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RESEARCH ARTICLE

**Parental Experience of Childhood Cancer using Interpretative Phenomenological
Analysis**

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Abstract

Whilst survival rates for childhood cancer have improved dramatically over the past three decades, it is still a devastating diagnosis for family members and an illness which severely disrupts the lifestyle of the family unit. Developing an understanding of the impact of the illness on the family is crucial to better support families' deal with the demands of the illness. In this study 9 families in which a child was diagnosed with cancer were interviewed twice over a 12 month period, approximately 6 months apart. Using Interpretative Phenomenological Analysis (IPA), a semi-structured interview was used to explicate parent's experience of childhood cancer. The results revealed 5 super ordinate themes; *(1) a pivotal moment in time, (2) the experience of adaptation in relation to having a sick child, (3) the nature of support, (4) re-evaluation of values during a critical life experience and (5) the experience of optimism and altruism.* Findings indicate that parents express both negative and positive experiences as they re-evaluate the meaning and purpose of life, seek to redefine themselves, often in terms of priorities, relationships, sense of community, and achieve degrees of optimism and altruism. Implications for addressing the needs of parents and for further research are discussed.

200 words

Keywords: *cancer, children; parents, lived experience; phenomenology*

Parental Experience of Childhood Cancer using Interpretative Phenomenological

Analysis

The survival rates of children with cancer have increased dramatically over the last three decades. Approximately two thirds of children with cancer survive their illness (Last, Grootenhuis and Eiser, 2005). However, childhood cancer still has the potential to be life-threatening, its onset is sudden and unexpected and treating cancer often involves a lengthy period of up to several years of invasive and intensive treatment. All of these factors affect the family unit as they embark on a major life transition (Cantrell and Conte, 2009).

Research to date has utilized quantitative or qualitative perspectives. Quantitative studies tend to examine parental experience from a symptom-focussed perspective, with some researchers arguing for the presence of posttraumatic stress disorder (PTSD) and posttraumatic stress symptomatology (PTSS) in both the childhood survivors of cancer and their parents (Bruce 2006, Cabizucaa, Marques-Portellaa, Mendlowiczb, Coutinhoc and Figueira, 2009). For instance, in a recent study by Wijnberg-Williams, Kamps, Klip and Hoekstra-Weebers (2006) parental psychological distress levels of distress conceived in terms of a trauma-response were shown to decrease significantly 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. At commencement 33% of parents exhibited post-traumatic stress symptoms, but there was a decline over time with 22% showing post-traumatic stress symptoms at the end of the research.

Such studies draw from the traumatological literature. This approach has, in turn been criticised for failing to recognise the fundamental differences between trauma and the experience of having a child diagnosed with cancer. Perhaps the most significant of these differences pertains to the nature of cancer where the sense of threat is quite different to that associated with trauma more generally. That is, the experience of having a child with a critical illness typically unfolds over a period of time, often in an uncertain context. Furthermore, the findings from such studies are inconsistent (Bruce 2006). In working towards developing a coherent body of knowledge to inform and guide clinical assessment and support of parents who play a critical role in the care of their children, we advocate a phenomenological approach based upon gaining an understanding of the experience of the parents of the children who present for treatment of cancer over time.

The Experience of Parents

Several studies, using a qualitative or narrative approach, have examined parent's experiences of their children undergoing treatment. The experience of parents' receiving a diagnosis of their child presenting with cancer has been explored by Beltrao et al. (2007) who identified three main themes: the attitudes and feelings of the parents, information as a support for coping with the diagnosis, and social support. An earlier study, completed some fifteen years ago explored the experience of parents of children with cancer from a qualitative and survivorship perspective (Van Dongen-Melman, Van Vuuren and Verhulst, 1998). ~~The investigators In a large sample of parents they~~ noted the absence of parental psychopathology and ~~identified focused their findings upon the~~ themes ~~which characterize the experience of the parents. The themes are~~ characterised by significant feelings of loss, and perseveration of these feelings. Parents reported feeling

more vulnerable after their experience and described how they “could never be the same relaxed person again, they had lost the experience of joyfulness, and felt disappointment in life” (van Dongen-Melman, Van Vuuren and Verhulst, 1998, pg 189). Consistent with this experience, they reported a general absence of positive changes. The researchers also reported on the impact upon the family including a sense of loneliness within the marriage and greater marital friction.

