the school wanting to cook meals for us and I said “no, I don’t want you to cook a meal for us”, my husband is very capable of cooking and when I am home we just want to have a normal family life. I used to get very agitated when the relatives or the in-laws would turn up every week...I used to get quite stressed and the kids would pick it up instantly...you know Mum’s voice, Mum’s body [language]...would change...I’d get very tense and that sort of stuff and at times I did get a bit...rude to them, to say, stop coming round...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

As provided above, some parents welcomed any support on offer while other’s resisted and resented it. Added to this complex notion was Belinda’s experience where she felt a significant lack of support. Belinda had experienced a number of previous difficulties, prior to her son Brian’s diagnosis, which she found hard to manage. Whilst her mother was still alive she was in a nursing home with a degenerative illness. The only sibling Belinda did have was a brother who died from a
brain tumour. Belinda’s Dad was still alive but he had his own health problems and so was unable to provide Belinda with appropriate support:

“I’ve had to cope with such a lot with Bryce as a baby…my mother being unwell…she is in a nursing home now, so yeah I don’t have support from her so that has been hard…I don’t have any other brothers and sisters too so I don’t have a lot of family support, that is the hardest thing for me…as wonderful as my partner is I don’t have any other siblings, because I only had my brother [now deceased] …so I don’t have my mother and I don’t have any siblings and my Dad…he has some health issues and stuff at the moment as well.” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

This sub-theme represents how family support can be experienced and interpreted differently. When support was viewed positively, it assisted families to function more effectively. The physical presence of family members was part of viewing support positively as not only did it provide emotional assistance but also practical assistance. When viewed negatively the notion of support did however present as being two-sided as some rejected the support on offer. A lack of support was also experienced which made the role of caring for a vulnerable child that much harder.

Supportive workplace. A number of parents viewed their workplace as being supportive of their circumstances. For these parents their workplace’s provided important relief and respite which parents viewed positively. This sub-theme was explicated from T1 only.

Carol was in the unique position of being employed at the hospital where her daughter was receiving treatment. Carol received immense support from her workplace as her employer was accommodating of her needs on a practical level:

“I appreciate the Mater…I mean my work place…like everybody has a work place but their support in allowing me to stay on full pay when Erica was in hospital, to change my hours to suit school hours or 3 days one week…giving me total flexibility, any time off when I needed it... ” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Belinda’s workplace was also very accommodating of her needs:
“But other then that I have been very lucky…it’s very hard for people to stay employed and say ‘I need a day off every so and so…my hospital appointments have averaged one every 18 days last year…to get an employer to put you on in those conditions, I think I’m very very lucky…she [my employer] has a child friendly [workplace], we work from a house, so it is set up if we need to bring him [Brian] in…there’s a lounge room, kitchen, playstation and TV and all that there…computer and bed…” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Employers proved to be accommodating and flexible regarding supporting parents’ needs. Parents were able to continue working if they so desired as well as attend to the needs of their child. Parents recognised this support provided by their employer and appreciated it.

Experience of the education system. Schools were conscious of parents’ concerns regarding the academic progress (or lack of) of their sick child. Parents were concerned about how their child would be affected by missing so much school as a result of their illness however parents experienced relief when they were informed their child would not be adversely affected in any way. One parent also expressed her gratitude for the support she felt her son received from his peers.

Sonia was the first parent to express her relief when she learned that her son would not be kept down a grade as a result of his illness but that he would be able to move up with the other children in his year:

“That was worrying me last year, cause I was worried about this coming year but the principal said don’t worry about it and this year when I spoke to him he said he would talk to the teacher about what expectations they would have for Timothy…he said that he doesn’t want to keep Timothy [down a grade], he wants him to go with the other kids in his group [year level]…” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Leanne was also relieved (for her son) when they too were informed Jarrod would be able to progress to his final year of school with his classmates. Leanne felt it was important for this to happen:

“But he’s been reassured that he’s on track to go back to school next year for Yr 12 with the same class and finish Yr 12 with his friends, I think that’s important…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)
Sandra experienced a different type of support provided by her son’s school. The support she recognised came from Jake’s classmates continually visiting him at the hospital. She felt that the constant contact between him and his classmates was a crucial component to Jake’s well-being:

“...and his friends...they were a lifeline, because they were there and kept ringing and coming up to the hospital, they just wanted to talk to him all the time, (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

The flexibility and support provided by the education system was welcomed by parents who were initially concerned about how their child’s long-term illness would affect their academic progress. Additionally, it was not only the education system which provided support for the children but also their peers who were experienced as being keen to demonstrate their support and concern.

Experience of being accepted. This sub-theme refers to the experience of being accepted by those around them. The experience of having a child with cancer allowed this feeling of acceptance to be revealed, as it was not present prior to the child’s diagnosis. This sub-theme was experienced by only one parent who participated in the research. The family who were of an Asian background had a unique experience where as a result of their son’s illness, they felt completely accepted for who they were regardless of the colour of their skin. For the first time. This sub-theme was explicated from T1 only.

Sonia discussed her experience of being accepted by all those she came into contact with, as a result of her son Timothy’s illness. Sonia was surprised by how receptive people were to them, as previous to this time, she had always felt that Caucasian Australians perceived her and her family differently:

“I guess something that I haven’t really thought about but that I’ve just come to realise after this is that you always think when you bring them to school that you are different because you know with our colour [Asian origin] but then when Timothy was
diagnosed everyone didn’t care what you looked like, they were just so supportive and generous and helpful and you think, oh they see past that [our Asian origin] whereas sometimes we see ourselves as being different to the general population…” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)

Sonia’s perception of how others perceived her was obviously different to her own perception of how she felt she was perceived. The experience of her son’s illness had provided her with new insight into how she perceived herself in a foreign country. The community as a whole had reacted in a positive way to Sonia and her family as they were indifferent to her ethnic origin.

*Feeling Safe Within the System*

Feeling safe within this system refers to the many different experiences parents encountered as a result of having a child receive treatment within a hospital and the inevitable interactions involved with the staff working in the hospital. Parents discussed their relationships with the staff and were often impressed by the staff’s dedication to their work and the closeness of the relationships they were able to form with the staff. Most of the difficulties parents experienced within the hospital environment pertained to issues beyond staff control. Parents also expressed some concern regarding the future of the health care system as at the time this study was being undertaken the oncology unit the participants were attending for treatment, was in the process of re-locating to the campus of another hospital.

This master theme contains five sub-themes: *staff as incredible people, moving beyond a job description, questioning professional expertise, negotiating the treatment setting and experience of change.*

*Staff as incredible people.* Many parents commented on the value of their relationships with the hospital staff and likened these relationships to being similar to that of family. This sub-theme was explicated from T1 only.
Jack was one such parent who compared the relationship he and his family had with the staff, to that of being just like family. This analogy indicates the closeness, bond and depth of the relationship that the family had with the staff:

“But you always look forward to who’s on tonight or who’s on the next shift and that cause you know they’re like your second family in there...” (Doris 40 years, mother of 15 year old daughter Annie, Int. 1)

Pamela also made the comparison of staff being like family but took it one step further by commenting on the good-natured yet hard working personalities of the staff:

“They are just the most awesome group of people, they are light-hearted, they are fun, they’re dedicated in their work, you can form a good relationship with them and yeah, they’re just like having family around…” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

Julie added further to the analogy of staff being like family by adding that this experience has opened up a world that was previously unknown:

“...and just the nurses up here are really quite incredible...you sort of feel like you are part of a family, part of a different community that you didn’t ever never know about before…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Sylvia expressed her relief by a different set of circumstances that she experienced as helpful. She felt a great sense of security in knowing that the staff were available 24 hours a day, that is, that the staff were easily accessible:

I like the fact that we’ve got reasonable access to the staff, doctors and nurses, even when we’re at home, if I have a question I can ring up 24/7...not like dealing with a GP situation, make an appointment and we’ll see you next Thursday kind of thing, you’ve got 24/7 access to medical support…” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Pamela also felt reassured by knowing that the staff could be contacted at any time of day or night if it was needed. However she also found comfort in knowing that the staff were highly trained and experienced in managing diagnoses similar to that of her son’s:
“They were trained professionals who had seen this diagnosis before, they know what to expect… I think just having them that you could contact in the middle of the night if something went wrong and they would give you advice either to come in or what to do [over the phone]…” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

The dedication the staff felt towards their jobs was apparent to the families being treated at the hospital. As a result, they were adored by parents such as Sandra:

“I was with Jane [close friend with cancer] right up until Jake [my son] was diagnosed and I thought they were very nice there [in the adults section] but when you actually have a child with cancer they were like Gods... Doctor X was so wonderful, Doctor Y was wonderful and the nurses, they were just so different, you could tell that they wanted to be there…” (Sandra 44 years, mother of 15 year old son Jake, Int. 1)

As can be seen here families repeatedly commented on the relationships with the staff as being comparable to family. Parents felt very close to the staff and responded well to the familiarity of the staff working in the oncology ward as opposed to having new staff on every time they had a hospital stay. Parents also highlighted the availability of staff as something they really appreciated. The 24 hour availability of staff provided parents with a sense of security during a time which otherwise, was scary and unpredictable for them as parents caring for a vulnerable child.

Moving beyond a job description. “Feeling safe within the system” involved staff being experienced as moving beyond their job description. Parents commented not just on the helpful aspects of staff but the extent that the staff went to, to support families, which was experienced as being above and beyond the role of their job description.

Sylvia was one such parent who felt the staff exhibited qualities which were beyond the role of their job description. She felt staff put in the extra effort needed to support a patient:

“And I get the feeling too that if they sense a patient is down or upset they kind of put in the extra 10% to try and help them, to carry them through...you know and that’s not exactly something you can put into a job description...for this job you must at this
particular time do this…” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Staff were affected when children died of their illnesses which is a good indication of just how committed they were to their jobs of saving lives. Julie observed and commented on this emotional strain the staff felt when the children they had cared for died. Julie highlighted how the staff are not dealing with the simple “run of the mill” illnesses but life-threatening illness. She was left with great admiration for the role the staff undertook on a daily basis in caring for the children:

“They’re not just dealing with broken arms, they’re dealing with kids dying. And there’s been a young boy on the ward who passed away…and there was one particular nurse who was close to him and had been with him through his whole treatment and it was really devastating to her. It’s just really amazing watching how they care.” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Sandra also commented on the commitment she observed that the staff displayed. She felt that to be able to undertake the role these people did, they had to have been special:

“I think to be in that scenario, working with kids, especially cancer kids, they have to be a special sort of person and I think they were all there because they wanted to be there…not because it was a job.” (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

Parents appreciated and were in awe of the staff. The level of commitment and dedication to their work was obvious to parents and so the staff were admired and highly thought of. Parents acknowledged that the nature of their work was extraordinary and that it also had the potential to affect them on an emotional level as they cared deeply for patients.

Questioning professional expertise. Feeling safe within the system involved acknowledging limitations some of the staff demonstrated. Whilst they were few in numbers parents discussed some of the-not-so-good experiences they incurred, which often resulted in them having to advocate for their own child to ensure their child was appropriately cared for.
Carol experienced frustration with one staff member’s necessity to follow protocol and refusal to listen to and trust her as a parent:

“We only had one run in with a theatre nurse…Erica at birth was given the name Erica-Jane which was an odd thing to do because we’ve always called her Erica but because it was on her birth certificate it was on her chart here, so when staff came across Erica they would call her Erica-Jane and as much as we’d say her name is Erica, this theatre nurse was going to refuse to let Erica have her operation because her medical bracelet said Erica and not Erica-Jane…so that made me see red thinking that that’s just taking protocol a little bit too far.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Julie was in a unique situation as her daughter experienced a number of severe life-threatening side-effects from the effect of the chemotherapy. As a result her daughter required additional medical treatment which resulted in additional medical staff being involved in her care. Julie found this process very complicated and felt she was often required to act on her child’s behalf to co-ordinate the different medical personnel involved rather than the medical staff doing this themselves:

“Yeah, and she had nutritionists and physiotherapists and the endocrine people, the bone people, the oncologists…all trying to whip in and do their own thing, but [they] weren’t aware of what anyone else was doing...and the physio’s would come up and [say] come on lets get you moving, [and I’d say] “no guys, the bone people have said don’t move [her] without this brace on, [and I would ask] have you spoken to them”, [and they would say] “well no, not really”...yeah so that balance of things, having to do that project management side for people that I consider professional that should have had that experience…” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

Sonia and her family felt that there was a significant lack of support received once their child had completed treatment. They felt ill-prepared to return to community life as they were no longer within the secure environment the hospital system offered:

“Like after his treatment there was nothing else, despite the number of times you’ve spoken to the occupational therapist, despite the number of times you’ve spoken to the social worker, it was like okay he has finished with his treatment and that was it, like there was no real follow up, we had to find our own ways to make sure he was okay. I just felt like you were just a number and once they’d seen you that day, that week or whatever, that’s it...” (Sonia 36 years, mother of 8 year old son Timothy, Int. 2)
Some of the difficulties parents experienced associated with feeling safe within the system were poor communication between staff, poor post-treatment support and an inability to deviate from protocol when following protocol was unnecessary. The examples within this sub-theme have shown that all experiences incurred were unique to the respective family and that encountering difficulties with staff was not common.

**Negotiating the treatment setting.** Parents described their experience of the hospital system as a whole and its impact on their experience of hospital life. Parents described both helpful and unhelpful experiences.

One of the components Carol was particularly impressed with was the ability to accompany her daughter on all tests and procedures. It was comforting too know that as a parent, Carol was included in all aspects of her child’s care:

“I liked that regardless of what Erica had done, whether it was an MRI or a CT, [I liked] being able to be there with her, not being excluded as in we’re taking her in now and then having to sit in the waiting room…that parents are allowed to be hands-on in that respect.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 2)

Common experiences existed regarding the difficulties parents had in dealing with issues that were beyond staff control. Parents expressed concern at the lack of facilities available for teenage oncology patients (as at the current time there are only paediatric and adult oncology units in Queensland):

Sylvia expressed the importance of providing an environment for teenagers where they could relax and feel more at home, in addition to having the opportunity to meet others their own age, as they would if they were at school:

“If there was just some place for older kids to hang [out], that enabled them to get out of their bed situation, be in a lounge, watching TV without having little kids around you where they might potentially meet other kids of a similar age in a “not too controlled environment”, a sort of more natural environment...” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)
Leanne expressed a similar view to Sylvia but also emphasized the difficulty she felt the staff had trying to connect with some of the older children, like her son. Leanne did however, feel that the paediatric environment was a very positive one:

“I think it has been a challenge for the older teenagers, that’s been the major thing, I think it’s been nice having the teenagers with the paediatrics, it’s been uplifting, positive, fun, distracting and good humoured all the way through but sometimes [the staff are] just a bit young with their approach and I think they’ve realised that, and they’ve said what can we do for this child who’s older and who shaves and who is too big for the bed…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

Pamela felt some of the facilities for parents within the hospital were poor. When parents literally lived at the hospital for periods of time, access to decent meals was a necessity but getting access to adequate meals was difficult. Pamela had to find time to get away from the hospital to go and look for food:

“One of the difficult area’s while you are in hospital is for the adults to actually get access to food and things, like you’d usually have to try and get out to a shop where you could have [something] because there is only a microwave [that we have access to]…” (Pamela 50 years, mother of 10 year old son Craig, Int. 1)

Leanne was in the unique position of being from a country town and so clearly felt the impact of having to move to a capital city to allow her son to receive the appropriate treatment, as paediatric oncology services were unavailable rurally. Leanne was unhappy with the centralization of health services:

“I want to write letters to everyone from the Prime minister down...oh yes, I’m going to go out there and change the world, not just for Jarrod but for all children because children depend on their environment ...and knowing various people we will be able to ask professional advice on how to go about advocating health in our area, Central QLD, so we can assist in some way, enabling more care, but only if governments are prepared to de-centralise [services]...(Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

As can be seen from the above parents experienced a number of different scenarios which required different levels of negotiation skills. Parents were relieved to know that they were included in all aspects of their child’s care which provided them with a sense of security and comfort. At the same time parents experienced a lack in
some of the facilities available which inevitably impacted upon their time at the hospital. This lack of facilities experienced by parents was not only for themselves but also their children. Parents experienced a lack of facilities regarding food options and the centralization of services for themselves and a need for amenities more appropriate for the teenagers to be made available.

