

'Feeling Very Left Out': Parents' Insights on Siblings of Children Treated for Childhood Acute Lymphoblastic Leukaemia.

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ABSTRACT

Although the experience of siblings of paediatric patients has received very little attention, the work that does exist indicates that there are significant problems and that the topic needs further exploration. As a contribution to furthering this area of research, the present paper presents findings on siblings experience from a study examining the impact of the diagnosis and treatment for childhood Acute Lymphoblastic Leukaemia (ALL) from the perspective of all family members. In particular, the effect of relocation upon the sibling, emotions and relationships between sibling and parent will be presented. The findings indicate that siblings are a vulnerable group who report 'feeling very left out' because of the enormous demands place on their families during the intense and prolonged medical drama associated with treatment for ALL.

Key Words: *Acute Lymphoblastic Leukaemia; Psycho-social; Siblings; Relocation; Qualitative Research.*

INTRODUCTION

Since the 1970s, cure rates for both Acute Lymphoblastic Leukaemia (ALL) and Acute Myeloid Leukaemia (AML) have improved dramatically. There is a cure rate of 70-75% for children diagnosed with ALL (Pui, 2000) and conditions such as standard risk ALL are now curable (Cole, 2008). However, while much has been published on clinical trials and improved therapies, there is still considerable work to be done examining the psychosocial aspects of treatment for childhood leukaemia for the patient and their family (Harpham, 1995; McGrath, 2000; O'Boyle, 1997).

Siblings of children with serious illness experience considerable, and relatively underestimated, psychological distress with the potential for long-term sequelae (Carr-Gregg & White, 1987). Unfortunately, most of the work in this area is now dated. Historically, studies have shown that the siblings of paediatric cancer patients can experience jealousy and guilt (Balk, 1983; Berman, 1978; Cairns et al., 1979; Koch-Hattem, 1986; Lavigne & Ryan, 1979), anxiety and a sense of responsibility (Fischloff & O'Brien, 1976; Koch-Hattem, 1986; Spinetta, 1982), school problems (Carr-Gregg, 1983; Kaplan et al., 1976; Stehbins & Lascari, 1974), feelings of rejection (Binger et al., 1969; Heffron, 1973) and poor relationships with their parents (Tietz et al., 1977). The scant recent studies that have been completed affirm the problems of siblings of paediatric patients, highlighting

concerns with schooling, self-image, anxiety and adaptive skill, and pointing to evidence of post-traumatic stress (Packman, 1999; Packman et al., 1997a; 1997b). In short, the work that does exist indicates that there are significant problems and that the topic needs further exploration.

As a contribution to furthering this area of research, the present paper presents findings from a study examining the impact on all family members of the diagnosis of childhood Acute Lymphoblastic Leukaemia (ALL). In particular, the article reports parent's insights on the effect of relocation upon the sibling, on siblings' emotions during treatment and on the post-diagnosis relationship between sibling and parent.

THE RESEARCH

The material in this article has been gathered from the first stage of a longitudinal study that looks at the psycho-social issues associated with the treatment of paediatric ALL. The Royal Children's Hospital Foundation and the Financial Markets Foundation for Children have jointly funded the study. The multi-disciplinary study is conducted by a psycho-social researcher at Central Queensland University in association with research clinicians from the Haematology and Oncology Unit of the Royal Children's Hospital (RCH). The study is an exploration of the experience of paediatric ALL treatment from the perspective of the child, their parents and well siblings.

Ethical consent to conduct the study was obtained from the University Ethics Committee and the RCH ethics committee. Participants were verbally informed of their rights in research and written consent was obtained for participation in the research.

Target Population

The research is accruing consecutive patients, aged from birth to sixteen years, who have been diagnosed with ALL enrolled at the Banksia Ward at the Royal Children's Hospital (RCH). During the initial stage of treatment the parents and siblings of these children were approached with regards to participation in the research. The findings presented here cover the interviews with the parents of the first twelve ALL children. Of the initial thirteen families approached, only one declined giving a response rate of ninety-two percent (n=12; 92.3%).