Kastel, Enskar & Bjork (2011) examined the information component involved in the first year of treatment and identified the need to better address parental needs for information during the initial period of the child’s treatment. They draw a link between the giving of relevant information and an increased sense of parental control and reduced insecurity. Additional variables ~~which have been~~ identified as contributing to increasing family coping and adjustment include: level of family support, quality of parents’ marital relationship, coping of other family members, lack of other concurrent stresses, open communication within the family, family income and socio-economic status, satisfaction with the medical care provided and a positive philosophy about life (Koocher and O’Malley, 1981; Kupst and Schulman, 1988; Spinetta, Swarner and Sheposh, 1981).

~~Kazak and Barakat (1997) report strong associations between parental stress levels and parent rated child quality of life. These results are consistent with those of (McCubbin, Balling, Possin, Friedrich, and Bryne 2002) where it was found that positive family recovery was predicted to result from strength based factors within the family from the perspective of the parents.~~

Narrative enquiry carried out by Woodgate (2005) similarly 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~~ of life-threatening illness. the cancer.

Parents’ own experiences of caring for a child with cancer are now 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. Such research has allowed for unique and individual experiences to be explored, enabling an open-minded and interdisciplinary approach to examine “close-up”, the experience of childhood cancer (Griffiths, Schweitzer and Yates, 2010). As a result the “altered identity” of the parent has begun to be revealed.

Objective

The aim of the study is to explore the experiences of parents who have a child with a life-threatening illness. The study will explicate the ways in which parents make sense of their experience. Furthermore, the implications of these findings for service provision will be discussed. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) will be used as it enables a fine-grained analysis of the phenomenon under investigation and so aims to understand the phenomenon from the participants’ unique frame of reference, their lifeworld. The specific aims of the study are to explicate parent’s experiences of having a child with a serious illness, and to explicate any changes that may occur over time which influence their experience.

Method

Design and Main Outcome Measures

Interpretative Phenomenological Analysis (IPA).

Pure phenomenology rejects that there is anything more fundamental than *experience*. Experiences are systems of interrelated meanings that are bound up in a totality of the “lifeworld”. 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). ~~One such approach, A number of qualitative approaches have used phenomenology as a basis for their own development and IPA is one such approach.~~

IPA ~~essentially~~ focuses on understanding an individual’s lived experience (Shaw, 2001) and how participants make sense of their 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 parents’ 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 the ways in which participants make sense of their personal world. ~~cognitive processes.~~

Participants

Ethical Approval. Approval was received from the Human Research Ethics Committee of a major hospital on the east coast of Australia. Subsequent approval was then sought and received from the relevant university ethics committee.

Participant Criteria. Participants were identified from the paediatric haematology oncology unit within the hospital. Potential participants were required to meet the following inclusion criteria:

Parents were required to have a child diagnosed with cancer or a cancer-related illness post January 2005 and aged between 8-17 years:-

Parent/s of the child were required to provide informed consent:-

Parents were assumed to be within the normal range of intelligence and be English speaking.

Sample Demographics. Data collection commenced in October 2006 and continued to January 2008. Nine families agreed to participate. Diagnoses of the nine children 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 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. At the time of the second interview, all children had completed active-stage treatment. The diagnosed children were aged between 8 and 16 years of age with the mean age being 11.89 years.

A total of 9 mothers and 2 fathers participated in the data collection. Parents ranged in age from 36 to 57 years with the mean age being 44 years. Prior to the child's diagnosis, all participants were in either full-time or part-time employment, apart from one mother who was a full-time stay at home parent. At the time of the initial data collection, 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 paid employment altogether. ~~and one out of the 9 mothers had transferred her employment from the family's home town in the country to Brisbane city. One of the 9 mothers did not have her employment affected as she worked from home. 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. Based upon respondents' postal codes and the Australian Bureau of Statistics (ABS) categories of socioeconomic disadvantage, 2 families came from areas of disadvantage, 1 family from an area of relative advantage and the remaining participants from non-disadvantaged backgrounds. Participants thus represent a reasonable spread of socioeconomic status.