Experience of change. Over the course of the study the oncology unit where the data was being collected merged with an already existing oncology unit in another hospital. Parents expressed their concern regarding how this merge would influence them and the treatment their child would continue to receive. Many families had become very comfortable in the oncology unit where their child had commenced treatment and so were reluctant to move to another hospital.

Sylvia was one parent who enjoyed the comfortable and familiar environment of the original oncology unit and was concerned that this same “familiar” atmosphere would not carry over to the new hospital:

“...and that’s one of the concerns I raised about moving where we will go from a hospital that services 50 patients to a hospital that services 150 and then combined we’re 200...so you can imagine, moving from this little ward of 9 beds to a ward of 50 beds, it will be 4 times the number [of staff]...I mean I just know for Letitia, it’s nice to come in and say “oh Tina and Jeremy are on” and today Kate is here, you know them [the staff], and they know you, you mightn’t have seen them for 3 weeks or 4 weeks, but it’s still nice...” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Leanne had a different type of concern. In the original oncology unit she felt as though she played a significant role in supporting her son and ensuring he was at his optimal health. Leanne was concerned how her and her husband would be treated and the extent to which they would be able to remain a significant part of their son’s care in the new oncology unit:

“To know we’re going to have a change of place soon, that’s going to be a challenge...are they going to be as free with their information [in the new setting]...we feel as part of the team [here], people don’t say “oh this is the nurses
job or this is the doctors job, they’ll do that, you don’t have to do anything”, cause we see ourselves as being important to Jarrod’s wellbeing, so that he is in the best frame of mind, and has the best attitude to receive treatment…” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

As a father Alex was worried about the care of his son transitioning to a new doctor when they moved from the original oncology site to the new one. Alex felt that the new doctor would not be as familiar with his son’s illness and treatment history as the current doctor and was concerned about how this would affect the quality of care his son received:

“There will be a transition, we will have a new doctor, this new doctor won’t know the history [of my son’s illness], he will be briefed about the history but it’s not going to be the same as Doctor X where he was there from the beginning…” (Alex 37 years, father of 8 year old son Timothy, Int. 2)

At the time the follow-up interviews occurred (T2), the treatment of some children had already been transferred from the original oncology unit to the oncology unit of the other hospital site. Parents reflected on some of their experiences once they had completed this move.

Leanne spoke about one of the differences she experienced in moving between oncology sites. She felt there was a lack of communication between staff and parents:

“Even ringing up for bloods, I used to ring up the old hospital and someone would be able to tell me straight away what Jarrod’s bloods were, now I might not even get a call back…” (Leanne 52 years, mother of 16 year old son Jarrod)

Sylvia also compared the treatment her daughter received between the different oncology sites. Sylvia felt the original oncology site where her daughter had received treatment was a much more supportive and friendly environment. The very lack in the quality of the services of the new oncology unit was highlighted even more so, by their experiences of the original oncology unit:

“and I didn’t realise until we moved across to here, how great it was that we had the staff at the old oncology site…it was a small unit so when you came back in Letitia knew the nurses and it was like “hi Letitia, how are you going” and they would remember a conversation from last time and ask about follow-up where as here it is
As can be seen from the above, parents had many fears associated with moving from one oncology unit to another while their child was in the midst of receiving treatment. At the original oncology site parents experienced a very personal level of care from the staff, which they appreciated and they were made to feel as though they were an important part of the team treating their child. Parents expressed concern that these same facets of treatment would not transfer over to the new oncology site and some of their fears were realised once they had made the move.

Re-evaluation of Values During a Life-Changing Experience

Having a child diagnosed with a potentially life-threatening disease such as cancer, inevitably led to parents re-evaluating their priorities and how they wanted to live their life individually and as a family. Parents re-considered what was really important or vital to them and to the continuation of their lives as a happy family.

This master theme is comprised of four sub-themes: an emerging awareness of new perspectives, making the most of every moment, a renewed sense of family and a renewed awareness of enjoyment.

An emerging awareness of new perspectives. The experience of having a family member diagnosed and treated for a potentially life-threatening illness led to parents’ re-evaluating what was important to them. Parents realised how precious and fragile a human life actually is and thus, developed a new awareness which involved valuing life more so and refusing to worry about the minor or petty issues that are often so easy to get caught up in on a daily basis. This sub-theme was explicated from T1 only.
Carol commented on how the experience of her daughter’s illness modified her own beliefs:

“I think that once any member of your family has a life-threatening illness, it really changes your perspective on life and what is important.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

In her state of renewed awareness Carol realized that human beings often think that misfortune and tragedy will never happen to them, but always to someone else. Carol went on to say that when a tragic event does happen to you, it will change your life suddenly and permanently:

...things always happen to other people...it’s always somebody else who gets cancer or somebody else who has a car accident...that I think a lot of us do take life for granted and then it’s not until something directly affects you that you think, “my life”, [it] can change forever in an instant and your life is never quite the same again.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Sylvia’s re-evaluation consisted of not letting the little things in life which used to bother her and were meaningless, bother her anymore. The experience of her daughter’s illness bought to light that it is not worth worrying about the minor things she once used to. There is so much more to life then worrying about the many little things that may go wrong on a daily basis:

“...little things don’t bother me, it’s that simple...I mean you know stuff that you might have got caught up in once, it’s like I don’t care...in fact don’t worry about anything if you can...you know if the computer breaks down, don’t worry about it, don’t stress, it will get fixed when it gets fixed and the 25,000 e-mails you didn’t get, will the world fall over because of it?...It [daughter’s illness] just puts it all into perspective, it’s just seeing it all [the bigger picture of life] and stepping right back and going well you guys can deal with all that petty stuff if you want, I’m bailing out. (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 1)

Belinda experienced a similar realization where the experience of several tragic events in her life led her to the belief that life is too fragile to worry about petty issues:

“I guess when you’re dealt with these things I think you look at life a little bit differently, you look at life a little bit more positively then what you did before, that’s probably the huge change in me, because I dealt with my brother [dying], then I dealt
with Brian and my cousin, it’s probably only weeks until he dies with the brain tumour as well, he was diagnosed two weeks after Brian... so I find that I don’t let stupid things worry me that used to worry me before, because life is too precious.”
(Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Julie had a particularly life altering experience since her daughter’s diagnosis.

For Julie life has become much more then just moving through the routine and mundane activities of daily life as she has a renewed focus on really wanting to enjoy life and get the most out of it. Julie realized that it was important to have time out and enjoy making a break from routine:

“...and I don’t want to sort of get stuck in the rut of life of... you know you go to work, you come home, you cook dinner, you do homework, you have a bath, you put the kids to bed, you stay up till 2 in the morning doing washing and lunches and... and it’s like... I want to pick the kids up from school and go and eat fish and chips by the water for dinner at night... I know you’ve got to fit all the “have to’s” in... you have to do homework and you have to wash clothes and you have to do things like that but just to every now and again take a big step out and go “hey lets blow the homework tonight”... it’s not going to kill anyone. It’s not going to kill anybody if I don’t do a load of washing that night...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 1)

For all these parents, having a child diagnosed with cancer had a significant impact on their perspective, how they wanted to live their lives from this point onwards and what they valued. Their experiences have brought them to a reality that appreciating life and their children were of the utmost importance. As a result of having a child diagnosed with a life-threatening disease, these parents are in the unique position of having new awareness of what living should really be about.

Making the most of every moment. The new awareness of the fragility of life that parents experienced as a result of their child’s diagnosis, led them to want to make the most of opportunities. Avoiding procrastination and organizing regular family holidays were key issues parents felt were important in an effort to make the most of opportunities. The notion of procrastination has become anathema to parents as they have a renewed value of living in the present.
As a parent living through a daughter’s diagnosis and treatment for cancer, Sylvia experienced a renewed appreciation of carrying through with commitments:

“It also has affected my life as in if I am planning to do stuff like catch up with a friend or I promised Letitia a trip to Melbourne for ages and getting her a dog and things like that, I plan to kind of action them...not just talk about them...” (Sylvia 45 years, mother of 14 year old daughter Letitia, Int. 2)

Belinda experienced a similar sentiment to Sylvia as she has a renewed sense of making the most of the current moment in time and the opportunities it presents. Belinda also acknowledged an awareness of the future being unknown, emphasizing the importance of making the most of the current time. In her renewed awareness of the fragility of life and the importance of making the most of opportunities she has developed an appreciation for those who have lived a long life:

“Yeah, we plan things and we do things and I do things as much as I can, I probably plan more since finding out he was unwell because you don’t know what the future is going to be...Brian has a great grandfather still alive, he is 93...so we try and visit him as often as we can...cause that’s pretty special still having someone alive at that age.” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Sandra confirmed that she would never have predicted she’d have a child diagnosed with cancer. As a result she feels she can no longer be complacent and careless in her attitude to life. The new awareness brought about by her son’s diagnosis has highlighted the importance of living life fully so that you never look back with disappointment:

“...and that’s the other thing I’ve got out of Jake’s diagnosis, I never dreamed one of my kids would get cancer, so I just think you’ve just got to be happy and healthy in your life decisions and live life a bit...have no regrets. (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

For these parents, the experience of having a child diagnosed with cancer has bought to reality the fact that life is fragile and can end at any moment in time for any of us, unexpectedly and without warning. As these parents are now aware of this harsh reality they have developed a renewed awareness of appreciating every moment
and doing the most they can to make it the best moment in time.

*A renewed sense of family.* As parents developed a new awareness of the importance of life and a newfound appreciation for making the most of opportunities, the importance of maintaining a happy and healthy family is paramount to this new way of life. The majority of parents interviewed in this study indicated that the focus of their life was to provide the best for their children that they were capable of.

Jack makes it clear that his children are his number one priority as he strongly feels that family comes first, even if it is at the expense of other facets of life:

“Well the important thing in life is your kids and if something is wrong everything has to stop…you just look after your kids first.” (Jack 57 years, father of 15 year old daughter Annie, Int. 1)

For Sandra the experience of her son’s illness has re-emphasized the importance of the family unit and spending time together:

“We’ve always been very family orientated and we’ve [myself and my husband have] always been with them with everything that they do…[we’re] probably more determined to spend time together…” (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

Carol re-iterated that for her and her husband their priority in life was to provide the best they could for their children. Carol wanted to ensure that her children have the best possible chance of achieving well and are provide them with the best opportunities to do so:

“[What is important to us is] getting our two children through school and that they grow into happy well adjusted adults that can be self-sufficient.” (Carol 42 years, mother of 8 year old daughter Erica, Int. 1)

Finally, in her experience of valuing the family unit Leanne provided a profound sense of why the family unit is of such importance. For her the family represents an identity source which can always be relied upon. The family unit is able to meet the basic needs of the family members and provide the required support as the
children in the family develop their sense of identify and independence. In this way the family unit provides a sense of security:

“I think families are good support structure, whether it be children leaving home and parents coming to the rescue or having homely advice about recipes, it’s just a connection or sense of belonging.” (Leanne 52 years, mother of 16 year old son Jarrod, Int. 1)

The renewed sense of family was a theme which many parents identified with and experienced as important. Parents demonstrated the importance of the family unit via multiple ways which included spending more time together and prioritizing their children’s needs above all else. Parents also emphasized the importance of providing the best they could for their children and identified the family unit as an important support structure in developing identity and independence.

A renewed awareness of enjoyment. Finding enjoyment in simplicity was a common theme experienced by many parents who participated in the research. The experience of having a child diagnoses and treated for a life-threatening illness had again developed a renewed sense of what it meant to be happy. As long as the primary goal of having all family members happy and healthy was attained, parents were often content to settle for a “low profile” lifestyle. This sub-theme was explicated from T1 only.

Sandra admitted that prior to her son’s diagnosis the family were very busy and spent little time relaxing and enjoying life together. Prior to Jake’s diagnosis Sandra and her husband had considered the prospect of slowing the pace of life a bit but this prospect was reinforced once Jake was diagnosed and the importance of family time together became critical:

“I don’t think we changed our values but before Jake got diagnosed we were a very busy family and they were all doing sports and before Jake even got diagnosed my husband and I said we were going to slow it down this year and have the weekends to ourselves and go away...we just wanted to slow it down and go to the beach and get the kids to do surfing...” (Sandra 44 years, mother of 15 year old son Jake, Int. 1)
Carol was another parent who placed an emphasis on family happiness being generated from simplicity. From her experience Carol realized that it is not necessary to have extravagant goals to define good family times together but that happiness can come from simple acts:

“We have little goals within our family of things we’d like to do but as far as the big main travelling overseas…nah…nah…we were happy going to Coffs Harbour…” (Carol 42 years, mother of 8 year daughter Erica, Int. 1)

Carol compared the fast paced life of her sister to that of her own, she relishes the idea of a quiet lifestyle characterized by a high degree of contact between herself and her family:

“[it’s important] just to smell the roses...you know I look at my sister who every afternoon takes her children to an activity, you know she doesn’t stop running 7 days a week, they’re always on the go…but now we sort of think if we have to do something different, it’s like we like being at home and pottering around rather than having to run around.” (Carol 42 years, mother of 8 year daughter Erica, Int. 1)

A result of having a child diagnosed with cancer is a renewed appreciation of not only preserving the family unit but doing so in an uncomplicated manner. Parents realised that much of their happiness and contentment as a family could be achieved via simple uncomplicated measures. This is consistent with their renewed appreciation of life in general.

Experience of Future Health Concerns in the Present

After all the changes and demands these parents experienced as a result of having a child with a potentially life-threatening illness, it was common for parents to express some concern about their future. Parents expressed concern about the fear of the unknown in terms of what the future held for their child’s health. This master theme is comprised of one sub-theme only being fear in response to child’s vulnerability.
Fear in response to child’s vulnerability. Parents often had a fear that their child’s illness would reoccur at a later stage and that they would again experience their child’s vulnerability in relation to the potential loss of their child.