Demographics

The child patients (n=12) recruited ranged in age from nine months to ten years and males predominated (male

n=7; female n=5). All were diagnosed with ALL (ALL, n=8; ALL/T Cell Lymphoma, n=2; Infant ALL, n=1; ALL/Philadelphia chromosome, n=1). The majority (n=11) were on the ANZCCSG study VII protocol (Standard risk Group, n=7; High risk, n=4) and one was on MRC UKALL Infant 1 Protocol.

All of the patients were from two parent families. All of the patients' mothers (n=12) and four (n=4) of the fathers participated. The age range of the parents was from twenty-eight to forty-four years. With the exception of three, all parents had other dependents (four other dependents, n=1; three other dependent, n=1; two other dependents, n=3; one other dependent, n=4) who ranged in ages from newborn to twenty years. The majority of families (80%) had one of the partners in full time employment (father full-time, n=8; mother full-time, n=3). Seventy five percent (n=9) of the families had to relocate from their home town to the metropolitan area for treatment. About half of the mothers (n=7; 58.3%) ceased employment (f/time, n=2; p/time n=5) at the point of diagnosis because of the demands of relocation.

Methodology

The experience of treatment is documented through qualitative research using open-ended interviews with the child patients, their parents and well siblings at key points in the treatment trajectory (T1 - End of Induction Remission; T2 - End of Reconsolidation; T3 - Continuation Therapy; T5 - End of Treatment Assessment; T6 - Post Treatment). The findings presented in this article are from T1 of the first twelve interviews with the parents of the paediatric ALL patients. The interviews were conducted by a psycho-social researcher with a counselling background and many years experience working with families coping with a member with a haematological malignancy. The time and location of the interviews are of the participants choosing. The interviews were open-ended and focus on the experience of treatment as it impacts on all family members. Participants were encouraged to tell their story from the point of pre-diagnostic symptomatology up to the present experience with treatment.

A phenomenological approach was taken to data collection and analysis. The aim of phenomenology is to describe particular phenomena as lived experience (Streubert & Carpenter, 1995). The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (Streubert & Carpenter, 1995; Polit & Hungler, 1995). The interviews were audio-recorded and

transcribed verbatim. The language texts were then entered into the QSR NUD*IST (Nonnumerical Unstructured Data Indexing, Searching, and Theorizing) computer program and analysed thematically. The computer package allows the entire data file from the transcriptions to be entered onto the computer program, each portion of the interview categorized (in the case of this study into free nodes) and then portions of the text corresponding to specified categories retrieved and printed (Polit & Hungler, 1995). Thematic analysis is a process, mainly used in phenomenology, which involves searching the data for related categories with similar meaning which are then grouped together (Holloway, 1997). All of the participants' comments were coded into free nodes, which were then organised under thematic headings. Thirteen (n=13) of the free nodes related directly to the issue of the impact of the treatment experience on siblings are presented here.

FINDINGS

Siblings Left at Home

Seven parents (n=7) spoke of the difficulty of worrying about the siblings left at home. When families have to relocate parents are forced into the very difficult position of having to decide whether to uproot the other children in the family. Parents talked about the difficult experience when older children are forced to relocate. For all families the relocation experience was the first time they have been forced to separate the children, and this is described as a significant disruption where the family have to adjust to being a smaller unit.

Parents had a sense of "*palming their children off*" as all arrangements were made in speed in response to the medical crisis. Irrespective of whether parents had to relocate or travelled long distances to remain in their home situation, there were descriptions of the constant pressure of making daily arrangements for the care of the siblings. The process was described as just the logistics of having to ring people at short notice and constantly organise child care. At times the lack of available help meant the income earner in the family had to lose income by having to take a night off work. In some cases where it involved hospital visits in the middle of the night, parents were dependent on the help of close relatives. These situations need the commitment of both parents, and problems multiply where one parent does not have that support.

Some children are left at home with either the other parent or under the care of grandparents. Mothers spoke of the difficulty of not being there to do the normal daily things

that children needed. This was particularly difficult when the parents knew that a particular child was previously very close to them and sensed they could not meet their normal need for dependency. However, there were reports of the older children doing well at home, enjoying school. However, even whilst acknowledging that these older children preferred being in their own home, there were reports of the children questioning why the family had to be divided. Parents noted that these older children were coping at this point in time but worried about the long term consequences of the separation.