Recruitment Process. The recruitment of potential participants involved sending an information letter to all families who met the inclusion criteria as identified by the treating oncologist. The information letter described the purpose of the study and

informed potential participants that they would be required to meet with the researcher on two occasions ~~at a venue of their choice, on two occasions~~ and complete questionnaire material and participate in an in-depth interview. Thirty letters were distributed, with nine families agreeing to participate in the study. Interviews were arranged with the respondents, at either their homes or the hospital, depending on their preference. More than half of the interviews were undertaken in the hospital context (55%) with other interviews being undertaken in the family home. Due to the nature of the study, which included interviews with both children and adults, interviews were most often undertaken with other family members being present. This paper focuses upon parental responses.

Materials

An open-ended interview was constructed using the following semi-structured schedule:

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?*

A similar semi-structured interview as the above was also used at time 2 (T2). Consistent

with the IPA approach, the second interview was conducted to obtain further insights into how people make sense of their experience and whether such interpretations change over the course of time. This approach was seen as important, to provide any unique insights into how parents make sense of their situation, given the changing clinical context over time, and the long term consequences of diagnosis and treatment for childhood cancer.

Explication

Preliminary coding. Interviews were recorded and transcribed. Interviews ran from 45 to 90 minutes in length. The data analytic technique involved the following steps. Each transcript was read and any preliminary themes or ideas which stood out were noted in the margin of the transcript. The transcripts were read again ~~and the emerging themes were identified~~ and divided into meaning units. Each meaning unit referred to a single aspect of the participant's experience. Each meaning unit was then given a code. Each code described the essence of the meaning unit (e.g. impact of the diagnosis). The analysis of each transcription was sequential. 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. Each transcript was "assigned" into Atlas.ti. 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 coherent topic or theme. These clusters or families of codes were then referred to as sub-themes. Sub-themes were then grouped into similar topics to provide an overarching thematic essence referred to as super ordinate themes (Smith and Dunworth, 2003). As super ordinate 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.

Inter-rater agreement on coding. Throughout the coding process the authors met to clarify codes and themes as a verification process. All codes were subject to a consensual process involving at least two of the authors. Due to the nature of qualitative research, any assessment on qualitative data is subjective, however such collaboration does allow for reflection on the analytical process and strengthens the credibility of identified themes.

Results

Explication of the Parent Interviews

Five super ordinate themes were explicated from the qualitative data collected through the semi-structured interviews: (1) a pivotal moment in time, (2) the experience of adaptation in relation to having a sick child, (3) the nature of support, (4) re-evaluation of values during a critical life experience and (5) the experience of optimism and altruism. All themes were identified at both interview time points, except for the theme “the experience of optimism and altruism”, suggesting the profound and enduring nature of these experiences for parents. To ensure the identity of the participants is protected, all names of participants are pseudonyms.

A Pivotal Moment in Time.

Parental experiences in response to the diagnosis were profound and personal. Parents responded in unique ways which varied from shock and deep sadness to denial. 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 super ordinate theme consisted of one sub-theme, *learning of your child’s potential mortality*. 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)

Parents as a group experienced the possibility of the death of their offspring as evoking a depth of experience. In this instance, the possibility is associated with shock, commonly associated with denial and the parent processes the potential loss of their child.

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 and the potential of losing one’s child. Despite this initial shock, parents described how they were able to continue to parent and take an active role in supporting and monitoring their child’s progress. This super ordinate theme was comprised of five sub-themes: experience of managing child’s illness, maintaining a sense of groundedness, acceptance of lifestyle change, living in the present, and the experience of faith as being a 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. For some 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)

Parents were thus introduced into a culture of support and played a role in the management of their child's affliction. They were no longer passive but had an active role in addressing the perceived cause of the family distress.

Maintaining a sense of groundedness. Another method parents used to manage their child's illness as identified through initial interviews 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 the perceived vulnerability 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.

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)

Acceptance of lifestyle change. Parents also demonstrated what can almost be termed 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 cannula put in tomorrow morning at the hospital and then . . . over to the [other hospital] and then from [there] back to the [-first hospital] 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)

Parents thus structured their lives and daily activities around the medical needs of their child.