As a parent Carol is full of hope that her daughter’s illness will not return, but admits that it is part of her ongoing awareness that she will constantly be reminded of Erica’s illness by their annual check-ups. As a result Carol and her family will not be able to move beyond the daughter’s illness completely and so will retain some long-term anxiety:

“...we’re remaining positive and optimistic that this is gone and that’s it’s not going to come back, but as far as feeling totally well, as I say until she gets to 18, it’s always going to be something that’s in the back of my mind every time we go and have our yearly skeletal, waiting for the result to say all the bones are clear, [it’s] something that’s going to be an annual anniversary sort of thing...” (Carol 42 years, mother of 8 year old daughter Erica, Int. 2)

Belinda is another parent who also worries about what the future might hold for her son but tries to manage this by living in the present and making the most their lives now:

“It still is a bit of a worry now (the brain tumor) but what I try to do now is, I try not to worry about the future, I just kind of take everyday or every week and I plan things...we’ve got a holiday booked in January...and I just try and treat Brian...normal...just do typical everyday things...and I try not to dwell on anything with him and that...” (Belinda 44 years, mother of 10 year old son Brian, Int. 1)

Sonia expressed a philosophy similar to that of Belinda. There is an underlying concern for what the future might hold that is always present, yet she attempts to live in the current moment. Sonia ignores what the future may or may not hold and clings on to the family’s typical lifestyle trying to maintain this as much as possible:

“I think for everyday life we just try to keep it as normal as possible, we try not to be overwhelmed by what is happening, we try not to dwell on it and you know if he has to do this or he has to do that we just go and get it over and done with, we try not to let it overwhelm us so much or the fear of the future or the fear of the unknown, we try not to think about it...” (Sonia 36 years, mother of 8 year old son Timothy, Int. 1)
Julie was not only concerned about the possibility of a recurrence but also the long-term side effects from the treatment her daughter endured. The future of her daughter’s health is not only dependent on a re-occurrence of her illness but also but on the side-effects of the treatment administered to date, that may present in the long-term:

“...you don’t know all the lasting side effects, will she be able to have children...don’t know till you get there, will she maintain her growth, will her bones ever recover from this...we don’t really know...” (Julie 37 years, mother of 8 year old daughter Chloe, Int. 2)

As a result of their child’s illness many parents demonstrated that the unknown future of the child’s health status had resulted in an underlying pervasive fear. The fear of an unknown future has been difficult to contend with and parents have attempted to move beyond their concerns and live optimistically in the present. Parents attempted to ignore their fears and get on with their lives by continuing their pre-diagnosis lives in addition to having events to look forward to in the future.

*The Experience of Optimism and Altruism*

This master theme refers to experiences parents had at the end of or after active treatment had been completed for their child. Parents felt joy when discussing their child’s progress after experiencing many months of invasive treatment. The experience of having a child diagnosed and treated for cancer also generated a desire for some parents to give something which was meaningful back to the community. Finally parents discussed how their newly acquired knowledge of cancer, which they had gained through having a child with the disease, had affected them.

This master theme was explicated from the follow-up interviews only (T2). It consisted of three sub-themes: *experience of child returning to well-being, giving back to the community and a new awareness of the prevalence of cancer.*
Experience of child returning to well-being. Parents experienced great joy at seeing their child improve and return to some sense of normality where they could participate in daily life activities once again. While most parents experienced little difficulty integrating their child back into the real world, this transition did not go well for all parents.

Julie was in awe at her daughter’s tenacity to survive. Julie’s daughter Chloe had been so seriously ill and her survival was such an unknown factor, that when Chloe did improve to the extent she was able to participate in community life, it was incredible:

“But you know a month ago, she was a flower girl at a wedding and when we were discussing the flower girl dresses last year, the bride and I were going, “well I wonder if she is even going to be around”, yet here she was and she just danced the night away, this is a kid that was in a wheelchair in December and you know at the end of May, she was dancing the night away at a wedding, and it was just like, WOW! So she has come along in leaps and bounds...” (Julie 37 years, mother of 8 year old daughter Chloe)

Carol felt relief at knowing her daughter was finally at a stage in her illness where she was able to return to some of the activities she participated in pre-diagnosis. For Carol she experienced this as a sense of being unleashed, after her daughter’s life had been restricted for so long:

“...being able to let her play sport, cause I feel Erica’s life for the last 2 years has been put on hold and she was in this bubble and that now finally she is starting to regain the freedom of having a normal life, like playing netball...” (Carol 42 years, mother of 8 year old daughter Erica)

Returning to school was an important milestone for Sylvia’s daughter Letitia, however, this progress and return to her former life wasn’t experienced with the same joy and relief as it was by the other parents, but met with difficulty and despair. Letitia had been out of the school system for so long that it was difficult to slide back in and resume her school life with her peers where she had left it. Her peers were at an
age where they had certain interests and these interests didn’t fit in with supporting
“an old friend” return to class:

“By the time she got back into school her peers had all moved on…they’re 14 so they
don’t really understand [what Letitia had been through] and at the end of the day
they are far more interested in what boyfriends they’ve got and their immediate
assignments and Letitia was so dislocated from the whole year by her lack of
attendance, it was hard for her to reconnect back in and then add to that the self-
conscious thing about wearing a bandana or a beanie…” (Sylvia 45 years, mother of
14 year old daughter Letitia)

Parents described feeling great joy at seeing their child return to a state of
well-being where they could once again participate in community life. For some
parents this experience was particularly special as the likelihood of their child
surviving had been seriously questioned. Other parents experienced this return to
community life as a sense of being freed after feeling as though their child’s life had
been imprisoned for so long. At the same time however, returning to a former lifestyle
was not always met with ease as some parents felt their child experienced difficulty
integrating back into their peer group.

Giving back to the community. Some families experienced a desire to “give
back” to the community as they had experienced their child as receiving good care
and so were keen to return the favour and support others in any way they could.

Pamela was very grateful for the high quality of treatment and support her son
had received from the hospital and so as a result was keen to return the good as much
as possible:

“We definitely try to give as much as we can to charities that are connected with
cancer and with this hospital and whenever we can do anything to help…” (Pamela
50 years, mother of 10 year old son Craig)

As a parent Sonia wished to express her gratitude in a different way. She
expressed a desire to potentially provide support to others via a therapeutic role, as
she had had first hand experience at being on the receiving end as a patients’ parent:
Later on in my life I may even want to do something like be an Occupational Therapist and be better at it then the one’s [I have met]...because you can see where the gaps are...”(Sonia 36 years, mother of 8 year old son Timothy)

Returning the good they had received was experienced as important to some parents as they wanted to express the gratitude they had received. Some parents opted to do this via giving what they could to charities and supporting the hospital where their child had been treated, whereas other parents felt that undertaking a therapeutic role in the future would be useful to future families and children undergoing the same experience.

New awareness of the prevalence of cancer. For many parents having a child diagnosed with cancer bought to mind the prevalence of it as a disease. Parents experienced that it wasn’t until their own child was diagnosed with the illness that they became aware of how prevalent cancer actually is in society.

Doris felt that the general population was not aware of how prevalent cancer is. She felt that it was not until you are forced to deal with it, as in having a family member diagnosed with cancer, that you realise it’s prevalence as it is at this time that you are thrust into a position of having no choice but to deal with it. By having a family member diagnosed with cancer you’re awareness of it around you then increases:

*I think you realise a lot, like there’s been a lot of things on the TV lately, I think it brings cancer in front of your face and you just realise there are so many people out there who are dealing with this, be it kids, be it adults, I just don’t think people understand paediatric cancer is just so prevalent until you’re actually within [it], you know it’s out there, but not to the extent [until] you get into it...”* (Doris 40 years, mother of 15 year old daughter Annie)

Sandra also experienced an increased awareness of the prevalence of cancer. Not only was her son diagnosed with the disease but she knew of other’s also with the disease which for her was a constant reminder of how prevalent it is:
“...it does [have an impact on your life] to a degree in every time you turn around someone has got some form of cancer, so you’re reminded how hideous this is, and it’s everywhere...I’ve just had a friend diagnosed and we had another one of Jake’s mates’ Mum...she was up visiting us at the hospital with her daughter to see Jake and then 3 or 4 months later she was diagnosed with breast cancer, it’s just everywhere you know...” (Sandra 44 years, mother of 15 year old son Jake)

Along with Doris and Sandra, Alex also gained new knowledge about cancer as a disease as a result of having his son diagnosed with it. However, Alex also felt that the new knowledge he had acquired about cancer had helped him to feel better about it and less afraid. The knowledge that treating cancer has become much more successful today then in previous years, provided relief for Alex:

“Our awareness of cancer prior to Timothy’s diagnosis was that we just knew about it, but when you get hit [with it], it’s like it’s totally different, your view about cancer is really different...if this was 20 years ago and you say cancer well that’s it, but now it’s treatable, treating cancer is more advanced now, for me the word cancer is not as scary as I thought before, it’s still scary but not as scary...” (Alex 37 years, father of 8 year son Timothy)

Having a child diagnosed with cancer inevitably meant that parents learnt a great deal more about this particular disease then they ever thought they would. By being forced into this position where they gained new knowledge of it, they also became aware of how prevalent cancer is in the community. Parents were dismayed by the prevalence of cancer and how the general public are typically completely ignorant of the spread of this disease. One parent experienced relief at his newly acquired knowledge of cancer as it involved acknowledging the progress that has been made in recent years to treat cancer, resulting in improved outcomes of survival rates.
Explication of the Child Interviews

The interviews carried out with the child participants resulted in five master themes emerging: the experience of illness, the upside of being sick, re-focusing on what is important, acquiring a new perspective and the experience of returning to well-being. The first four master themes described below were explicated from both the first and follow-up interviews. Due to the range in ages of children who participated in this study there may be great variation in the experiences explicated within some of the sub-themes.

The Experience of Illness

This master theme refers to the experiences children endured as they had no choice but to undertake many months of invasive and extensive treatment all in an effort to survive their life-threatening disease of cancer. Children reported many of the medical procedures as being painful and unpleasant. Not only were the children required to withstand severe medical treatment but also suffer the side-effects which accompanied this treatment. Many of the side-effects noted also had negative and severe consequences the children were required to cope with. There are two sub-themes within this master theme: illness as a horrible experience and feeling restricted along with other horrible things.

Illness as a horrible experience. Children reported numerous negative treatment experiences. Most of the medical procedures involved were invasive and painful. Some of the procedures such as surgery were also approached with fear as this was the first time for some children to ever experience hospital, let alone an operation. The after-effects of treatment were also described by children as being unpleasant such as when waking up after surgery or wanting to vomit after oral medication.
Letitia noted the pain associated with the needles. Her comments referring to the needles she was given infer that they are worse than any ordinary needle:

*L: “The needles and the operations…the blood test needles and the chemo needles which really, really hurt and cannula needles.”*  
*I: “Are they not like normal needles?”*  
*L: “They are but they’re injected into the muscle so that hurts really, really bad.”*(Letitia, aged 14 years, Int. 1)

Craig did not like the taste of the oral medication he was required to take, so much that it made him feel sick:

“The medicines I had everyday were gross. I nearly wanted to vomit after them.”  
*(Craig, aged 10 years, Int. 2)*

Chloe found the after-effects of surgery difficult to manage:

*C: “[I don’t like] surgery.”*  
*I: “What’s terrible about surgery?”*  
*C: Getting put out and then waking back up.”*  
*I: “What don’t you like about that?”*  
*C: “Well it makes your head feel all fizzy and dizzy and then you wake back up it tastes yuk.”*  
*I: “You have a yukky taste in your mouth?”*  
*C: “Yeah, and it makes you angry, like it’s not you, but it makes you angry. So that’s the hardest part.”* (Chloe, 8 years, Int. 1)

For Erica, anticipating surgery was enough to make her feel nervous. The mere thought of having an operation was enough to make her physically feel sick:

*E: “[The hardest part about being sick was] probably getting ready for operations, like the first time I got so nervous I almost felt like being sick.”*  
*I: “What did you think was going to happen?”*  
*E: [I thought I might] lose too much blood…and actually [I felt] worse sick after my operation.”* (Erica, aged 8 years, Int. 1)

Whether it was anticipating surgery, the after-effects of surgery or another medical intervention, children experienced them as scary, painful and unpleasant tasting. The irony of this situation is that treatment the children were required to endure seem to cause as much pain and sickness as it was curative.

*Feeling restricted along with other horrible things.* Different experiences were associated with this sub-theme. One of the more obvious experiences were the
limitations children experienced physically. Participating in sporting activities was common among participants and without this aspect to their lives, children felt directionless and without meaning. Added to this is the isolation they felt by being taken away from their peers and usual activities. In the current sample both academic and sporting activities provided crucial contact with their peers and played a large part in defining who they are as individuals.

Jake found it difficult to identify another activity or pastime he could participate in, when he was unable to continue playing sport. He felt a great sense of loss as a result of being taken away from his sport and was unable to fill the gap it created:

J: “[The biggest change when I was first diagnosed was that] I couldn’t play sport.”
I: “Was that the biggest impact on you or was it something like losing your hair or spending everyday in hospital?”
J: “No, I couldn’t play sport, the rest didn’t matter. I spent a lot of time playing sport and I like playing sport. If I can’t do that I have to find something else to do and I don’t know what that is.” (Jake, 15 years, Int. 1)

Annie also felt restricted as she was unable to engage in many of the activities she had done pre-diagnosis. Annie described this in a way which indicated she was or at least felt completely free in her pre-diagnosis lifestyle, but was now bound to boredom:

“Well before I could do anything…you know, but now, I can’t swim, I can’t play netball…and get money from umpiring…[life is] boring.” (Annie, aged 15 years, Int. 1)

Hospital life didn’t appear to be particularly inviting either, as both Craig and Chloe explain some of their dislikes about hospital life. Living away from home bought many new experiences for the children, which were sometimes difficult to adjust to such as eating food their parents didn’t cook and sleeping in a bed other then their own.

“I didn’t like the hospital food…It wasn’t McDonalds.” (Craig, aged 10 years, Int.)
“Hospital food [is yuk]. It’s like it was 12 months old.” (Chloe, aged 8 years, Int. 1)

Upon returning home, Chloe had the following comment about home life:

“Sleeping in my own bed [is also good]…they’re rock hard [in hospital].” (Chloe, aged 8 years, Int. 1)

Children also experienced negative reactions from their peers regarding their illness. Ten year old Brian had a tumour in his brain which was blocking the hypothalamus region and so was affecting his growth rate. As a result Brian was taller and bigger than most other children his own age and maintaining an appropriate weight and height for his age was difficult. As can be seen from below Brian suffered the impact of this height and weight gain. Both his physical ability and self-esteem were affected:

“I used to be a fast runner before I discovered this tumour…oh I was so fast but now I’m so slow because I’m so heavy and I can’t carry my body weight.” (Brian, aged 10 years, Int. 1)

Brian went on to say:

“Oh, [life is] pretty hard because of this growth I’ve got, all the bigger kids at school tease me about it, because I’m big, I’m fat, I’m ugly and that just really hurts, that’s all…

Chloe also described the unfavourable reaction she received from her peers when she returned to school, regarding the loss of her hair. Returning to school after many months off would have been difficult enough, then to also have to contend with taunts:

C: “I have no hair…”
I: “What’s that been like…has it bothered you or you don’t care?”
C: “A little bit…”
I: “What bothers you about having no hair?”
C: “Kids tease me…” (Chloe, aged 8 years, Int. 2)

Within this sub-theme a number of different experiences are evident. Children experienced restrictions associated with no longer being able to participate in sporting activities, some of the younger children struggled to adapt to hospital life and children
were teased as a result of the physical impact their illness and its side-effects had on them. Overall, children had many hardships to contend with as not only did they have to deal with the severity of treatment but also the implications of the treatment which affected many facets of their lives.

*The Up-Side of Being Sick*

Among all the difficulties and hurdles the children had to undertake as part of a lengthy and complicated treatment process, they were able to identify some positive experiences which provided them with hope and some reprieve during an otherwise morose time. Two sub-themes contributed to this master theme: *pleasantness of being sick and medical intervention at its best.*

*Pleasantness of being sick.* This sub-theme centred on nice experiences children incurred as a result of their illness and which they typically would not have experienced if it had not been for their illness. As can be seen from the quotes below one of the nice experiences associated with being ill was being the centre of attention and receiving presents from family and friends. It was a common experience for children to receive gifts shortly after they were initially diagnosed.

