

Treatment for childhood acute lymphoblastic leukaemia: the fathers' perspective

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Abstract

Research on parental adaptation to a child's chronic illness is still scant, and this is particularly so in relation to the experience of treatment for paediatric Acute Lymphoblastic Leukaemia (ALL). The work that does exist on parental reactions tends to conflate maternal responses with paternal responses, as fathers are usually seen as having a secondary role. Consequently, little is known about how fathers cope with treatment for childhood ALL. The present discussion seeks to make a contribution to this area by presenting findings on the paternal experience of treatment for paediatric ALL from a longitudinal study conducted at Royal Children's Hospital in Brisbane, Queensland. The findings from this research clearly indicate the emotional pain that fathers face in their struggle to accept the diagnosis of a serious, life-threatening illness such as ALL in their child. The findings challenge the notion of the male stereotype by showing that the shock of diagnosis, the emotional pain of coping with the illness, the expression of pain through tears, the desire to be with the child, the struggle to cope with the medical interventions, and concerns about other family members are not gender specific, but are rather issues common to both parents.

Background

It is now well documented that having a child diagnosed with cancer is a devastating experience for parents (Bracken 1986; Brown 1989; Lansky 1985). Hearing the news that their child has been diagnosed with a life threatening condition such as cancer is a life-altering event for parents that will have an impact on the quality of the rest of their lives (McGrath 2000a; Van Dongen-Melman et al. 1998). Characteristically parents undergo reactions of shock and generalised alarm upon receiving their child's diagnosis (Koocher & O'Malley 1981; Lewis & La Barbera 1983; Magni et al. 1986; Powazek et al. 1980). However, early work in this area is only beginning to describe the depth and breadth of the impact of such a diagnosis, particularly in regard to the challenges involved in coping with the stress of treatment (Hillman 1997; McGrath 1999; 2000; Speechley & Noh 1992).

Acute Lymphoblastic Leukaemia (ALL) is the most common form of childhood cancer, accounting for 80% of all paediatric oncology cases below the age of fifteen years (Souhami & Tobias 1995). ALL has provided a landmark in cancer therapy as the first disseminated and otherwise lethal malignancy to be curable in the majority of patients (Emanuel et al. 1990; Greaves 1993; Nygaard & Moe 1989). In the 1950s, a child diagnosed with ALL would be expected to die in just over a year, whilst today 60-80% of all newly diagnosed children are cured (Holland 1989; Robinson et al. 1991).

Although the success rate is high, the benefit is achieved through a long, invasive and very arduous treatment process. Most treatment schedules (protocols) extend from two to three years and require the children to spend lengthy times in hospital (Emanuel et al. 1990; Henderson et al. 1992).

A standard protocol for ALL involves the intensive chemotherapy treatments of remission induction and consolidation, followed by central nervous system treatment administered to spaces such as the brain and spinal cord, and finally maintenance chemotherapy (Souhami & Tobias 1995). Treatment interventions can include lumbar punctures, high doses of intravenous drugs or cranial irradiation. The experience of undergoing such intensive treatments affects not only the child, but also the entire family (McGrath 2000a; 1999).

Research on parental adaptation to a child's chronic illness is still scant, and this is particularly so in relation to the experience of treatment for paediatric ALL (Cayse 1994; McGrath 2000a). The work that does exist on parental reactions, usually in relation to non-oncological conditions, tends to conflate maternal responses with paternal responses, as fathers are usually seen as having a secondary role (McKeever 1981).

To date, there has been limited research conducted on the father's experience with serious chronic illness in their child, particularly in relation to the paternal response to childhood cancer (Cayse 1994; Sterken 1996). Consequently, little is known about how fathers cope with treatment for childhood ALL. The present discussion seeks to make a contribution to this area by presenting findings on the paternal experience of treatment for paediatric ALL from a longitudinal study conducted at Royal Children's Hospital, Brisbane, Queensland. It is the hope and expectation that the findings will make a contribution to beginning to document the father's journey in relation to this serious illness and in so doing will affirm the need for further research in this area.

The Research

The data for this article were gathered from the first stage of a longitudinal study of the experience of paediatric ALL treatment from the perspective of the child, his/her parents and well siblings. 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 psychosocial researcher at the Centre for Public Health Research (QUT) in association with research clinicians from the Haematology and Oncology Unit of the Royal Children's Hospital (RCH).