The value of living in the present. Parents demonstrated a specific style which assisted them to manage their child’s illness. Pamela found it easier to cope with each dilemma or situation as it arose. 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)

Parents thus “slowed down” and addressed each new demand as they arose.

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. 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 [than] move quite competently to the next step. (Pamela 50 years, mother of 10 year old son Craig, Int. 2)

For some families, a sense of faith and relationship with a greater power than the perceived effectiveness of the health system fostered family's capacities to move forward.

The Nature of Support.

Parents commented on the support they received as being a salient part of their experience. Within this super ordinate theme many different types of support were mentioned, including the extended family, parent's place of work and the education

system supporting the child. This super ordinate theme was comprised of four sub-themes: experience of family support, supportive workplace, experience of the education system and the experience of being accepted.

Experience of family support. Many parents reported that their extended family responded in positive ways. 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, 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)

Supportive workplace. A number of parents viewed their workplace as being supportive of their circumstances. For these parents their workplace provided important relief and respite which parents viewed positively. 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 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)

Experience of the education system. Parents were concerned about the impact the illness and the extended periods of time away from school, would have on their child's learning capacity. However parents experienced relief when they were informed their child would not be adversely affected in any way. Sonia expressed 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:

I was worried about this coming year but the principal said don't worry about it, 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)

Experience of being accepted. The experience of having a child with cancer allowed feelings of acceptance to be revealed in an Asian parent who was not born in Australia and had previously felt like an outsider, 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. 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 than 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)

Parents experienced new found support across multiple domains, from extended family, their workplace, their child's educational setting and the wider community.

Re-evaluation of Values During a Critical Life 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 important or vital to them and to the continuation of their lives as a well functioning family. This super ordinate theme 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. Parents expressed a new found realisation relating to the preciousness and fragility of human life and developed a new awareness which involved a deep valuing of life and refusing to worry about minor or petty issues that were previously easy to get caught up in. In her state of renewed awareness Carol expressed a realisation 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. 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)

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. Belinda experienced a renewed sense of making the most of the present moment and the opportunities it presents. 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 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)

A renewed sense of family. As parents developed a new awareness of the importance of life and a new found appreciation for making the most of opportunities, the importance of maintaining a happy and healthy family is paramount to this new way of life. 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 just more determined to spend time together. (Sandra 44 years, mother of 15 year old son Jake, Int. 2)

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 diagnosed and treated for a life-threatening illness had again developed a renewed sense of what it meant to be happy. Carol placed an emphasis on family happiness being generated from simplicity. From her experience Carol articulated her realisation that it is not necessary to have extravagant goals to define good family times 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 (local holiday spot). (Carol 42 years, mother of 8 year daughter Erica, Int. 1)

The sub themes attest to the capacity of the participants to have purposeful and meaningful family experiences based upon the emergence of a new perspective

characterised by simple things gaining a renewed sense of meaning, the bonds of family life being affirmed and the sources of enjoyment and life satisfaction being redefined.

The Experience of Optimism and Altruism.

This super ordinate theme refers to experiences parents following 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. This super ordinate theme comprised 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 normalcy where they could once again participate in daily life activities. 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. She described Chloe as having improved and the extent to which she was able to participate in community life as being 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...so she has come along in leaps and bounds. (Julie 37 years, mother of 8 year old daughter Chloe, Int 2)

These experiences surpassed her beliefs as to what was possible.

Giving back to the community. Some families experienced a desire to “give back” to the community as they had experienced their child receiving good treatment and care. Parents were 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, we do anything to help.

(Pamela 50 years, mother of 10 year old son Craig, Int 2)

Parents expressed a new found sense of reciprocity.

New awareness of the prevalence of cancer. Parents experienced that it was not until their own child was diagnosed with the illness that they became aware of how prevalent cancer actually is in society. It was not surprising Alex felt that the new knowledge he had acquired about cancer had helped him to feel better about it and less afraid. He felt relief from the knowledge that treating cancer has become much more successful today than in previous years:

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, Int 1)

Parents expressed a new found sense of optimism and wish to make a contribution to their community. They had experienced profound fear but also a sense of freedom

derived from facing that which they feared most. Their capacity to confront fear was channelled towards a wish to give back to their communities.