Erica described her experience of receiving gifts:

*E:* “[One of the good parts about being sick was] getting lots of presents...and I like attention.”
*I:* “Who did you get the presents from?”
*E:* “[I got the presents from] Mum’s workmates, grandparents, aunts and uncles, cousins...and I got the attention from the same people.” (Erica, aged 8 years, Int. 1)

Letitia had a similar experience appreciating the gifts she received from those around her but was also able to acknowledge that the gift giving occurred only as a result of her being sick:

*L:* “You get more presents...people give you stuff.”
*I:* “Who has been giving you the presents?”
*L:* “Family, friends, relatives, yeah…”
*I:* “What’s it been like getting all these presents?”
“Like you’re spoilt...” (Letitia, 14 years, Int. 1)

Also noted as being a nice experience whilst receiving treatment in hospital was the influence of the Starlight Foundation. The Starlight Foundation provides entertainment for children in hospital. In most hospitals a room is provided (commonly known as the Starlight Room) where children can go and play in a safe environment. The Starlight Room offers children respite from their hospital bed and has a number of different toys and games suitable for most age groups. The Starlight Foundation is often responsible for providing funding so that sick children in hospital may meet famous people such as their hero or heroine, providing them with gifts and also organises and funds family holidays. The Starlight Foundation is the ultimate “gift giver”.

Craig’s experience of the Starlight Foundation included the following:

“I met Delta Goodrem [through the Starlight Foundation] and got lots of presents...including a dog [from my family].” (Craig, aged 10 years, Int. 1)

Chloe also had a nice “Starlight” experience:

C: “I like Starlight.”
I: “What’s Starlight?”
C: “A foundation on TV.”
I: “What do they do?”
C: “I met the Veronicas, which was good and I was on TV...and I met Marcia Hines and Demi and the Red Bulls and an AFL player...and I won lots of games and won one colouring in competition.” (Chloe, aged 8 years, Int. 1)

There were also some unique experiences some of the older children discussed in relation to their illness. While most other children did not enjoy the experience of losing their hair Jake found it amusing and for him it seemed to be a method of connecting with his peers. Jake demonstrated a capacity to make fun of himself:

“That [losing my hair] was fun...everybody at school signed my head. I was just sitting there one lunch time, and one guy was like, can I sign your head and then just everybody did it, I even got a couple of teachers to sign it...it was pretty fun...I drew things on it when ever I was bored.” (Jake, 15 years, Int. 2)
Children experienced great joy being the recipients of gifts from their family and friends. For one participant enjoyment was even experienced from a side-effect of the treatment, losing his hair.

*Medical intervention at its best.* Positive experiences the children reported were associated with spending less time in hospital as this meant less time out of their comfort zone or their own home or typical lifestyle. It should also be noted here that this sub-theme only appeared in the follow-up interviews (T2) with the children, perhaps because by this stage children were receiving less treatment and so didn’t have to attend hospital as much and so were not able to reflect on the course of their treatment and view it from a different perspective.

Erica described the benefit of being able to receive treatment from home. This was a much more relaxing and less anxiety provoking experience for her:

_E: “One more thing that I liked about it is that I didn’t go to hospital to have my blood tests, a lady from the hospital came and gave me the blood tests at home…I got hot pink bandaids to put on after wards.”_
_I: “What made it better about the nurse coming here [home]?”_
_E: “I think at that time I still got pretty nervous about going to hospital and I didn’t have to worry about getting ready or anything, I could still be in my pyjamas and have my blood test…” (Erica, aged 8 years, Int. 2)_

Jarrod also experienced relief when his hospital stays decreased. Knowing that he only had to attend hospital for several hours, rather than be admitted overnight, was a much nicer experience:

_I: “What’s all the treatment like that you have been going through?”_
_J: “It’s easier now.”_
_I: “What has made it easier?”_
_J: “The fact that I don’t have to be admitted into hospital anymore because I hate the hospital. I only have to go for a couple of hours and then I get out.” (Jarrod, 16 years, Int. 2)_

Reduced hospital visits were viewed as a really positive experience from the children’s experiences along with having to attend the hospital for much shorter periods of time. These experiences were encountered with relief and ease.
Re-focusing on What is Important

The third master theme explicated reflected the relationships that the children valued in their lives. Two sub-themes were identified within this theme being valuing relationships and recognizing the importance of family support. These sub-themes emerged during an exploration of what the children perceived was helpful during their illness experience or if there was anything that had changed for them during their illness experience.

Valuing relationships. Children demonstrated an ability to be appreciative of the support that had been available to them throughout their experience. Whether this support had come from a family pet, hospital staff or friends the children were able to identify that it had a positive impact on them and was one which played an important role in helping them through their experience. This sub-theme was explicated from T1 only.

The relationship that Erica had with her cat was a very important one as she was very fond of her cat. As Erica had good memories associated with her cat she used this to her advantage by thinking of her cat every time she was faced with a difficulty or dilemma:

E: “Well, I’ve got one thing [that is really important to me] and I basically put that in my mind every time I’ve got something hard [to do] and I have to get over it...my cat.”
I: “Why is she the most important thing to you?”
E: “Well I got her on my third birthday so she is 6 now. She’s just a good memory to me, and even though she is a cranky old thing, I still love her...” (Erica, aged 8 years, Int. 1)

Brian was able to recognise the value of his friendships and how he found reprieve in these friendships. Brian also had positive relationships with those he met in hospital and so was appreciative of these relationships:

“Other nice stuff is there is always nice people like you coming up and talking to me [here in hospital] trying to help me out... and your friends always help you out. I’ve
got a few friends that live down the road and one friend from my school that lives near me...” (Brian, aged 10 years, Int. 1)

Jake was also appreciative of the support his friends provided but also recognised the value in meeting new people at the hospital whether they were patients or staff:

“Knowing that all my friends cared about me and they came up a lot [to hospital] and family, and I got to meet new people. I met lots of people like patients and the patients’ parents and I met all the doctors and all the nurses...” (Jake, aged 15 years, Int. 1)

This sub-theme reflects the children’s ability to be appreciative of those around them and realise the importance of supportive relationships. The children found support via their pets, friends and also the hospital staff.

Recognizing the importance of family support. Children were also able to identify the fundamental support their families and religious beliefs provided for them. They were able to show gratification of this (most of the time, along with a sense of humour).

Craig placed his family and his faith in God on the same level. He found support and strength in both of them:

C: “God and family.”
I: “Why are they the most important?”
C: “Family because they helped me through everything and do everything for me...and God because he made us.” (Craig, aged 10 years, Int. 1)

Letitia’s view was slightly different but probably typical of someone her age. She felt that she did not have much choice, so might as well get along with her family!

L: “Family [are the most important thing].”
I: “What makes family so important?”
L: “Because you’ve got to live with them...so you might as well get along with them.” (Letitia, aged 14 years, Int. 1)
Brian recognised the value of his family as they were always there for him but also recognised when other things became more important!

B: “My family and my food [are the most important things to me].”
I: “What makes your family so important?”
B: “Oh, they’re always there for you, they’re always there when you’re having needles and doctor appointments…”
I: That’s pretty good…and has this always been the most important thing? Was there ever a time when food was more important than your family?”
B: “Last night…all you can eat…just if it’s an “all you can eat restaurant”. “All you can eat” is when my family goes out of my life. They can come back in as soon as I’m finished.” (Brian, aged 10 years, Int. 1)

Jarrod recognised that his relationship with his family had changed as a result of his illness experience and that it had changed for the better:

I: “What has changed most in your life since you were diagnosed?”
J: “My relationship with my family.”
I: “What is the relationship with your family like?”
J: “Now it is more open. Before I was like, I didn’t really tell people stuff until they needed to know, unless they asked me.”
I: “What do you think has made that happen?”
J: “Just being around them all the time.”
I: “And what’s it like now, being more open with your family?”
J: “I don’t know, it’s just different.”
I: “Do you think it’s good or bad or do you have a different relationship with your parents?”
J: “I think I get along with them better.” (Jarrod, 16 years, Int. 2)

Both the sub-themes within this master theme demonstrate that children (of various ages) have the capacity to show gratitude and understand the value of the relationships they have with those around them and how these relationships have influenced their lives for the better.

Acquiring a New Perspective

The overall essence of this master theme depicts how the children have survived their experience and describes some of the perspectives that they have reached by the end of their experience. There are two sub-themes within this master theme being dealing with adversity and self-reflection and re-evaluation.
Dealing with adversity. This sub-theme reflects the attitudes or actions that the children felt helpful to exhibit in order to survive their illness experience. This sub-theme demonstrates how the children have established insight into their illness and how they managed it.

Brian found some practical strategies to be useful when he was undertaking certain medical procedures as they diverted his attention away from the immediate situation which involved pain:

“...my other thing is also to sing a song quietly or play a game while I’m having a needle, or watch the tellie, or look at a poster...that’s what I did with one blood test.” (Brian, aged 10 years, Int. 1)

Letitia found that one of her “helpful strategies” was simple to do what was required in order to get it over and done with as soon as possible:

“Just do what the nurses tell you to do, if you’ve got to have a needle, just get it and don’t complain otherwise it will go on forever...” (Letitia, aged 14 years, Int. 1)

Jake’s carefree attitude and desire to always have fun supported him:

“Just wing it, I couldn’t care less about it or what happens, just have fun, that’s about it.” (Jake, aged 15 years, Int. 1)

Craig found solace in his faith that God was always there for him:

C: “Don’t worry...[about it], and remember God is always looking after you.”
I: “If you did say that to someone...how do you think that would make them feel better?”
C: “[Because] to know that someone is actually looking after them [would make them] happier.” (Craig, aged 10 years, Int. 2)

This sub-theme reflects both the practical applications and beliefs and attitudes the children had which supported them through their illness experience. Even though only a few have been mentioned here, it is easy to see the vast range of supportive methods the children employed.

Self-reflection and re-evaluation. The children demonstrated their renewed perspectives which is a reflection of how they as human beings have changed as a
result of their experience. This change has occurred in different ways whether it was about being more knowledgeable about cancer, refusing to worry over the little things in life or whether it was refusing to see yourself as being any different from anyone else, even though you have cancer. This sub-theme is a good indication of how the children have grown emotionally as a result of their experience. This sub-theme was explicated from T2 only.

Craig was aware that he had acquired new knowledge as a result of his illness:

“I didn’t understand cancer before I had Hodgkin’s but now I do understand cancer.”
(Craig, aged 10 years, Int. 2)

Letitia developed a new appreciation of what was important to her and what was no longer important based on her experience of having cancer. This new perspective had a profound influence on how she felt about her own self-image:

L: “I suppose just not to worry over little, little thingy’s that people stress over and that’s probably it.”
I: “What are some example’s of the little things that you would worry about?”
L: “Cause your hair looks really messy when you go to school and all the girls worry about their hair and I’d just like to have some…I always used to complain about my hair but compared to now it’s like, I don’t care I’ll have messy hair.” (Letitia, aged 14 years, Int. 2)

From Jarrod’s illness experience he realised that he was no different to anyone else even though he had a disease called cancer:

I: “What’s it been like having cancer and having to go through all of this?”
J: “I don’t see myself as having cancer as I don’t have it anymore...”
I: “Did you ever see yourself as having cancer?”
J: “Yeah, but I’m not different from anyone else...” (Jarrod, aged 16 years, Int. 2)

On a much deeper level Jarrod experienced a change in his attitude to life. His experience of having cancer impacted upon his perception of how viewed himself and the world around him:

J: “I suppose I’ve changed, like my outlook on life and stuff...”
I: “How has it changed?”
J: “Just to live life and not worry about anything, maybe just go ahead and do it...like if you want to do something you should just do it and not let anything stop you.”
I: “What sort of attitude did you have before?”
J: “Only do things if you are allowed to do them.” (Jarrod, 16 years, Int. 2)

This sub-theme demonstrated children’s ability to reflect on their entire illness experience. Some children acknowledged acquiring new information about the topic of cancer while other’s acknowledged that their illness experience had changed their view of themselves and what they valued. For others, their experience had reinforced that they were no different to anyone else, regardless of whether they had cancer or not.

The Experience of Returning to Well-Being

This master theme relates to the transition children experienced as they moved from a place of illness to that of health. This master theme has been explicated from T2 only and it was likely that this occurred as it was towards the end of their treatment regime that the children were able to note improvements in their condition. Children were also keen to return to their former lifestyle, after a lengthy period of experiencing a limited lifestyle. This master theme contains two sub-theme’s being desire to return to my former life and experience of improving.

Desire to return to my former life. This sub-theme represents the desperation children experienced where they did not care if they injured themselves further.

Erica experienced a strong desire to return to activities she participated in prior to her diagnosis. This desire to return to her former lifestyle was so strong that she was not concerned about the prospect of re-injuring herself:

“Well at the moment I’m so desperate [to return to gymnastics] that I wouldn’t really care if I had to have so many operations [if an injury occurred] because I’m just so desperate to do it…” (Erica, aged 8 years)

Jarrod had been required to move to Brisbane temporarily to receive treatment for his diagnosis as it was unavailable in the rural area he resided in permanently. He was therefore keen to return to his former lifestyle as for him this meant returning to
his hometown:

“I’ve got one month left of treatment and then we’re going back home (country town) and right now I just want to get it over and done with.” (Jarrod, aged 16 years)

It was almost a sense of urgency that participants experienced in wanting to return to their former lives. Their desire to return to their former lives and activities was considerably strong as their freedom had been restricted for so long.

Experience of improving. This sub-theme refers to the children’s ability to note improvement in their own sense of well-being and provides a sense of looking forward to and anticipating a future. As can be seen from below the children often recognised this improvement in their condition by a physical ability to do more and by having to come to the hospital less often.

Erica noted the improvement in her physical ability and assessed this via activities she was not able to participate in:

“Well it’s definitely a lot different because I couldn’t do any sport and now I can…I’m doing netball, I’m doing PE, I’ve done high-jump, long-jump and I did cross-country for the first time this year which is a 1.4 km run…so I can do a lot more. (Erica, aged 8 years)

Craig identified that his need to attend the hospital less and less, was a sure sign that he was improving:

“It’s better coming only once every 3 months now for check-ups [to the hospital] because it means it’s been longer without cancer.” (Craig, aged 10 years)

Letitia experienced her progress by feeling more energetic and a sense of being ready to move forward in life:

L: “I’m just more energetic and ready to just get on…”
I: “What’s it like having all that behind you now, like not having to stay in hospital?”
L: “Oh it’s good because I hate staying hospital.”
I: “And, what is it like being more energetic?”
L: “Good…” (Letitia, aged 14 years)

The above examples demonstrate that the children had the ability to monitor their own health status and that they did through a variety of means. For Erica it was
the ability to do more physical based activities where as for Craig improving meant attending the hospital less and less. Letitia experienced her improvement as an inner sense of being ready to move on.
Discussion

The current study has highlighted the value of examining the experiences of a particular phenomenon and in the case of childhood cancer, those experiences have been revealed as life-threatening, life-changing but also life-rejuvenating. The current study has explicated these experiences using the rigorous qualitative methodology of IPA, which has enabled a rich account of the experiences of children and their parents to be presented. As a result this study has been able to extend the findings of previous research which has focused on clinical imperatives. The findings of the current research emphasise that it is particularly important for a well-founded and thorough perspective on childhood cancer to be presented, not only for the purpose of research but to better inform clinical practice, policy and intervention. This study plays an important part in deepening our understanding of childhood cancer as experienced by the children and their parents.

Previous research in the area of childhood cancer has been dominated by quantitative approaches. Whilst the outcome of such research has provided a solid foundation of knowledge to build upon, interpretive approaches, as undertaken in the current study, have the potential to deepen and clarify the findings of this previous research. The development of a wider field of childhood cancer research offers new insight and an opportunity to broaden our understanding of the experiences associated with childhood cancer.