There were descriptions of the impact of the absence of the mother on all ages of siblings. For the pre-schooler this can mean not being around to put them to bed, for the school age child it can mean not being there after school or missing out on swimming lessons, for the teenager it can mean having to cancel a part-time university course. At all ages there are particular problems.

The Pre-school Sibling

Four parents (n=4) spoke in detail about their concerns with regards to the pre-school sibling. It was stated that pre-school children present difficult challenges at both the hospital and at the accommodation centres where they can become "*pokey and annoying*" because of their need for activity. Because of all the demands in the hospital environment, parents can not give the pre-schooler the focus of attention they need for their age. There are not other children around to play with. Even when there is appropriate playground equipment this is of little use as the preschooler cannot go down by themselves to play without supervision. The difficulties were exacerbated when they were children from the country as they are used to wide open spaces and there is not much room at the hospital or the accommodation centre.

Parents had to make endless daily arrangements to have the pre-schoolers looked after as they need a high level of care. To reduce the negative impact of being away from the mother the arrangements were presented to the child as exciting events to look forward to. Parents spoke of trying to frame the arrangements positively to the siblings by making statements such as "*you are going to play*" or "*grandma is coming around*".

One mother noted that it was important to have a continuous person, there at all times, for the young child. Grandparents were an important back-up and mothers spoke of appreciation for the grandparents. Although parents were confident of the good care the siblings were receiving, there were worries about breaking the bond with their child.

Returning home to the pre-schooler can be a difficult time of re-establishing the bond. Pre-school siblings were reported to “*shy away*” from the mother, get angry, become “*naughty*” or “*lashes out*”. Mothers reported having to take steps to re-affirm the bond with the child. The difficulty is that at this age it is not possible to explain the situation and the sibling just does not understand why the parent has to leave. When time is available mothers try to compensate by giving the sibling special attention. The pre-school sibling’s life is described as very disrupted because of the focus on the child patient.

One of the difficulties in relation to pre-school siblings is that their understanding of the situation can be quite limited. Where previously the siblings had been able to play freely, the sickness and side effects of treatment meant that the sick child now had to be handled differently. Parents reported that the pre-school sibling does not understand the need to be gentle with the child patient. However, there is also evidence that the older pre-schooler can comprehend a great deal about leukaemia. One mother reported that her pre-schooler tells friends that the sick sibling has “*got sick blood and he has got to go to the doctors for a long time to make him better*”. In spite of all of the stress that pre-school siblings are under there were stories of genuine concern from the sibling for the sick child.

In cases where fathers play an increasing role with the siblings because of the mothers absence, mothers report that pre-schooler begin to bond with the father.

The School Age Sibling

Four parents (n=4) spoke of the problems with school age siblings. There were reports of the children at this age valuing being able to stay in their home and remaining in school and sporting activities. Underpinning these descriptions, however, were references to the siblings missing the parents and wanting the family to be re-united. Significant times when school age siblings can feel a particular loss of the parent is during the morning in preparation for school and in the afternoon on returning home. For all families the previous pattern of the mother being there had been disrupted. Even where alternative arrangements had been made, parents expressed a sense that the siblings were just sent to who ever was available at that point in time, which is far from optimum conditions. Parents expressed concern about the long term effects of the school aged siblings sense of “*feeling very left out*”. School age siblings also had to shoulder the responsibility of extra chores to help with the household management. It was seen as difficult when these chores involved ones that were previously the responsibility of the sick child. At a time of

lack of attention the sibling can feel burdened by such extra responsibilities.

The Teenage Sibling

Four parents (n=4) spoke of the impact of the experience on the teenage siblings. At this stage in the child’s development they have strong ties with the outside world that can be severely disrupted by the medical drama. If forced to relocate teenagers can be resentful and parents have the added burden of having to deal with the sibling’s anger. Others return home to get on with their life, even though the parent may miss them, and worry about the effect of the family disruption.