Discussion

The aim of the study was to explicate parent's experiences of having a child with a serious illness, and to explicate changes that may occur over time which influence their experience with a view to contributing to the support needs of family members dealing with a child needing care for cancer. 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. The level of shock and deep concern that parents felt upon hearing of their child's diagnosis was experienced as beyond anything they had ever known previously. Parents revealed that their lives changed in an instant when they learnt of their child's diagnosis. Similar results were found in a research by Martinson and Cohen (1988) and Dixon-Woods, Findlay, Young, Cox and Heney (2001), where it was indicated that not a single parent had considered their child's initial symptoms were of a serious nature. Such findings emphasise the significant threat that a diagnosis of cancer has for parent's wellbeing, as it seriously challenges one's expectations and wishes for a normal family life and plans for the future. Other studies have similarly noted that parents experience a "biographical disruption" as a result of having a child diagnosed and treated for cancer (Dixon-Woods, Young and Heney, 2005). Parents are thus required to redefine themselves. For example, a study by Young, Dixon-Woods, Findlay and Heney (2002) 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. Other studies have reported that parents of a child diagnosed with cancer 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 to manage their own identity as strong and optimistic parents (Young, Dixon-Woods, Windridge and Heney, 2003). Such re-negotiation of parent-child relationships has profound implications for one's sense of meaning and purpose. ~~The parent's own quality of life is thus often compromised not only by the sheer stress and strain of their obligations, but also by the need to confront loss of wishes and desires, and a reduced ability to function in other important aspects of day to day living.~~

The findings from the current study revealed family life to revolve around the sick child for an indefinite period. The 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. Families were often isolated as they were forced to comply with the demands of their child's treatment regime. This situation left families feeling detached and disjointed. 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. While there are some areas of commonality with Van Dongen-Melman et al. findings (1998), we did not identify the same degree of loss, nor the degree of preservation of uncertainty and anxiety about the recurrence of disease reported in their study. In contrast to their findings, we also identified some positive changes expressed by parents in the current study. This may be

explained in terms of cultural factors but it is also possible that the outlook for children has become more positive over the past 15 years, since the Van Donegan et al. study which in turn has impacted upon the experience of parents at this time. ~~However, the current findings share the experience of previous findings which attest to the vulnerability of parental relationships during times of threat to their offspring. These results suggest that the structure of the family unit in today's Western society may not easily lend itself to major family disruptions.~~

Many parents 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 than others or by comparing the time-frame of their child’s illness to 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. Such findings suggest that in a time of crisis, humans are able to re-evaluate and reframe the situation to demonstrate gratefulness and appreciation. Similar results were found in a study undertaken in Taiwan by Yeh, Lee, and Chen, (2000) who reported the adaptation process of parents as comprising a series of processes including: confronting treatment, maintaining family integrity, establishing support, and searching for spiritual meaning.

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~~ (Yeh, Lee, and Chen, 2000; Purow, Alisanski, Putnam, and Ruderman, 2011).

Parents reported experiencing support from their extended family members which served to assist them both emotionally and on a practical level. Other mechanisms of support were found to be parents' place of work and the school the sick child was attending. Similar to the findings by Yeh et al., (2000) 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, again underpinning the importance of social support for families caring for a child with a critical illness.

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 staffs as families were impressed by the level of competence and care demonstrated by the staff. Parents re-evaluated what was important to them and reassessed how they wanted to spend their 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 to provide 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 person's life story. **The**

~~current findings support Clarke's view. In the study by Van Dongen-Melman et al. (1998) participants experienced a restructuring of their self view and world view. Common ways of coping included perspective taking along with re-focusing on the here and now and living in the present.~~

The aim of the study was to explicate parent's experiences of having a child with a serious illness, and to explicate changes that may occur over time which influence their experience with a view to contributing to the support needs of family members dealing with a child needing care for cancer. Additional ways in which parents coped and sought meaning was evidenced by some parents who, as a result of having a sick child, experienced a sense of altruism. This was expressed in diverse ways such as a desire to support the hospital via charities (and participating in the current study) or undertaking formal education to help future families in similar situations.