The results of early research in this area saw children marginalised as they were deemed to be incapable of responding to or providing for themselves and so were often not included in decision-making which affected them. The idea that children should “be seen but not heard” has been a common occurrence until recently. It was not until the early 2000’s that researchers of nursing and sociological
backgrounds provided children with a “voice” and it is only now that psychology is beginning to explore the experience of illness, particularly from a child’s perspective. Fochtman (2008) argues that to truly understand another human being, we need to investigate how he or she perceives the experience. The importance of developing a thorough understanding of the experience of childhood cancer has also been highlighted by the idea that children have the ability to give meaning to their experiences and view the world via their interpretation of their experiences. In this way “childhood” is seen as the early part of the life course and has a particular cultural phasing (Dixon-Woods et al. 2005). This view can be taken further by indicating that childhood is not a universal state with consistent features, but one which varies over time and cultural context. With a renewed perspective on the state of childhood, an important framework has been established which invites the exploration and understanding of the experiences of childhood cancer. This need invites a phenomenological approach (Fochtman, 2008) to examine the perspective of those affected by childhood cancer. Dixon-Woods et al. (2005) argue that parents’ and families’ experiences of childhood cancer are important to develop a complete understanding of childhood cancer. Fochtman (2008) goes on to say that it is only when clinicians truly understand the meaning of this illness that interventions can be designed which ease suffering and improve the QoL of these families.

**Interpretation of Parent Results**

The results saw the emergence of a number of sub-themes and master themes. In the following section the main components of the results are discussed and interpreted.

*The shattering of assumptions.* The impact of having a child diagnosed with a potentially life-threatening disease was unimaginable and unfathomable as parents did
not have the slightest inkling that their child had cancer when their child initially became sick. The level of shock and deep concern that parents experienced upon hearing of their child’s diagnosis was beyond everything they had ever known previously and it was a completely unexpected event. Parents revealed that their lives changed in an instant when they learnt of their child’s diagnosis. Similar results were found in a study by Martinson and Cohen (1988). In their study 33 families were followed over a five year period. Their results indicated that not a single parent had considered their child’s initial symptoms were of a serious nature. In another study by Dixon-Woods, Findlay, Young, Cox and Heney (2001), parents initially thought their child had a virus, muscle strain, constipation or other minor ailments which explained their initial presenting symptoms. The current findings confirm these findings and underpin the significance of an unexpected diagnosis of cancer.

The findings of the current study indicate that a dramatically life-changing and potentially fatal event is not usually expected among the complete realm of life’s possibilities. However, when such an unexpected event does occur, it challenges all the assumptions that the parents may have had regarding the level of controllability they had over their own lives. Parents were forced to come to terms with the reality that they actually had very little control over their lives. That is, the ability to plan and ensure their family’s safety was not guaranteed.

Whilst improvements in medical treatment have seen survival rates increase significantly over the past three decades, many parents in the current study still perceived that a diagnosis of cancer was a sure death sentence. Similar results were found in the study by Yeh, et al. (2000) who also found that parents perceived the diagnosis of cancer in their child as a sign of death. These results indicate that the disease of cancer is still very much perceived as incurable.
Not only did parents experience a shattering of assumptions when they first learnt of their child’s diagnosis but they reported an ongoing fear that the illness may return. It was a common experience for parents to fear that their child’s illness may reoccur at a later stage. This fear of recurrence was experienced as a constant reminder. Parents lived in fear of the unexpected occurring again. Parents attempted to manage this fear by focusing on the present moment and making the most of the present moment. Anxiety and fear about recurrence of the disease was also found to occur in all parents who participated in the study by Van Dongen-Melman et al. (1998). Van Dongen-Melman et al.’s study, which focused on parental experiences of childhood cancer survivors, found that this theme emerged as being one of the most important long term effects.

Significant grief and loss issues were experienced as parents grieved for their ill child and an unknown future. Parents grieved for the life that they once had which seemed predictable and comfortable. The experience of having a child diagnosed with cancer also meant a loss of their former identity as parents took on a new role, one in which they would forever be the parent of a child with cancer and one which altered their capacity to identify as protectors of their children.

*Emotional pain.* A definite difficulty parents experienced in adjusting to their circumstances was the anguish and distress in coming to terms with the knowledge that they were unable to control the health of their child. Parents struggled emotionally to let go and place the care and life of their child, in the hands of someone else. Such results demonstrate the unique bond and unconditional love a parent has for their child. In the study by Yeh et al.(2000) parents attempted to maintain a sense of control over their child’s health by learning the appropriate medical terminology and clinical status of the child as this helped parents to feel as
though they could adequately monitor the child’s status. These results also infer that a parent’s identity is tied closely to the relationship with their child.

*Capacity for adaptation.* The findings from the current study indicated that having a child diagnosed with cancer was a certainty that for a specified period of time, family life would revolve around the sick child. The extent of this impact on the family was similar to that of a domino effect, in the sense that it was not only parents’ lives which were altered indefinitely but also siblings’ lives, and in some cases the lives of extended family members. As the priority of the family instantly became that of tending to the child with cancer, families were segregated as they were forced to comply with the demands of their child’s treatment regime. This situation left families feeling detached, disjointed and isolated as one parent was often required to stay with the sick child in hospital and the other parent remained at home caring for the other children in the family or working to maintain an income for the family. Some parents also experienced a reduced ability to continue working in paid employment and siblings may have been cared for by friends or extended family members. These results confirm families struggled to maintain their comfortable, stable and structured life whilst also catering to the needs of a seriously ill child.

Whether it was negotiating the relationship with their spouse or juggling the desires of their child against the restrictions imposed on them by their physical condition, parents entered new territory and so were required to develop and devise new methods of managing their unique circumstances. These results offer insight into the notion that the current structure of the family unit in Western society does not easily lend itself to major family disruptions.

Participants did however cling on to whatever they could of their “former lives” as it seemed that they found some salvation and sense of normality by doing
this. Parents needed to feel as though their entire existence was not being consumed by their child’s illness. In the current study some parents demonstrated a general acceptance of their situation and so were easily able to adapt to regular and lengthy hospital visits. Other parents found that developing a new routine of their child undertaking radiotherapy and chemotherapy and learning the relevant medical terminology assisted their adjustment to their current circumstances. For one parent, adapting and responding to her vulnerable child meant keeping up with the constantly changing status of her child’s health condition and moving on, even though her child almost died on several occasions.

Martinson and Cohen (1988) also found that parents had a compelling need to normalize life as much as possible by developing and restoring routines and relationships. In the current study the experience of having a child diagnosed and treated for cancer even allowed one parent to experience a renewed appreciation for the mundane and boring components of her daily life, that were often taken for granted. It is an interesting thought to acknowledge that one may have to experience an unwanted, unexpected and horrific ordeal to appreciate daily life.

Parents commented that the unrelenting co-operation and consenting attitude of their child assisted their own adjustment. Most parents reported that their child demonstrated a unique ability to accept their diagnosis and the severity of their condition with ease, which they as parents, found to be supportive. With the exception of one family who participated, none of the other parents indicated that their child questioned why they had been inflicted with such a serious illness. These results lend support to the idea that the children in this study may have had a better capacity to cope with the adversity at hand than their parents. While there was only one family in this study in which the parents did have difficulty assisting their child adapt to the
diagnosis and undertake the necessary treatment, it should be noted however that this
is not necessarily an unusual outcome. As Cassano, Nagel and O’Mara (2008) state, a
diagnosis of cancer can be difficult for adolescents to digest as this is a time when in
their life when they want to make gains in terms of their own independence. A
diagnosis of cancer brings this emergence of a teen identity and independence to a
sudden halt. All of a sudden the adolescent is not able to spend as much times with
peers their own age and is forced to spend more time with their parents either at home
or at the hospital.

Many parents also experienced a “sense of groundedness” as helpful to
adjusting to and living with a vulnerable child. Parents achieved this sense of
groundedness by viewing themselves as better off then others or by placing the time-
frame of their child’s illness within the whole of their life-span. During a time in
which families were experiencing a “crisis” they demonstrated a clear ability to see
themselves and their situation positively which then worked as a supportive
mechanism. The results of this study indicate that it is not until something “bad”
happens that one is able to reframe the situation and demonstrate gratefulness and
appreciation. Again similar results were found in the study by Yeh et al. (2000) where
it was common for participants to compare their situation to others who were worse
off. The authors of this study suggest that parents who stay optimistic are likely to
have better medical compliance.

Several families in this study demonstrated a strong faith in God or a higher
power. These families were often unwavering in their belief that their child would get
well and overcome their illness. Not only did having a strong faith in God produce an
unwavering belief amongst these parents that their child would get better, many of
these families described how this belief provided them with an increased ability to
make sense and meaning from their experience, as it provided them with an understanding as to why their child was diagnosed with cancer. In some cases, the children of these particular families also appeared to find solace in their religious beliefs as their faith in God provided an assurance that they would get well.

*Feeling connected and community support.* Parents reported experiencing support from their extended family members which served to assist them both emotionally and on a practical level. One mother did not have the family members to help her and so experienced this as a lack of support and felt this as a loss. Family support however, was also seen to be a hindrance as one family expressed that they did not need or want the support of their extended family but rather preferred to rely on the immediate family. Other mechanisms of support were found to be parents’ place of work and the school the sick child was attending. All experiences parents reported about their workplace were positive as employer’s were accommodating of parents’ needs in allowing parents to work part-time or reduce their hours to suit their child’s medical appointments. Schools were also regarded as highly supportive as all parents who commented on their child’s school did so in a positive way. The children in this study were not kept down a grade or penalised in any other way as a result of missing large amounts of the academic year due to their illness or medical treatment requirements. These results indicate that for this particular sample community sources such as employers and educational settings were generally supportive and accommodating towards the families in their time of crisis.

A unique type of support was experienced by one family who were of Asian ethnicity. This family felt that Caucasian Australian’s perceived them to be “different” as they were not of Australian background. It was not until their experience of having a sick child that they came to realise that Caucasian Australian’s
didn’t perceive them as being any different. The family were accepted and supported wholeheartedly, regardless of their skin colour. The experience of having a sick child thus enabled this family to view themselves differently to what they had done prior to their child’s illness, and that was seeing themselves as the same as everybody else. Results such as this have not been widely documented previously. That is, the impact of having a child diagnosed with a life-threatening illness has changed a family’s self perception due to ethnicity.

Anxieties were alleviated and parents reassured via their connection with the staff caring for their children. Parents spoke highly of the staff and close bonds were formed with the staff, particularly the nursing staff as families were impressed by the level of competence and care the staff demonstrated. Families were of the utmost admiration for the staff as they gave so much of themselves in their jobs. Some parents did incur difficulty in relating to staff, however these experiences were fewer in numbers in comparison to the positive experiences parents recounted. Poor communication among staff was a key factor for one parent, which made the role of caring for her daughter all the more complicated and demanding. Another parent experienced a significant lack of support once her child had completed treatment and returned home to recover. This particular parent felt ill-prepared to care for her child at home.

Other concerns parents described pertained to matters above individual staff control as they referred to the general facilities of the hospital and oncology unit. Several parents of teenage children expressed concern at the lack of facilities made available to this older group. Parents also commented on the lack of facilities made available to them. For example, parents were often required to stay in hospital with their sick child for weeks at a time yet few eating amenities were made available to
them. Finally, one family who was from rural Queensland would have appreciated the decentralisation of services, as this would have enabled their son to receive treatment in their home town rather then having to temporarily move to the capital city to receive treatment.

Another important issue raised by parents occurred as a result of this study being carried out at the same time that changes to the structure of the children’s oncology health service within the Queensland Government were taking place; the two paediatric oncology units within Brisbane were merging. Parents expressed concern at the impact this merge would have on their child’s treatment and the quality of staff support they would continue to receive post-merge. Parents relished the fact that they were part of a small oncology unit which oozed comfort and a “family-like” feel and so understandably feared the consequences of being part of a bigger oncology unit with new staff.

Re-assessment of life, values and happiness. Parents re-evaluated what was important to them and reassessed how they wanted to spend their time. The experience of having a child diagnosed with cancer brought a new awareness that tragic events can occur unexpectedly at any time. Being aware of the harsh reality that life can end at any moment influenced many parents to develop a new appreciation of making the most of the current moment in time. Many parents demonstrated a stronger belief in following through with their commitments such as promising to get their child a pet) and wanted to continue living life with no regrets. Paramount to this new value of living in the current moment was a renewed sense of provide all their children with the best possible opportunities to do well in life. In this way, the experience of having a child diagnosed with cancer reaffirmed parents’ goal and focus of wanting to provide for their children. Clarke (2004) cites evidence which suggests
that significant life experiences can be transforming as they forever change the
to person’s life story. The current findings support Clarke’s view.

The study revealed a unique finding associated with families being able to find
happiness. The results indicated that some families established a new basis for
happiness, which was expressed as working towards a simple life. These parents often
developed a renewed sense of enjoyment which came from spending time with their
families, having healthy children and slowing down the pace of life to better enable
them to appreciate the current moment in time. These results are also similar to those
of Van Dongen-Melman, Van Zuuren and Verhulst (1998). In Van Dongen-Melman,
Van Zuuren and Verhulst’s study, positive changes were reported where participants
experienced a restructuring of their self-view and world-view. Perspective taking was
common, along with re-focusing on the here-and-now and living in the present rather
than planning the future.

Parents experienced great joy witnessing their children return to the activities
they engaged in pre-diagnosis. Some parents described this improvement as regaining
a sense of freedom, as the contrast between life with cancer and life after cancer was
extreme. Other parents however, were aware that their children experienced difficulty
reintegrating back into society after treatment for their illness ceased. One participant,
being a teenage girl, found it difficult to reintegrate with her peer group as they had
“moved on” whilst she had been away in hospital. Added to this was the dilemma of
returning to school with hair loss and scarring that further only isolated her

Some parents experienced a sense of altruism as a result of having a sick child
yet this altruism was experienced differently. One parent was appreciative of the
support and treatment her child had received and so had a desire to support the
hospital via charities (and participating in the current study). Another parent
expressed a desire to give back to the community by indicating an interest in training to be an allied health professional, which would then allow her to support future families undergoing the same experience. By having a child diagnosed and treated for cancer this parent felt she would have “inside knowledge” on how best to support future families.

Finally, some families acknowledged that the presence of having a child diagnosed with cancer resulted in an increased awareness of the prevalence of this disease. Parents were more attuned to its occurrence in others around them and its presence in the media. Parents acknowledged that it was not until they experienced a personal account of cancer, that they took any notice of it at all. For one parent, relief was experienced following their newly acquired knowledge of the disease of cancer as it involved becoming aware that the treatment for cancer and survival rates had improved significantly over recent decades.

*Interpretation of Child Results*

It is important to note that the age range for child participants in this study was limited to eight to 16 years. As such, interpretation of the findings need to be undertaken in the context that while some experiences may be common for children with cancer at any age, there may also be differences in the experiences and perceptions for children who are younger than those who participated in this study. With this in mind, a number of key issues have emerged which provide important insights about the experiences of children in this older age group and adolescents.

*Physical and Emotional Pain.* Children experienced many aspects of their illness as unpleasant as it involved experiencing a number of uninviting components such as painful needles, foul tasting oral medication and surgery. Some children feared surgery as it was a first time experience while others felt nauseas from its side-
effects. These results are consistent with those documented by Hedstrom et al. (2003) who noted that some of the most unpleasant experiences children reported were those associated with pain caused by treatment. This finding was also similar to that of Ljungman, Gordh, Sorenson, Kreuger (1999) who reported that children were more concerned with treatment related pain then cancer related pain.

