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Childhood Experiences of Cancer: An Interpretative Phenomenological Analysis
Approach.

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Abstract

Paediatric oncology has emerged as one of the great 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 more recent years. However, very little is known about how children actually experience the diagnosis and treatment of their illness. Nine families in which a child was diagnosed with cancer were interviewed twice over a 12 month period. Using the qualitative methodology of Interpretative Phenomenological Analysis (IPA) children's experiences of being patients with a diagnosis of cancer were explicated. The results revealed five significant themes: 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. Changes over time were noted as children's experiences' were often pertinent to the stage of treatment the child had reached. These results revealed rich and intimate information about a sensitive issue with implications for understanding child development and medical and psychosocial treatment.

Keywords: cancer, children, lived experience; phenomenology

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Introduction

Children faced with a life-threatening condition or serious disease such as cancer, have specific medical, psychosocial, emotional and spiritual needs (Jones and Weisenfluh, 2003). However, we have little understanding of the experiences and the needs of children afflicted with a life-threatening illness. Developing an understanding of the impact that such a serious illness has on a child is crucial to being able to provide a comprehensive and sensitive approach to the child and family (Woodgate, 2005).

A socially constructed approach to child development takes into account that people give meaning to the world via their actions and interactions. Childhood is thus not viewed as a purely biological phrasing, but as a cultural phrasing of the early part of the life cycle. Children are active social agents who shape their experience of childhood and so need to be recognised as critical consumers of their health care. Children have the ability to make sense and meaning from their experiences.

Research is required to facilitate children communicating their thoughts and feelings associated with their illness (Woodgate, 2008). Discovering what children think and feel about their symptoms will assist healthcare professionals provide a more comprehensive treatment approach. The principles behind accessing the experiences of children with cancer, allow for a greater understanding of the experience of childhood illness. A phenomenological approach which investigates the perspectives of those affected by childhood cancer is crucial to developing a more comprehensive understanding of childhood and childhood illness. Dixon-Woods, Young and Heney (2005) proposed that such research into childhood illnesses could reveal a great deal of information about the theoretical development of childhood. Woodgate (2008) agrees that an interpretative approach is necessary as it is a method

which informs clinical understanding related to human illness experiences, which in turn, has implications for patient management.

Physical symptoms such as pain are obvious features of the experience of childhood cancer from the child's perspective. Woodgate and Degner (2003) found that the nursing staff were often unaware of the full range of symptoms the children were experiencing. Their research suggests that the children along with their parents believed that experiencing symptoms distress was an inevitable and unavoidable component of the illness. As a result parents may not have attempted to relieve the symptoms. Hedstrom, Haglund, Skolin and Von Essen (2003) indicated that pain resulting from diagnostic procedures and treatments along with nausea and fatigue were the most difficult symptoms to manage. The physical side effects of the treatment were seen to be the worst components of the disease in research by Enskar, Carlsson, Golsater and Hamrin (1997). These results indicate that research on not only the pain children experience but also the severity and distress caused by the pain is important, so that staff working with children can respond accordingly. Finally, a qualitative study noted that children were not only able to describe physical symptoms but the children were also able to describe how they felt via the use of "feeling states" (Woodgate, 2008).

Previous research has indicated that the emotional difficulties children may 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. Results such as these suggest that children may experience important changes in their identity as a result of their cancer experience. These changes in identity may threaten and have detrimental effects on the child's persona and self-image.

The Current Study

The current study will explore the experiences of children with a recent diagnosis of cancer, as they live through and attempt to make sense of the vulnerabilities and life-threatening component of their illness. The study will explicate the ways in which children make sense of their experience and children will be interviewed at two points in time, approximately 6 months apart. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) will be used to focus on understanding the experience of having cancer from the perspective of the child. IPA enables a fine-grained analysis of the phenomenon under investigation and so aims to understand the phenomenon from the participants' unique frame of reference, hence, the child's lifeworld. The specific aims of the study are to explicate the child's experience of living with cancer; explicate any changes that may occur over time which influence their experience and which contribute to current theories of coping and the experience of childhood illness in the context of cancer.

Phenomenology and Interpretative Phenomenological Analysis (IPA)

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 as described by the participants. Phenomenology requires a mode of data collection and analysis that presents the participants’ experiences precisely from their particular perspective.