Implications of the Findings

Contemporary approaches to the support of children with cancer requires a team approach in which parents play an important role in the management of their child's condition. Given that all parents described the time of the diagnosis as the most difficult part of their experience, and given their role to support their child, it seems critical to ensure that appropriate emotional and informational support is on available at this time to assist parents adjust and to feel empowered in the process of responding to their child's needs. Informational support needs to be provided in a manner which is responsive to the emotional state of the parents and covers such areas as learning about medical terminology and the implications of the diagnosis and prognosis and also covers practical issues such as parking facilities on hospital grounds. -Nurses play a critical role in

translating medical information into more practical support as they are reportedly closer to the families and have a direct presence on the ward during the course of treatment. As health psychologists are playing an increasing role in the support of families where a child is undergoing treatment, they are also likely to play an increasingly significant role in addressing the informational and emotional needs of the members of the family.

Studies with adults suggest that cancer patients require different types of information as they progress through the cancer journey (Mistry, Wilson, Priestman, Damery and Haque, 2010). Health professionals therefore need to undertake continuing assessment of preferences and readiness to accommodate quite complex and potentially distressing information, so that these variations and changes over time are taken into account (Young, Dixon-Woods, Windridge, and Heney, 2003). Our finding suggesting that parents are present-focussed may serve to guide the content and ways in which information is provided to family members. Counselling support could be aimed at assisting families

maintain a sense of normality (as this is what parents in this study reported, helped them).

Similarly, parents may be assisted to anticipate the impact of the experience on the marital relationship and encouraged to recognise the strains which the experience has been shown to place upon marital relationships and assisted to find a greater sense of togetherness in dealing with an undoubtedly difficult time.

Theoretical and Philosophical Implications

~~The current study has potentially generated more questions than it has answered. For example, the results 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 experienced as threatened, people re-evaluate who they are, what is important and how they really want to live their life to find a renewed sense of meaning.~~

~~The majority of parents indicated that their child was very accepting of their illness and required treatment. This leads to questions; 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

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? While two fathers participated in the current study, a fuller exploration of the experience of fathers is warranted. Interviews were often undertaken in the presence of other family members which may have contributed to a potential positive bias in terms of experiences shared. In

~~addition It is also acknowledged that~~ the sample used in this study was self-selected and represents a particular demographic and cultural group. Therefore, the results may not be reflective of all parents and children where the child has a diagnosis of cancer.

Conclusion

The experience of having a child with cancer had a significant and life changing impact on the families who participated in the study. However, in contrast to at least one previous qualitative study, undertaken some 15 years ago, families did not evidence mourning over the psychological losses or anticipated death of a child as reported by Van Dongen-Melman et al. (1998). The findings of the current study suggest that parents dealing with a child who has been diagnosed with cancer can best be understood in terms of an adaptive meaning-making perspective which includes seeking support and evaluating their own priorities and values as opposed to a trauma-based model of response. The emotions and feelings associated with being a parent of and wanting to protect a vulnerable child were often tested throughout the 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 reflective transition where they re-evaluated themselves, their values, the importance of the family unit and how they wanted to continue living their lives. Information and support services are today part of the mainstream service provision in paediatric oncology settings, with a growing body of literature on psycho-educational strategies for parents and children facing a diagnosis of cancer (Peek and Melnyk, 2010). Evidence to guide

psychotherapeutic approaches to support parents is more limited. The findings of this study highlight the potential benefits of meaning centred [counselling psychotherapy](#) in supporting families in these circumstances.

An awareness of the process involved in responding to this critical life event needs to inform our understanding of family adaptation. Theories about family adaptation need to incorporate the crisis that parents experience when they first learn of their child's diagnosis. The internal struggle that parents experience as they reluctantly relinquish control of their child's health to the expertise invested in medical staff is an important part of the process which requires recognition. 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 bonds that families developed with staff are important in assisting families manage their own anxieties and concerns. Whilst a diagnosis of childhood cancer has long been described as a traumatic and life-changing event (Bruce 2006), the current findings suggest that the experience may need to be re-evaluated as a potentially life-threatening and also a life-rejuvenating event as parents experience a profound need to re-evaluate the meaning and purpose of their life as they seek to redefine themselves, often in terms of their priorities, relationships, sense of community and achieve degrees of optimism and altruism both individually and as a family.

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