Emotional difficulties which occurred as a result of the illness were associated with the restrictions that their illness placed upon them. Children experienced this restriction as a real loss of identity as they were unable to continue sporting activities and other recreational pursuits they had once engaged in. Not only were these activities a means of exercising but also a means of connecting with peers and socialising, an important component of a child’s development. Children struggled emotionally to deal with these restrictions.

Hospital life proved particularly difficult for some of the younger children as it meant incurring a number of new and off-putting experiences. Some of the younger children found hospital food unpalatable and struggled to adapt to hospital facilities such as the uncomfortable beds.

Finally, another difficult experience associated with their illness were some of the side-effects children experienced and how this impacted upon their relationship with their peers. Children were often the victim of teasing and taunts which caused them to feel further isolated, lonely and emotionally unstable. Similar results were found in a study by Fraser (2003) where children who had been treated for cancer experienced rejection, isolation and loneliness from their school peers. School friendships were adversely affected. These results indicate that even after surviving a lengthy and painful ordeal children were further alienated by their peers as being accepted back into their social group was not always easy.
Acceptance. Additionally, most of the children in this study demonstrated a high level of tolerance in accepting their condition unquestioningly and were not concerned about the extent of the treatment involved or the outcome of the treatment administered. These results could suggest that the children may be less aware of, or may possibly be less focused on outcomes and what the future may hold. It might be argued that such findings suggest these children are able to live in the present moment concentrating on what they are required to at that point in time. The children also demonstrated an unwavering faith in believing that the “adults” around them, meaning their parents and health professionals involved in their care, were doing their absolute best to treat their condition.

Recognition of Support. Children also reported experiencing support from their family, friends and parents’ work colleagues. The most common supportive experience children reported was the receiving of gifts. The giving of gifts to an ill person, particularly a child seems almost ritualistic in Western society. Whilst the gift has no impact on the status of the child’s health, it is still seen as a means to make them feel better. The children in the current study felt privileged to be the centre of attention to be receiving such gifts and appreciated the generosity of those around them. Children also identified with a range of supports such as pets, family, friends and hospital staff.

Renewed Perspectives. Parents were not the only participants who experienced a broadening of views or a renewed perspective of values. Whilst it was mainly the older children in the study, some children did demonstrate a clear ability to re-evaluate what was important to them and how the experience of cancer had impacted upon their beliefs and view of themselves in relation to the world around them. Children acknowledged their increased knowledge about the disease of cancer. One
child reported that she had learnt not to “sweat about the little things”. Another child was able to identify that the relationship he had with his parents actually improved as a result of his cancer experience. The experience of having cancer enabled him to become closer to his parents. This child also developed an awareness that he had cancer but observed that his illness made him no different to anyone else.

Children experienced a strong desire to return to their “former lives”. The physical restrictions their illness placed on them and the treatment they were required to endure provided them with a sense of desperation as they longed for their former existence. Children were then able to note improvement in their own condition when this occurred, and often judged this improvement on changes in their physical ability. When children were able to return to former recreational activities or attend the hospital to a lesser degree, this was experienced as relief and a sign of their health status improving.

Relating the Results to the Theoretical Frameworks

The results of this study support components of the two theoretical frameworks that have been described earlier in this study. As the “Resiliency Model” claims and as supported by this study, in a time of crisis families do act to adjust and adapt to their circumstances and they do this by relying on already established patterns of behaviour as well as developing new patterns of behaviour when the old patterns are not sufficient to sustain the family unit in an optimal way. As individuals, both parents and children demonstrated a range of coping strategies via actions they may take in relying on external sources (problem focused) and/or in their attitude or beliefs (emotion focused) that they have formed about the illness. Some of these approaches used have also been “old” patterns that the parents and children have
relied on in other situations and some of them have been “new” patterns which they have devised for the particular experience of cancer.

However, whilst the results of the current study can be linked to the theoretical frameworks described, such frameworks have not captured the totality of what these parents and children have experienced. These theoretical frameworks which are commonly used to describe and explain parent and child reaction to stressors do not adequately reflect the severity, intensity or extent of the experiences reported by the parents and children in this study. These frameworks do not allow for individual or unique experiences to be told. They also do not adequately allow for consideration of the important outcomes for parents and children from the experience, such as self-reflection and re-evaluation.

*The Resiliency Model of Family Adjustment and Adaptation.* The adaptation phase of the resiliency model claims that families are required to establish new patterns of functioning to manage in times of a crisis. If this is the case, then the adaptation phase was reflected in the experiences of the families in this study. In the current study families significantly modified and altered their daily routine and way of living to adapt to caring and living with a child with cancer. As previously stated parents were required to cease working altogether or at least reduce their hours of work so that one parent was constantly present with the child. In one couple one of the parent’s often remained working to ensure the family maintained an income whereas the other parent would almost assume complete care of the sick child by spending weeks to months in hospital with the child. Siblings were often cared for by friends or family. Families also developed new routines which involved attending to rounds of radiotherapy and chemotherapy on a daily or weekly basis. In this way families fought to regain some sense of stability and routine which the period of the
initial diagnosis stole from them. By establishing new patterns to continue functioning in the face of adversity families fulfilled the assumption (as outlined in the literature review) of this model which assumes that families work to restore order in the midst of change.

However the theoretical framework does not adequately depict that life, for an indefinite period of time, revolved completely around the sick child. It was not just a matter of establishing a new routine to restore order in the midst of chaos, but it was more that every second of every day was controlled by the status of the child’s health and the stage of treatment they were undertaking. Life existed like this for many parents for an indefinite time. The outside often did not exist at all.

The fourth assumption of this model was also met; families draw from the network or relationships and resources in the community in times of stress. In the current study almost all families relied on the support of their extended family to assist them through their difficult time. This support was extended to mechanisms which would not normally be called upon to provide support which were parents’ work places and children’s schools. Parents also relied heavily on the support from hospital staff, a mechanism parents would definitely not have had to rely on previously.

However, the theory lacks the ability to depict much more detail about how families operate and experience childhood cancer. For example, many parents described that learning of their child’s diagnosis was in fact the hardest part of their total experience. Learning of their child’s diagnosis represented a turning point in time that for the families who participated, was completely unexpected and unpredictable. Dixon-Woods et al. (2005) also cite research indicating that parents experience considerable distress in the immediate aftermath of their child’s diagnosis.
Secondary to learning of their child’s diagnosis was the harsh reality and fear of letting go, that parents experienced when they realised the outcome of their child’s illness was beyond their control. Unlike the common cold or flu parents had no other option but to be physically present to support their child emotionally, as they were unable to do anything else. This was a difficult experience for parents as they felt helpless and struggled to surrender the status and control of their child’s health to the professionals. The qualitative nature of the current study allowed for these crucial and intricate findings to be revealed, which might not have otherwise.

The bond that families formed with the staff was another interesting phenomenon that the qualitative data highlighted. From these results it can easily be seen that the experience of being a parent of a child with cancer is one which involves the staff in such a personal and “family-like” way, that it is certainly different to many other hospital experiences which can be impersonal and cold. Parents perceived that the staff gave so much of themselves to their job, they were considered to be really special people.

Finally, another benefit of the qualitative nature of this study was that it also highlighted some of the difficulties families experienced and of course the benefit of this information is that it allows us to consider whether it is then necessary and possible to resolve the difficulties noted. Whilst most of the difficulties noted were experiences unique to that particular parent or family it still provides us with insight into some of the dilemma’s parents were forced to face and negotiate.

*Stress and Coping Model.* The stress and coping model concludes that a diagnosis of childhood cancer in the family would be appraised and evaluated as a definite threat, and so would result in attempts to reduce the threatening element. Reducing the element of threat would occur by individuals engaging in either or both
problem-focused coping and emotion-focused coping as outlined in the literature review. While not a focus of the study, problem-focused and emotion-focused strategies were demonstrated by both parents and children in this study, as outlined in the personal accounts.

Parents. One couple found that ensuring they had time together away from their sick child, helped them to deal with their child’s illness when they were required to. It was a common experience for other couple’s to divide tasks and responsibilities even if just temporarily, to maintain some sense of control over their stressful event, as families attempted to continue meeting the normal demands of working and paying bills yet also caring for their sick child. Parents also reached out for practical support from staff, family, friends or their employers to assist them cope with the situation at hand. This support manifested in a number of ways including family and friends cooking meals for the family, family or friends caring for the sick child’s sibling/s, staff providing information or listening to parents’ concerns and employers demonstrating flexibility in allowing parents to reduce their hours of work.

However, the qualitative methodology employed in this study allowed for unique experiences to also be portrayed. There was one parent who participated, whose daughter was described as being close to death several times throughout receiving treatment. This parent described how it was almost a surreal feeling of having her daughter almost die on a number of occasions, yet she had no choice but to react in a very “matter of fact” fashion as she was forced to move on to the next stage in the treatment protocol. This particular parent also described the bizarre circumstance of knowing that her child would die without treatment but that her child could also die from the treatment, because the treatment reportedly had so many adverse side-effects.
Emotion-focused strategies could also be identified. For example, many parents viewed themselves as better off than others and having this perception allowed them to minimise the severity of their circumstances. Beliefs in God or a higher power may be seen as another form of emotion-focused strategies which supported parents in feeling better about their circumstances as these beliefs acted as an assurance that their child would get well. However, those families who demonstrated strong religious or spiritual beliefs did not report that they just used this beliefs as an emotion-focused strategy. These families often described an unwavering belief that their child would survive the experience of cancer and get well. Not clearly depicted in either of the two theoretical frameworks, this phenomenon is important to consider as it played a significant role in how some parents responded to and made meaning from their experiences.

Another facet the theoretical frameworks reviewed above do not include is how parents often compared themselves to others as a means of almost making themselves feel better. The sense of groundedness and relief that parents gained as they felt their circumstances were not so bad, is particularly important as it allowed parents to feel that having a child with a potentially life-threatening disease was manageable.

Children. The children’s responses could also be understood as demonstrating problem and emotion focused coping strategies as a means of assisting them manage their difficult circumstances. For problem focused strategies children found solace in their parents, pets, staff and friends. Problem focused strategies in the form of distraction were also used to support children through painful medical procedures. Children with strong religious beliefs appeared to be reassured by these beliefs that they would get well which could be seen as utilising emotion focused strategies. Other
strategies children reported using consisted of a “get it over and done with” approach to again, assist with painful medical procedures, which again can be viewed as emotion focused coping.

Yet the experiences explicated by the children who participated in this study revealed so much more then just problem-focused or emotion-focused strategies. A strong relationship with their social and recreational life was found. The children struggled with the loss they felt when their health status forbid them to engage in sporting activities, recreational activities and attend school. This result indicates that children in this study identified strongly with a lifestyle that supported their emotional and social development and that when this was taken from them, it was almost experienced as a ‘loss of who they were”. These findings make sense when one considers the results of Cassano’s (2008) study examining perceptions of adolescents with cancer. The author’s of this study found that adolescent’s feel supported when they are among others of a similar circumstance and appreciate engaging in “normal” activities. The author’s also state that the necessary treatment for cancer cause a major disruption in adolescents normal social networks.

The results of this study also revealed that the children had a clear ability to be appreciative of the support they experienced, whether it was from family, friends, school peers or pets. Children were grateful for this support and recognised it as a contributing factor to their health status.

Several of the older children also developed a clear ability to reflect and re-evaluate their own lives. As a result, relationships with parents improved and issues which were previously of concern, appeared somewhat insignificant against the context of cancer. For example one teenage girl stated that prior to her cancer diagnosis she worried constantly about messy hair. After experiencing the loss of her
hair from the cancer treatment, she no longer cared about having messy hair, but would have been happy just to have some.

*The Developmental Context of the Findings.* The purpose of this study was not necessarily to examine children’s understanding of their illness as defined by the developmental theories, but it was to examine their perception and experience of their illness. However, the findings of this study can still be compared to the developmental theories noted earlier in this thesis. All children, regardless of their age, demonstrated an inherent understanding that they were ill and so understood that this was the difference between them and others around them. This is consistent with Koopman et al. (2008) belief that the child’s ability to view themselves in relation to others commences between the age of 2 and 7, termed *proximity*. Again, all children, regardless of their age, were able to recognise the symptoms of their illness. The ability to be aware of symptoms associated with an illness is reflected in Koopman et al. (2008) fourth phase of development being *contact*. Children are typically aged 7 to 11 when they develop this skill. Both the quantitative and the qualitative data reflected that children of all ages in this study were able to develop and be aware of their own coping strategies, whether they were practical or emotional. This result is consistent with Piaget’s *concrete operational stage*, which marks the period where children aged 7 to 11 are able to use logic to solve problems. Finally, the older children in this study demonstrated a capacity to be reflective and re-evaluate their lives and relationships with those around them, as a result of their illness. This ability to think abstractly is reflected in the final stage Piaget’s theory, *formal operational stage* and which commences at about age 12.
The findings of this study revealed the importance of not just being aware of how children perceive illness and the differences this generates across the different ages of children, but also the importance of being aware of the impact that the illness has on them. The developmental theories discussed earlier in this paper are very clear in indicating the stages which children move through which relates to their understanding of the concept of illness. These theories also indicate that one of the main reasons we need to have an understanding of children’s perception of illness is to improve communication between health professionals and children, that is teach and provide knowledge at a level congruent with the child’s cognitive level of development. However, there is arguably even greater benefit in having an awareness of how children experience illness. The knowledge of how children experience illness allows health professionals to have a much more in depth and detailed account of how children perceive this experience. More importantly, it is as though we have discovered a phenomenon not previously revealed, that which comes from a demographic previously untouched. The findings of this study provide credence to the idea that children are actual human beings with minds of their own and who have the ability to understand, interpret and make sense of their illness experience. Within this, a number of important findings should be attributed to furthering the developmental theories identified earlier in this paper.

1. The majority of children who participated in this research impressed as being accepting of their illness. No child expressed a desire to know why they had become ill. No child demonstrated a “why me” attitude. Therefore, accepting and undertaking the necessary (although painful) treatment occurred unquestionably.
2. No child ever expressed any concern at the possibility they may not get well and furthermore, no child ever expressed concern that they may die as a result of their illness. The fact that children demonstrated a complete faith that they would get well, may reflect a lack of awareness on the part of the children about the implications of their disease. It, however, also reflects an example of a positive outlook that may be important to managing their situation.

3. Many of the children, regardless of their age revealed great difficulty being isolated from their peers. This was often the hardest part for the young participants which is important to note as peer connection is obviously a crucial part to their self-identity and feeling secure and happy within themselves. This finding is consistent with previous research. Furthermore, it was not only loss of peer contact, but loss of being able to participate in sporting activities which children found difficult. Recreational pursuits are clearly a large part of social development.

4. Children of varying ages demonstrated the ability to be appreciative of the support around them and this extended not only to people but also to pets. This is another important point which needs to be noted, as it has not often been reflected in the previous literature that children actually do have an ability to understand how the actions and thoughts of others can benefit them. This phenomenon was experienced by both young and older children who participated.

5. Several of the older children demonstrated a clear ability to reflect upon their illness to note the positive changes it had had on their lives. Reflective functioning in this way is a notion often discussed in adult illness literature, but less so in child illness literature. This is the only factor from the children’s
results which can be related to the developmental theories already discussed, as it may not be until children are older and have a developed cognitive capacity, that they have the ability to reflect on their experiences.

6. Children of various ages demonstrated a clear ability to note progress in their illness and physical state. Children were able to mark their own progress via an awareness of their own energy levels ability to return to pre-illness activities. This phenomenon was observed in both young and older children.