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

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.

Participant Criteria

Participants were identified from the paediatric haematology oncology unit within the hospital. Potential participants aged between 8-17 years were required to meet the following inclusion criteria: have received a formal diagnosis of cancer or other serious illness post January 2005, provide informed consent and assent, assumed to be within the normal range of intelligence and speak English.

Sample demographics

Data collection commenced in October 2006 and continued to January 2008. Nine families 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).

As the date of the diagnosis and type of illness ranged considerably, there was great variation regarding the treatment stage of each participant at the time of participation in the study. At the point of initial contact 5 children were actively receiving treatment (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.

Procedure

Recruitment process. The recruitment of potential participants involved sending an information letter out to all families identified by clinical staff, as meeting the above inclusion criteria. 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. Both parents and children were interviewed, however this article contains the qualitative material obtained by the children only.

Materials. A semi-structured interview was used, so participants were asked to respond to the following questions.

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?*

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

Analysis

Preliminary coding. Following the principles of IPA each interview was taped using a digital voice recorder. Child interviews were approximately twenty minutes to forty minutes in length. All interviews were transcribed verbatim. The primary researcher read each transcript in its entirety. Any preliminary themes or ideas which stood out were noted in the margin of the transcript. After a general understanding of each transcript was achieved, the transcript was then read again and the emerging themes were divided into meaning units. Each meaning unit was then given a code.

Each code described the essence of each meaning unit (e.g. impact of the diagnosis). 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 the 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. Once each transcript was coded by hand it was “assigned” into Atlas.ti, a software program. Each transcript was then re-coded onto the software. 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. Themes were then divided further into sub-themes with an overarching thematic essence referred to as the master theme (Smith and Dunworth, 2003). As similar codes were identified or as master themes emerged the transcripts were continually re-checked in an iterative process 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 resulting in total immersion in the data..

Inter-rater agreement on coding. At various points in time throughout the coding process the authors met to achieve consensus upon and clarify codes and themes. Due to the nature of qualitative research any assessment of qualitative data is subjective, however such collaboration does allow for reflection on the analytical process and ensures the credibility of identified themes.

Results

The interviews resulted in the emergence of 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*. In reporting the results pseudonyms have been used to protect the identity of the participants.

The Experience of Illness

This master theme refers to the experiences children endured as they had no choice but to undertake invasive and extensive treatment all in an effort to survive their life-threatening disease of cancer. 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.

Letitia noted the pain associated with needles:

L: "...the blood test needles and the chemo needles really, really hurt and cannula needles... 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, to the extent 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)

Children experienced their treatment as painful and unpleasant tasting. The irony of this situation is that to be cured, the children were required to experience so much extra hardship.

Feeling restricted along with other horrible things. One of the more obvious experiences reported by participants were the limitations regarding activities.

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 excluded from his favourite past time 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... 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)

Living away from home bought many new experiences for the children, which were sometimes difficult to adjust to.

“I didn’t like the hospital food...It wasn’t McDonalds.” (Craig, aged 10 years, Int.)

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 difficult 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 positive experiences which children incurred as a result of their illness and which they typically would not have experienced if it had not been for their illness.

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 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)

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 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. The children reported positive experiences which were associated with spending less time in hospital. 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 attendance at hospital had decreased.

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: “I didn’t go to hospital to have blood tests, a lady from the hospital came and gave me the blood tests at home...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 a blood test...”(Erica, aged 8 years, Int. 2)

Jarrood 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:

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 positive experience from the children's perspectives. 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.

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.

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 our mind every time I've got something hard [to do] and I have to get over it...my cat...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)

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 support most of the time, along with a sense of humour.

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

C: “God and family... because they helped me through everything and do everything for me...and God because he made us.” (Craig, aged 10 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?

B: “Last night...all you can eat...just if it’s an “all you can eat restaurant”. “All you can eat” is when family goes out of my life. They can come back in as soon as I’m finished.” (Brian, aged 10 years, Int. 1)

Both the sub-themes within this master theme demonstrate that children across the age range of the study 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 their illness experience.

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)

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)

This sub-theme reflects the approaches and attitudes the children had which supported them through their illness experience.