These problems were not exclusive to relocated families. Even when parents were able to commute between hospital and home, there were reports of complete disruption to the lives of teenage siblings. Older siblings could not make plans as they were needed as child minders and it was never possible to say in advance whether the parent would be at the hospital or at home. There were reports of disruptions to important events in the teenager’s life such as attendance at the end of school formal, missed employment opportunities and cancellation of part-time university course. This was because teenagers would not know when they would be needed for child minding or when the parent would be available for formal functions. The demands of the medical drama had to take priority and all other activities either reorganised to fit into the hospital schedule or just deleted completely. The implications of this over a period extending for more than two years of the teenagers life was seen to be quite serious. A vignette provided by one parent provides some insights into these very real practical dilemmas,

“(the teenager) could get a phone call saying, ‘Well look, I’ve got a job interview for you are you able to come down this afternoon?’ But, it’s like, he says, I can’t I’m sort of baby sitting my brothers at the moment.’ When he explains to them it is because my (sibling) has leukaemia and mum and dad are at the hospital, they say ‘Oh, oh I’m sorry’, but (the teenager) doesn’t get a call back.”

Sibling Emotions

Ten of the parents (n=10) spoke in detail about their perceptions of the siblings emotional states. It was acknowledged that every member of the family see the situation from a different perspective. There are a wide

range of emotional states described as being involved in the adjustment, including anger about disruption to their lives, sadness at loss of contact with friends, frustration from restriction in the limited accommodation, a sense of neglect from lack of attention from the parents, a feeling of being left out, a sense of jealousy about the attention the sick sibling is receiving, a negativity from the stress of the strain of the situation, rejection (in the case of pre-schoolers) of the parent because of a feeling of abandonment and above all a longing for or sense of grieving for the parents and the sick sibling.

Parents talked about the difficulty for the well-siblings of all the attention that the sick sibling received. It was a common occurrence that friends and family would send extensive gifts to the sick child without mention of the well siblings. This placed the well siblings in the difficult position of feeling both jealousy and guilt about that jealousy. Parents noted that it would help greatly if visitors could understand the need to acknowledge the needs of the siblings.

Disappointment is also another challenging emotion (n=4) that siblings have to deal with. The disappointment can be when siblings plan time with their parents and this is cut short because the parent had to return to the hospital, or because visitors were not interested in them but only asked questions about the sick child. Parents spoke of the disappointment siblings must feel when they are not there in the morning or not around to take them to school.

Underpinning all of the comments, however, was the ongoing theme of the siblings missing out on quality time with the parents. The challenge for parents is how to meet the needs of sick child and to keep some semblance of a normal existence for the well siblings.

A key problem in relation to the siblings' adjustment is the disruption to the family's sense of normality. All of this discussion must also be put in the context of the findings on problems of coping with relocation and the major difficulties associated with coping with such a long treatment protocol, presently submitted for publication (McGrath & Rogers, 2000).

Positive Impact on Parent-sibling Relationship

Three of the parents (n=3) noted that because the mother had to stay at the hospital with the sick child the father had to be far more involved with the siblings at home. This change in the father's role was described in positive terms as creating a strong bond between the father and the siblings left at home. Fathers were reported to enjoy the changes.

In some cases where there already was a strong relationship with the father that remained strong.

Negative Impact on Parent-Sibling Relationship

Five parents (n=5) spoke of the negative impact of the experience on their relationship with their other children. In retrospect, parents could see that the sheer stress of the situation caused them to be irritable with their children, at times excessively. One solution to reducing the negativity was found to be to spend quality time with siblings who were missing out on attention. The reverse situation happens where parents have to deal with siblings angry emotions from being left.

One of the central difficulties is that the demands of the hospital drama mean that there is no longer sufficient time for appropriate attention for the siblings. Even when there is a parent at home with the children the added duties they have to perform in the absence of their partner means that they are also not in the position to provide sufficient quality time. One parent summed up the situation in discussing the negative impact of this situation,

The siblings will never forget that they did without a full family all of this time.