It is findings such as these noted above that now need to be added to extend current developmental theories. Furthermore, the findings of this study has been gathered from sick children which is particularly important given that it is often well children who are used as the basis for developing theoretical frameworks, even when the theories are about the topic of illness.

*Changes over Time*

Another crucial component of the current study was its emphasis on collecting data at two points in time. The collection of data across time revealed interesting results. Most master themes did occur at both times in which data was collected. However, there was at least one master theme for both the parent group and the child group which occurred at one of the time points only.

*Parents.* For parents, the master theme of “experience of optimism and altruism” occurred at Time 2 only. This is an important finding as it provided insight into the impact that the passage of time had on parents’ perceptions of their child’s illness. For example, it was at Time 2 that many of the children who participated had completed active treatment or were nearing the end of receiving treatment. Parents described the experience of joy and a renewed freedom from seeing their child’s health status improve. It was at this time that parents were able to view their child as
regaining some sense of freedom as life was able to return to something similar to what it was pre-diagnosis. The recognition and return to former lifestyles’ was well received.

Altruism was also experienced towards the end of treatment journeys. As parents were grateful for the progress their child had made and to those who had helped their child overcome the illness of cancer, it was not uncommon for some parents to want to give something back. Whilst each parent who expressed this feeling of altruism demonstrated wanting to return the good in a different way, it was relevant to their own individual experience. That is, parents wanted to provide support in areas in which they feel they would have liked more support themselves, when they were experiencing the illness with their child.

*Children.* Changes across time also proved relevant for the children. The master theme of “the experience of returning to well-being” was the only one which occurred at one point in time, being Time 2. This master theme has two components, children’s desperation to return to their former lives as well as the immense appreciation they experienced when they could return to activities they engaged in pre-diagnosis. At Time 2 it could easily be seen that children were becoming tired and impatient with their illness as it had been happening for a long time by this stage. The impatience, frustration and feeling of being “locked in” was showing for some. It was however, also at this time that other children were able to note the improvements in their own progress. They relished their renewed energy and ability to re-enter the world of living.

These results confirm that the collection of longitudinal data is important when considering an illness such as cancer. Cancer is an illness which has such a lengthy projection of time, it affects people’s lives for a lengthy period of time.
Experiences are then likely to vary greatly across time and these can often be subject to what stage of treatment is currently being undertaken. An extraction of information collected at one point in time is simply not enough to represent all the experiences associated with the phenomenon of childhood cancer.

Implications of the Findings

Parental Practical Implications. Interpretation of the findings of the current study has led to many areas in which psychological support could assist. For example, given that all parents described the time of the diagnosis as the most difficult part of their experience, as they were forced to come to terms with a harsh and unexpected reality, it seems critical to ensure that extra support is on hand at this time or shortly afterwards to assist parents adjust (e.g. learning about medical terminology and practical issues such as parking facilities on hospital grounds). Counselling support should be aimed at assisting families maintain a sense of normality (as this is what parents in this study reported, helped them). To live in the moment and not be concerned about an unknown future is another area counselling support could assist, as parents feared what the future might hold for their child. Supporting parents regarding the internal struggle they experienced in handing the care of their child over to medical staff, is another area psychological intervention could provide relief. Achieving “groundedness” was another area families felt helped their emotional adjustment to their child’s illness. Therefore, psychological support could act to facilitate this process for parents.

The current research was also able identify areas for potential improvement of services provided to families who have a child with a diagnosis of cancer. Oncology centres with familiar staff that parents can develop close and trusting relationships with, would definitely be appreciated. One family reported significant difficulties
readjusting to life at home once their child was finally discharged from hospital. A transitional program which allowed for a slower and supported return home would have been appreciated. Another parent experienced difficulties whilst her daughter was receiving treatment in hospital as she felt there was a lack of communication between the staff involved in her daughter’s care. These results are consistent with those of Earle, Davies, Greenfield, Ross and Eiser (2005). This study revealed families were unhappy with the level of communication concerning the status of their child’s health. Parents in the current study also felt there was a lack of information and support provided regarding follow-up services that needed to address residual emotional issues. Returning to “normal family life’ was not easy for every family.

There were also commonalities among parents regarding other concerns. Several families expressed concerns pertaining to the lack of eating facilities available in the hospital for parents. This was a significant issue parents faced, as they spent weeks to months in hospital sleeping and sitting by their child so regular access to an appropriate food outlet was particularly important. Another common concern expressed by parents was the lack of facilities available to the adolescent aged children. Parents were thankful their child was placed in a paediatric setting as apposed to an adult setting but were aware of the emotional and social differences between their child and some of the younger children. Parents recognised the importance of having a designated area that the teenagers could “hang out” in, as they would at home, away from watchful parents and annoying siblings. The results of the Cassano (2008) study also confirm the importance of tending to adolescents’ needs. It is important for this age group to be supported by others their own age in a similar predicament as this provides them with the opportunity to normalize their experiences. Whilst modifying medical systems to accommodate some of these
recommendations may be difficult and time consuming, the first stage in this process
is for us to at least have an awareness of issues relevant to families in this
circumstance.

Finally, in the current study most parents felt that their child’s diagnosis of
cancer was a certain death sentence. These results indicate that whilst the majority of
children diagnosed with cancer today survive, there is still a definite feeling that
cancer inevitably leads to death. Not only parents but the community would therefore
benefit from being educated about the survival rates of childhood cancer. Dixon-
Woods, Young and Ross (2006) express concern at the lack of evidence for many
psychosocial interventions that have become routine in clinical practice. Based upon
the current findings, services aimed at supporting these families is in need of
continuous improvement.

*Child Practical Implications.* Even though it was the children who had the
illness, it seems as though they faired better then their respective parents. The
majority of the implications relevant to the children are in the context of service level
recommendations. Medical services for children would benefit from creating a
hospital environment as similar as possible to their home and school environment.
Ideally this would involve more opportunities for the children to meet other sick
children their own age. It would also be nice for hospital life to include recreational
and sporting activities (as appropriate as possible given their illness). Any way in
which children can feel less isolated from their peers by their illness, is likely to be
beneficial. Given that some of the younger children found components of hospital life
to be hard (food and beds), this may also need to be an area which is reviewed. In this
circumstance, thinking outside of the square may be helpful. Can children be provided
with the option of bringing their own bedding in to hospital if they so choose? Could
children have the option of having favourite meals such as MacDonald’s be as a treat once a week? Although it was the younger children in particular who found it more difficult to adjust to components of hospital life, little alleviations such as these may go a long way in providing a “warmer” environment for children in hospital.

Also, at least one child in the current study commented on how they appreciated receiving treatment at home. Medical treatment carried out at home may work to improve emotional and psychological distress experienced by the children, as almost all the children in the current study admitted that the experience of staying in hospital was an unhappy one. Increasing the amount of treatment able to be carried out at home may therefore be an important point to consider. Earlier research has already suggested that providing chemotherapy at home may improve adjustment to the illness (Bauman, Drotar, Leventhal, Perrin, and Pless, 1997).

Given that some children experienced difficulty returning to school, integrating with their peers and were sometimes the subject of ridicule, measures to reduce these experiences should be considered. A potential response would be to provide children with the option of having a staff member visit the school prior to the child’s return to explain to the class and prepare the children for the child with cancers’ return. Obviously not all children would appreciate this type of support but some may find it appealing. Current work carried out by the allied health staff in Queensland is already indicative of this.

The main area in which psychological support would be beneficial would be that of pain management. As the majority of children experienced physical pain as one of the most difficult parts of their entire experience, this may warrant consideration of therapeutic programmes aimed at teaching children pain management skills, to be made a regular component of their hospital experience. It is important to
consider this topic of pain especially as the pain experienced from the treatment is usually greater than the pain experienced from the illness symptoms.

*Theoretical and Philosophical Implications.* The current study has potentially generated more questions then it has answered. For example, the results of the current study indicated that participants struggled to come to terms with an unexpected event. Why do people not expect the unexpected? Does the structure of the family unit in Western society lead to struggle when incidents considered to be outside of the usual day-to-day existence occur. Would families in other societies or cultures cope better? More importantly, why does it take a crisis for people to develop an appreciation of life, as evident in the current study? The current findings suggest that when a life is almost taken, people re-evaluate who they are, what is important to them and how they really want to live their life to find a renewed sense of the meaning of happiness.

It is interesting to note that the majority of parents indicated that their child was very accepting of their illness and so unquestioningly underwent the required treatment with minimal complaint. This then leads to questions such as, do children cope better with adversity than adults? Does the naivety that comes with childhood mean that children are more receptive to responding constructively to adversity? As adults, do we then need to return to our youth at times and respond with the naivety of that of the children?

Finally, those parents in the current study who had strong religious beliefs reported greater certainty that their child would get well. Further research will enable us to gain a better understanding of the impact of strong religious or spiritual beliefs on adjusting to serious illness.
**Limitations of the Current Study**

Whilst the current study entered new territory and explored a particular phenomenon beyond that applied by quantitative measures and beyond that of the theoretical frameworks, it is certainly not without its limitations. There are several limitations which further research could address.

Recognition needs to be given to the differences in experiences which can be attributed to age. Whilst some experiences were common across child participants there were certainly experiences that were unique to the younger ages (8-10 years of age) and experiences that were unique to those children who fall within the adolescent or teenage age group. Ideally a big enough sample where child participants were divided into age groups would provide more generalisable results. For example, the parents of teenage children in this study noted the lack of hospital facilities suited to this age range. Differences were also noted in the experiences of the teenage aged children in comparison to the younger children. For example, several of the younger children in this study noted the difficulty in adjusting to hospital life whereas the older children commented more on the difficulties they experienced due to lack of social and peer contact. Earle and Eiser (2007) recently undertook a study which divided children into age groups. The age groups were 0-4 years, 5-9 years and 10-14 years. Mothers were required to comment on their child’s behaviour and coping. Participants were recruited over a period of 18 months, multiple sites were used and data collection occurred over a 2-3 year period and was collected at three points in time. The results of their study concluded that across the three different data collection points, the oldest group of children experienced the most difficulties adjusting to the illness and its side-effects and so therefore as a group, require special consideration.
Most of the parents who participated in the current study were mothers. Whilst this is indicative of the fact that it was usually the mother who remained close to the child’s side in hospital and so was available for research purposes, it also begs the question, what is the father’s experience of having a child with cancer? Two fathers participated in the current study however their experience as a group is certainly worth exploring further. Differences and similarities in their experiences in comparison to that of mothers is important information that could further explain the experiences of parenting a child with cancer.

It is also acknowledged that the sample used in this study was self-selected. Therefore, the results may not be reflective of all parents and children where the child has a diagnosis of cancer, but merely of those who were managing well. This can be confirmed via the quantitative measures that were administered in this study as they indicated that the sample was one which was responding well to the experience of childhood cancer as all families who participated reported that they were coping well, most had good marital satisfaction and no psychopathology was noted. Therefore, families who were not coping well may have responded differently and highlighted other issues of contention or experiences, if they had participated.

Additionally, as most of the interviews took place with both parents and children present together, either one of the participants may have been reluctant to discuss certain issues in front of other family members. Even though participants were provided with the option of whether they wanted to be interviewed alone or with other family member’s present, the practicalities of the environment did not always allow for private interviewing to occur.

Given that the participants had not met the researcher until the time of their agreeance to participate in the current study, this may have produced bias. The
opportunity to meet with and build rapport with participants prior to commencement of data collection may have increased the participation rate as well as willingness to engage with the researcher.

Further Research

The findings of the current study have opened up a plethora of potential areas that could be addressed by future research. For example, future research would benefit by exploring further children’s ability to cope with adversity in comparison to that of adults. Do their shorter lives with fewer expectations developed mean that they are more receptive to managing unexpected events? Further research would also benefit by measuring the impact that strong religious and spiritual beliefs have on adjustment and whether there is are any relationships with health outcomes. Comparisons with a non-religious/spiritual sample would also be useful. Whilst this study is potentially the beginning of adding valuable information to pre-existing developmental theories, further research examining children’s experiences of childhood illness in general could also add valuable information to developmental theories about childhood experiences and the nature of childhood itself.

Further research addressing the limitations of the current study would also be useful. Multi-site studies and grouping children into age groups as carried out by the Earle and Eiser (2007) may allow for a more robust study. Such a study may then allow for a greater capacity for generalisations to occur. Further research would also benefit from focusing on the differences between child and adolescent age groups to gain greater insight into the similarities and differences of their experiences. Larger sample sizes which include a much wider group of respondents such as those who are coping well and those who are not coping well, are also necessary if a more complete and thorough understanding of the experience of childhood cancer is to be obtained.
It is important to note the use of the quantitative measures in this study. As a result of the small sample size, the quantitative measures were unable to be used for the purpose of performing reliable statistical analyses. They were only able to be used for the purpose of descriptive statistics. As a result of this limitation, triangulation of data was unable to occur. Comparing parent and child QoL ratings was also unable to occur. Further research would benefit from the comparing both qualitative and quantitative measures as well as, parent and child perceptions of QoL.

Conclusion

The experience of being a parent was certainly challenged through having a child diagnosed with cancer. The emotions and feelings associated with being a parent of and wanting to protect a vulnerable child were often tested throughout the entire process from the point of diagnosis to the point of returning to “normal” life. The role of being a parent and what being a parent meant was challenged and experienced as an internal battle. All parents demonstrated an irrefutable bond with their child, one which would endure the greatest of painful experiences. The qualitative nature of this study revealed that families underwent a huge reflective transition where they re-evaluated themselves, their values, the importance of the family unit and how they wanted to continue living their lives. Not clearly depicted in any of the theoretical frameworks, the experience of having a child with cancer had an incredible impact on these families as it was a truly life-changing event.

The diagnosis of childhood cancer is one which signifies not just a traumatic event but a life-changing and life-renewing experience for all those involved. It is this information which now needs to be incorporated into existing theories, those which are relevant to both family adaptation and child development. Theories about family adaptation need to incorporate the shock that parents experience when they first learn
of their child’s diagnosis. Recognition needs to be given to this time-frame as it is perceived as the hardest part of the entire cancer experience. The internal struggle that parents experience as they reluctantly relinquish control of their child’s health to the medical staff is another important part of the process which requires recognition. This is a unique experience as cancer is one of the few illnesses parents have no control over. Whilst it is recognised that families adapt in times of crisis, it needs to be recognised that the sole focus for an indefinite period of time revolves around the sick child. It is not a matter of simply readjusting one’s lifestyle, but every waking moment of the family’s time is controlled by the treatment schedule and health status of the sick child. The unique bond that families identified as having with staff is crucial to assisting families manage. Staff also need to be recognised for going above and beyond their job description in caring for these families. Finally, whilst a diagnosis of childhood cancer has long been recognised as a traumatic and life-changing event, it also needs to be recognised for being a life-rejuvenating event. It is an experience which prompted families to re-evaluate themselves (individually and as family), along with their goals, values and the meaning of happiness.

Most importantly recognition needs to be given to the material explicated from the children. Children of all ages identified as experiencing a loss of identity as their illness distanced them greatly from their peers. This study highlighted how important social contact with peers is in relation to the healthy development of a child, and thus how isolated and alone children feel without social connection. Again, children of all ages showed an appreciation for others who supported them. The notion of connection and support confirms that children do actually have the ability to recognise the support of others and thus the importance of the relationship of someone else to themselves.
The experiences of both parents and children varied over the course of the study. Whilst only a few differences across time were explicated, this study demonstrated the value of a longitudinal methodology and the ways in which people not only adjust to unforeseen difficulties but develop new attitudes, values and appreciations across time.