Self-reflection and re-evaluation. The children demonstrated their renewed perspectives which is a reflection of how they as human beings changed as a result of their experience. This change 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 themselves as being any different from anyone else, even though they had been diagnosed with cancer. This sub-theme is a good

indication of how the children grew 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...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)

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.

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 our former life* and *experience of improving*.

Desire to return to our 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)

Jarrold 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)

Children reported a sense of urgency in wanting to return to their former lives. Their desire to return to their former lives and activities was considerable 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 the following responses children noted an improvement in their condition by their physical ability to do more and by having to attend 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)

Children had the ability to monitor their own health status and were able to gauge their own level of well-being.

Discussion

This study plays an important part in deepening our understanding of childhood cancer as experienced by the children themselves. To truly understand another human being, we need to investigate how he or she perceives the experience (Fochtman, 2008). 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 through their interpretation of their experiences. In this way “childhood” is seen as the early part of the life course that has a particular cultural phasing (Dixon-Woods et al. 2005). 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 children and their families.

The findings of this study provide credence to the appreciation that children have minds of their own and have the ability to understand, interpret and make sense of their illness experience. Within this, a number of important findings may be understood within the context of contemporary theories; the majority of children who participated in this research impressed as being accepting of their illness. That is, no child expressed a desire to know why they had become ill. No child demonstrated a “why me” attitude. Accepting and undertaking the necessary (although painful) treatment occurred almost unquestionably.

No child ever expressed any concern at the possibility they may not get well, nor did they express 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 however,

it may also reflect the positive outlook that the children took as an important component to managing their situation.

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 identity and feeling secure and happy within themselves. 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 appear to play a large role in social development.

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.

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. 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 and ability to return to pre-illness activities. This phenomenon was observed in both young and older children.

The five master themes generated from this study revealed some interesting results.

Illness as a horrible experience. 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. 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 than 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 also proved particularly difficult for some of the younger children as it meant incurring a number of new and off-putting experiences.

The Up-Side of Being Sick. 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. Reduced hospital visits or receiving treatment from home was also viewed positively by the children. Perhaps, allowing children to stay in the "comfort zone" as much as possible whilst receiving treatment, is an aspect modern medicine should consider.

Re-focusing on What is Important. Children reported experiencing support from their family, friends and parents' work colleagues. Children were able to identify with a range of supports such as pets, family, friends, hospital staff and God and recognised the importance of these relationships in their lives. These results suggest that children have a capacity to develop an appreciation of others, very early on in their lives.

Acquiring a New Perspective. Children demonstrated both practical and philosophical methods of helping them manage aspects of their illness. They acknowledged their increased knowledge about the disease of cancer. Children also demonstrated 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. These results infer that young people have an ability to adapt and devise methods of support which are personal to them, they have an ability to be reflective about how they had changed as a result of their illness experience.

The Experience of Returning to Well-Being. 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.

Changes over Time

The current study collected data at two points in time, approximately 6 months apart. Most master themes did occur at both times in which data was collected. However, there was at least one master theme which occurred at one of the time points only. The master theme of “the experience of returning to well-being” was the one theme 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 they had been unwell for a long time by this stage. Their impatience and frustration at being ill started to take its toll. 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. Experiences are likely to vary greatly across time and these can often be influenced by the stage of treatment the patient has progressed to. 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

The findings of this study have implications for child related services. The findings support the need for delivering medical services and creating a hospital environment as similar as possible to children’s 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 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.

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).

The majority of children experienced physical pain as one of the most difficult parts of their entire experience. This factor 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.

Limitations and Further Research

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, 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. Research which includes data collection from multiple sites which allows children to be grouped into age brackets would be useful, Earle and Eiser (2007). 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.

Given that the participants had not met the researcher until the time of their agreement 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.

The findings of the current study have opened up a plethora of potential areas that could be addressed by future research. Future research would benefit by exploring further children's ability to cope with adversity. Do their shorter lives with fewer expectations mean that they are more receptive to managing unexpected events? Whilst this study adds to our understanding of child development, further

research examining childhood experiences could add valuable insight into developmental theories.

Conclusion

The diagnosis of childhood cancer is one which signifies not just a traumatic event but a life-changing and life-renewing experience. It is this information which now needs to be incorporated into existing theories, those which are relevant to child development. 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 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.

The results of this study confirm that 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.

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