DISCUSSION

There are recent calls in the literature for research exploring the experience of siblings of cancer patients as to date the evidence is limited, especially in relation to the period of hospitalisation (Gursky, 2007; Kramer & Bank, 2005). The dominant theme connecting all of the findings from the study presented in this article is the siblings' pervading sense of being 'left out' and thus missing out on a 'normal' family existence. The demands of the medical drama necessitate an exclusive parental focus on the sick child which means that the needs of the well siblings, by necessity, must be secondary. This situation is exacerbated by the fact that the drama continues over an extended period of two to three years. The constant uncertainty precludes any possibility of planning and requires that *ad hoc* arrangements are constantly made for the care of siblings. This situation can be emotionally and practically demanding for parents, as well as distressing for the siblings. Wilkins and Woodgate's (2007a) research on siblings experience with paediatric bone marrow transplantation also emphasises the disruptive nature of such treatments on family life. The findings from the study reported in this article indicate that the issues vary according to the age of the child. Similarly Massimo & Wiley (2008) emphasise

taking age into consideration in understanding the emotional reaction of siblings. Pre-schoolers can be highly demanding, requiring close attention and are very sensitive to parental absence, often reacting with withdrawal and aggression. The parental challenges for this age group include maintaining continuity of care, finding quality time, managing the toddler in child-unfriendly situations, coping with the limited understanding of situations, and overcoming the anger and withdrawal resulting from parental absences.

Although more independent and able to care for themselves, the school age child provides their own unique challenges for the parents. Distracted by the intense medical drama, it is often impossible for parents to address their fears, to be there at significant times of the day and for special events, provide the opportunity to talk about and acknowledge the complexity of the child's feelings (guilt, jealousy, protectiveness, grief) and to be mindful of not placing too much responsibility on their shoulders. Consequently, it is all too easy for siblings to 'feel very left out'.

The disruption to family life and parental attention makes the teenage sibling vulnerable at a time when they are beginning to deal with the demands of the outside world. The need for talk, companionship and guidance at this difficult period is paramount, and although older, teenage siblings miss and need their parents as much as the younger children.

The situation is accentuated for families that have to relocate to a specialist metropolitan hospital (McGrath, 1998; 1999a; 1999b; McGrath & Rogers, 2000). In such situations, family life may be totally disrupted as siblings may be physically separated, by hundreds of kilometres and for long periods, from their parents and sick sibling. In some cases there can be a positive impact on the relationship between the care-taker parent and the siblings, but this is not always the case. The sheer stress of the situation can limit the emotional resources parents have available.

It is obvious from these findings that it is essential to provide support for families going through the lengthy and demanding crisis of coping with childhood ALL. There are many creative ways in which family members, friends and professionals can respond to the needs of siblings. The offer to child-mind, the thoughtful gift or letter, the readiness to respond at short notice to a crisis, are all practical ways others can help. It is essential that siblings are provided with continuous, stable, supportive relationships with significant others. The opportunity to talk honestly about the full range of their feelings, from

protective altruism to jealousy and grief, with someone who understands and affirms non-judgmentally the normalcy of such emotions is important in allowing the sibling to come to terms with their situation. Nolbris and associates (2007) affirm these insights with research that outlines emotions experienced by siblings of child cancer patients, including a sense of protectiveness, anxiety, worry, and conflicting sense of loyalty. Wilkins and Woodgate (2007) indicate that providing the opportunity to share feelings is especially important for siblings when the child patient is going through intensive treatment such as a bone marrow transplant. The chance to visit the hospital, and at times stay, can offer insights to the sibling as to what the parents and sick child are coping with, and thus will go some way to helping them to understand the need for separation. The key factor in any strategy is to devise ways to provide attention to the sibling and affirm their importance to the family.

CONCLUSION

Although research on the experience of siblings is still in its infancy, the knowledge that is presently being gathered is that they are a vulnerable group that require immediate attention. The psycho-social equation needs to be balanced in favour of the needs of the whole family during the lengthy period of the intense focus on the sick child. There are a myriad of creative strategies that significant others, be they family, friends or professionals, can take to ensure that the sibling does not 'feel very left out' but is rather affirmed as an important member of the family, with significant and individual needs of their own.

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