Interpretative approaches offer new insight into an area previously dominated by quantitative research. As Dixon-Woods et al. (2005) state, rigorous qualitative research is needed to balance the quantitative research and to be able to attend directly to the experiences of those affected by childhood cancer. There is value in an interdisciplinary approach where the contributions from disciplines such as nursing, sociology and psychology are considered together rather than as being defined within the disciplinary boundaries (Dixon-Woods et al. 2005). The current study contributes to this new body of work. The findings have provided a rich and intimate understanding of a phenomenon which has all too often been previously misunderstood and misrepresented.
References


Appendix A
Dear

We are writing to invite you and your child to participate in a research project looking at how children and their parents manage when a child has a serious illness. We hope that this study will provide information that will help us in offering support to patients and their families.

The research is being carried out by Maya Griffiths, a psychologist who has specialised in working with children and involves the Haematology/Oncology Unit at the Mater Children’s Hospital and the Queensland University of Technology.

If you and your child are interested and choose to participate, you will both be required to meet with Maya on two occasions. It is expected that Maya will be able to see you both when you are next attending an appointment at the hospital. On each of these two occasions you will be asked to fill in a set of questionnaires (which will take about 20 minutes) and answer 6 questions each. The 6 questions are designed to find out what sorts of things help kids and their parents cope when a child is sick.

If you and your child do choose to participate in this research all information obtained will remain confidential.

If you are interested in finding out more about this research or would like to participate, please fill out and tear off the section below and return it in the self-addressed prepaid envelope provided, as soon as possible. Maya will then be in contact with you to tell you more about the research and answer any questions you may have.

If you have any questions regarding this research, please do not hesitate to contact Maya on 3840 8708, who is more than happy to discuss the research with you.

Kind Regards

Professor Ross Pinkerton
Director of Cancer Services,
Mater Health Services

Maya Griffiths
Psychologist
Queensland University of Technology

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..............................................................................................

Please fill out and return if you would like to be contacted regarding this research.

☐ I wish to be contacted by Maya regarding this research project.

Name:.................................................................

Name of Child:...........................................................

Contact Number:...........................................................
Appendix B
Description of the project
We would like to invite you and your child to participate in a study run in the Mater Children’s Cancer Unit. The aim of the project is to gain an understanding of how parents and their children cope when the child has a serious illness. We would like to understand more about the strategies and resources which help parents and children adjust and manage in this situation. This will help to plan the provision of future services to support families during a very difficult period. The project is being conducted by a qualified psychologist, Maya Griffiths, through the Queensland University of Technology (QUT) and is part of a PhD.

Your involvement
Your involvement in the project will require you and your child to meet with Maya twice over a 12 month period. Each time you meet with Maya you will both be required to fill in a set of brief questionnaires. The questionnaires should take about 20 minutes each to complete. These questionnaires are designed to collect information about quality of life and coping strategies. Some participants may then be asked to answer six questions which will cover in more detail some of the issues dealt with in the questionnaires. This will take 30 minutes to one hour.

Risks
It is unlikely that you will experience any problems or difficulties by participating in this study. However, you may feel uncomfortable answering some of the questionnaire material or answering any of the six short questions. In the event that you or your child does feel uncomfortable taking part in any component of the study then you are free to only respond to those parts of the questionnaires or six questions you wish to.

Benefits
By gaining an understanding of how families manage when a child is sick and receiving treatment from a hospital, health professionals working with such families will be able to provide better support and care for future families who go through the same experience. These future families will then be better informed about the factors that play a role in helping parents and children adjust when a child is sick.

Confidentiality
All responses and comments will be allocated codes and the data will be maintained under these codes in a locked filing cabinet at QUT. No identifying information will be used in any of the findings.

Voluntary Participation
Both you and your child’s participation in this project are voluntary. If you agree to participate you are both able to withdraw from participating at any time throughout the course of the project without comment or penalty. Your decision to participate or not participate will have no impact on the treatment your child receives.
**Cost to Participants**
There are no costs associated with taking part in this study.

**Feedback to the Participants**
If participants wish to find out the results of the study, please provide your address details on the Consent Form attached to this Information Sheet. A summary of the study and its results will then be sent to you once the principal investigator has completed the research.

**Contact the Principal Investigator**
Please contact me on the number provided at the beginning of this Information Sheet if you require any further information, or have any questions regarding this study that you would like answered.

**Mater Research Secretariat**
This study has been approved by the Mater Health Services Human Research Ethics Committee. Participants may contact the Mater Research Secretariat on 3840 1585, should you have any complaints about the ethical conduct of the research or wish to raise any concerns.

Researcher: Maya Griffiths  
BA (Hons) MA (Clin Psych)  
Queensland University of Technology  
School of Psychology and Counselling  
Beams Rd, Carseldine  
Ph: 3864 4925
Consent for Parents/Guardians to Participate

Parent and Child Experiences of Childhood Cancer: An Interpretative Phenomenological Analysis Approach

Researcher: Maya Griffiths
BA (Hons) MA (Clin Psych)
Queensland University of Technology
School of Psychology and Counselling
Beams Rd, Carseldine
Ph: 3864 4925

Statement of Parent/Guardian consent

By signing below, you are indicating that you:
• Have read and understood the information sheet about this project
• Have had any questions answered to your satisfaction
• Understand that if you or your child have any additional questions you can contact the researcher
• Understand that you or your child are free to withdraw at any time, without comment or penalty
• Have been informed of the possible risks associated with the study.
• Understand that the study is for the purpose of research and not for treatment
• Have been informed that the confidentiality of the information obtained from you will be maintained
• Agree to you and your child participating in the research

Name ____________________________________________

Signature _________________________________________

Date _____/_____/______
Patient Assent to Participate in Research Project

Parent and Child Experiences of Childhood Cancer: An Interpretative Phenomenological Analysis Approach

This form will help you decide whether you would like to take part in this project.

What the project is about
My name is Maya and I am doing a project through the university I go to. Part of the project involves talking to children and teenagers like you. The aim of my project is to find out how children and teenagers cope when they are sick. For example, some of the things I might like to know are what sorts of things have helped you cope over the time you have been sick, what are the hardest parts about being sick or what has changed for you since you have been sick. I would like to find out this sort of information so that other children and teenagers who go through the same experience as you can get better help.

What you will have to do
To help me carry out my project I will need to meet with both you and your parents. I will then give you and your parents a set of questionnaires to fill in. (You will have different questionnaires to your parents.) This should only take about 20 minutes. I may also ask you to answer a set of six short questions for me but not everyone who takes part will have to do this part, so I’ll let you know if you do. I would then like to meet with you again about 6 months later to see how you are going and give you the questionnaires to fill out again.

Other things you should know
All of the information you give me will be kept a secret. That is, any information which has your name on it will be given a special code that will be used in place of your name.

If you agree to take part in this project you can change your mind at any time and not be a part of it anymore. Whether you decide to take part or not, the care you receive from the doctors and nurses at the hospital will still be the very best.

If you do sign this form and agree to take part you get a copy of this form to keep.

Also, before you sign this form make sure you ask me, your doctor or your parents any questions you have about taking part in the project.

I _______________________________________ agree to take part in this research project which Maya has told me about.

Please sign here ______________________________________
Parent/Guardian signature ________________________________ Date ______

Researcher’s Signature ________________________________
Demographic Information
(to be completed by the parent/guardian)

Parents/Legal Guardian:

_____________________________________________________________________

(Last Name)                                         (First Names)

Child

_____________________________________________________________________

(Last Name)                                           (First Name)

Age of Child: _____________________
Date of Birth: _____________________
Diagnosis: _______________________
Date of Diagnosis: _________________

Parents/Guardian marital status: ________________________________
Religion: _________________________________________________
Ethnic background: _________________________________________
Appendix D
Parent Questionnaires

1. Family Crisis Orientated Personal Evaluation Scales (F-COPES)
Please circle a number (1, 2, 3, 4 or 5) to match your response to each statement.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Not Sure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sharing out difficulties with relatives.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Seeking encouragement and support from friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Knowing we have the power to solve major problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Seeking information and advice from persons in other families who have faced the same or similar problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Seeking advice from relatives (grandparents, etc.).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Seeking assistance.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Knowing that we have the strength within our own family to solve our problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Receiving gifts and favours from neighbours (e.g. food, taking mail in).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Seeking information and advice from the family doctor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Asking neighbours for favours and assistance.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Facing the problems “head-on” and trying to get a solution right away.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Watching television.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Showing that we are strong.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Attending church services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Accepting stressful events as a fact of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Sharing concerns with close friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Knowing luck plays a big part in how well we are able to solve family problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Exercising with friends to stay fit and reduce tension.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Accepting that difficulties occur unexpectedly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Doing things with relatives (get-togethers, dinners, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td><strong>21.</strong> Seeking professional counselling and help for family difficulties.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>22.</strong> Believing we can handle our own problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>23.</strong> Participating in church activities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>24.</strong> Defining the family problem in a more positive way so that we do not become too discouraged.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>25.</strong> Asking relatives how they feel about problems we face.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>26.</strong> Feeling that no matter what we do to prepare, we will have difficulty handling problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>27.</strong> Seeking advice from a minister.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>28.</strong> Believing if we wait long enough, the problem will go away.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>29.</strong> Sharing problems with neighbours.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>30.</strong> Having faith in God.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
2. Family Problem Solving Communication
When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>False</th>
<th>Mostly False</th>
<th>Mostly True</th>
<th>True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>We yell and scream at each other</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.</td>
<td>We are respectful of each others’ feelings</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>We talk things through till we reach a solution</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>We work hard to be sure family members were not hurt, emotionally or physically</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5.</td>
<td>We walk away from conflicts without much satisfaction</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>We share with each other how much we care for one another</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7.</td>
<td>We make matters more difficult by fighting and bring up old matters</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8.</td>
<td>We take the time to hear what each other has to say or feel</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>We work to be calm and talk things through</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>We get upset but we try to end out conflicts on a positive note</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### 3. Abbreviated Dyadic Adjustment Scale (ADAS)

1. Most persons have disagreements in their relationships. Please indicate below the approximate extent of the agreement or disagreement between you and your partner for each of the following three items.

<table>
<thead>
<tr>
<th></th>
<th>Always Agree</th>
<th>Almost Always Agree</th>
<th>Occasionally disagree</th>
<th>Frequently disagree</th>
<th>Almost always disagree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philosophy of life.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Aims, goals and things believed to be important.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Amount of time spent together.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

2. How often would you say the following events occur between you and your partner?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Less than once a month</th>
<th>Once or twice a month</th>
<th>Once or twice a week</th>
<th>Once a day</th>
<th>More often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a stimulating exchange of ideas</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Calmly discuss something</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Work together on a project</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

3. The dots on the following line represent different degrees of happiness in your relationship. The middle point, “happy”, represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely unhappy</td>
<td>Fairly unhappy</td>
<td>A little unhappy</td>
<td>Happy</td>
<td>Very happy</td>
<td>Extremely happy</td>
<td>Perfect</td>
<td></td>
</tr>
</tbody>
</table>
### 4. Kessler Psychological Distress Scale

**Directions:**
The following ten questions ask about how you have been feeling in the last four weeks. For each question, mark the circle under the option that best describes the amount of time you felt that way.

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I often have the feeling that I cannot handle things very well.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2. I find myself giving up more of my life to meet my children’s needs than I ever expected.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>1. I feel trapped by my responsibilities as a parent.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2. Since having this child I have been unable to do new and different things.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>3. Since having a child I feel that I am almost never able to do things that I like to do.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4. I am unhappy with the last purchase of clothing I made for myself.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. There are quite a few things that bother me about my life.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6. Having a child has caused more problems than I expected in my relationship with my spouse (male / female friend).</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7. I feel alone and without friends.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>8. When I go to a party I usually expect not to enjoy myself.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
**Child Questionnaires**

1. **Kidcope**  
Please read each statement and circle the answer (not at all, a little, a lot) that you think is right for you in your current situation.

<table>
<thead>
<tr>
<th>Coping Strategy</th>
<th>The child is asked: “Did you…”</th>
<th>Not at all</th>
<th>A little</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distraction</td>
<td>Try to forget it?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do something like watch TV or play to forget it?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>Stay on your own?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keep quiet about the problem?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive restructuring</td>
<td>Try to see the good side of things?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Self criticism</td>
<td>Blame yourself for causing the problem?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Blaming others</td>
<td>Blame someone else for causing the problem?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Problem solving</td>
<td>Try to sort out the problem by thinking of answers?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td></td>
<td>Try to sort it out by dong something or talking to someone about it?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Emotional regulation</td>
<td>Shout, scream or get angry?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td></td>
<td>Try to calm yourself down?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Wishful thinking</td>
<td>Wish the problem had never happened?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td></td>
<td>Wish you could make things different?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Social support</td>
<td>Try to feel better by spending time with others like family or friends?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
<tr>
<td>Resignation</td>
<td>Do nothing because the problem could not be sorted anyway?</td>
<td>Not at all</td>
<td>A little</td>
<td>A lot</td>
</tr>
</tbody>
</table>
2. Paediatric Cancer Quality of Life Inventory – 32 (PCQL-32)
Here is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you this past month by circling: 0 if never a problem, 1 if sometimes a problem, 2 if often a problem, 3 if always a problem.

<table>
<thead>
<tr>
<th>Scale Item No</th>
<th>Item description</th>
<th>Never a problem</th>
<th>Sometimes a problem</th>
<th>Often a problem</th>
<th>Always a problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease and Treatment-Related Symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Becoming anxious when having to go to hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>Becoming nauseated during medical treatments</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Food not tasting very good</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Becoming nauseated while thinking about medical treatments</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>Being anxious about needle sticks</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>Aching in joints and/or muscles</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>Being anxious about bone marrow aspirations and lumbar punctures</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>Hurting or aching</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Medical procedures hurt a lot</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Participating in sports activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>Doing chores around the house</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Walking or moving around</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Lifting something up</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>Running</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Psychological Functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Feeling afraid</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>Feeling sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Worrying about the</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>#</td>
<td>Question</td>
<td>0</td>
<td>1</td>
<td>2</td>
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Note: The parent version of this form is identical, other than it being presented in the third person. As a result the parent version of this form has not been recorded in the “parent questionnaires”.
Appendix E
Audit Trail

The following is an excerpt taken from one of the parents who spoke about their daughter’s diagnosis. The sections which have been blocked out refer to words or sentences which were not coded. The number’s and slashes highlighted in red denote the end of a meaning unit or code:

No, I’ve been working two days a week. The first two months were fairly overwhelming and getting used to and she couldn’t walk either so that was quite a struggle//6 but you know being in hospital and accepting the diagnosis and [I] went back to work for a little while and then she got the pancreatitis and then [so] it was off for [a number of weeks], because she was in ICU for a bit and off for a number of weeks and then eventually going back two days a week//7 and because she can’t go to school, she needs constant care and my Mum still works and her father’s Mum is not really capable of taking care of her with… not with just being unable to mobilize at the moment and if she gets a temperature it could be really serious and giving drugs [may be necessary] and things like that so it’s either been him [husband] or me. So he works three days a week and I work two days a week../8

The first reading of the document involved the division into meaning units which were marked with number’s and slashes. Codes were then devised at the second reading of the transcript:

6 = impact of diagnosis

7 = lifestyle change/unpredictability of illness

8 = lifestyle change/focus on sick child/demands of caring for child
When the transcript was entered onto Atlas.ti and merging with other codes occurred, the following codes were developed:

6 = impact of diagnosis

7 = experience of managing child’s illness

8 = (double coded as) child as the focus and experience of lifestyle change
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