Ethical consent to conduct the study was obtained from the QUT's 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

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) have been enrolled in the study. 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 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, one infant, one a high risk because of the presence of the Philadelphia chromosome, and two with the further complication of T Cell Lymphoma (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 Australian and New Zealand Children's Cancer Study Group (ANZCCSG) study VII protocol (Standard risk Group, $n=7$; High risk, $n=4$) and one was on Medical Research Council, United Kingdom, Acute Lymphoblastic Leukaemia (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 number of fathers participating in the study is low. However, because of the difficulties associated with including fathers in research (unavailability because of work, reluctance to participate in research) and the lack of previous work including fathers, this sample is seen as making an important, albeit preliminary, contribution.

There was strong congruency between the statements made by the mothers and the fathers, a factor that strengthened the credibility of mothers providing initial insights on the male experience. 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 (full-time, $n=2$; part-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; T4- End of Treatment Assessment; T5 - 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 following discussion will outline the methodology specific to these interviews. 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 were of the participants choosing. The interviews were open-ended and focused 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.

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. All of the participants' comments were coded into free nodes, which were then organised under thematic headings. An experienced qualitative researcher established the coding. The project officer, a Child Life Specialist who had intimate knowledge of the interviews gained through transcribing, validated the coding. Eight ($n=8$) of the free nodes that related directly to the issue of the fathers' experience with treatment are presented here.

Findings

The Father's Reaction to the Diagnosis

The majority of participants ($n=15$) made comments about the father's reaction to hearing the child's diagnosis. The language texts contained evidence of the father's extreme emotional pain in dealing with the fact of the child's diagnosis. Fathers made statements such as 'I'm a very emotional person at the moment, I'm grieving, I'm like, I'm hurt and I'm angry, and all that in one' or 'initially it was just full on water works... full on, it was devastating, I was devastated' or 'like its just like a big bad dream and you don't want to wake up to everyday'. Similarly, their partners made reference to their pain with statements such as '(the father) was finding it very difficult in the beginning' or 'because that was the hardest thing for my husband, he was very upset and cried a lot when I told him' or 'I could see that he was upset, very upset about it'.

There were indications that fathers found the news as difficult as, or perhaps more difficult than, their wives. This was expressed by the fathers, 'I think I found it more difficult than (my wife) at times' and their partners, 'my husband probably took it worse than I did'.

The Father's Response

There were clear indications that although the fathers were in a distressed state they did want to be with their child during the treatment situation. These statements were made by both the fathers, 'I could probably go home and go back to doing my work, but at this stage I don't want to. I want to be here' or 'I find it easier

being up here (the hospital) with the (sick child) because I am up to date with what is happening', and their partners commented as well, 'my husband's attitude is (our child) is most important'.

Although they indicated that they wanted to be with their child, there were also reports of how difficult the fathers found witnessing the treatment, for example, 'in the beginning it was the emotional stuff, just holding (the child) down and him crying, you know, because they (father and child) were so in tune' or 'he is there to support me, but not really on the medical side of things'.

Fathers talked about how they coped by taking time out from the situations. For example one father stated, 'I spend a lot of time down at the unit... that's how you cope, I think, is by coming and going'. This is described as a strong need, 'I just have to go because I can't stand to see my little (child) like that... that is just how I feel I just have to get out'. Their partners also noted this coping strategy of taking time out, 'sometimes I can see he doesn't cope, he just goes for a walk, he'd just say oh I'm going for a walk and he would go for a walk' or 'he wouldn't stay in there (the treatment unit) he mustn't be able to cope with it, he kept finding all of the reasons in the world to go out of that unit'.

There were statements by the fathers to indicate that they may not be expressive of their feelings, for example, 'sometimes I mightn't show it how other people do, but I do (have strong feelings), I love them both (partner and child) very much'. Their partners also commented on this reserve with expressing feelings, 'no he hasn't said anything about it. Maybe that's where the kids get it from where they don't sort of talk much about things' or 'whereas my husband doesn't like talking about it a lot, because he gets quite upset and he doesn't like to show that emotion' or 'he is more typically male where you bury your head in the sand'. Some fathers were seen to be managing their emotions by 'working harder'.

Even where fathers were able to talk about their feelings the notion was expressed that they found it difficult to find others who would listen, for example, 'it's a typical situation of men don't network as well as women do... there is less people to talk about it to. With the people that I'm talking about with may not have been my first choice of a person to discuss it with'.

Men do cry

A number of the language texts dealt specifically with the issue of men expressing their pain by crying. Reference was made to the gender stereotype that 'men don't cry'. Both male and female participants spoke of the lack of basis in this stereotype. Women made general statements such as 'It is just like this thing ... men don't cry ... but they do'. Men gave descriptions of their experiences with crying such as 'initially it was just full on water works'. Women also noted examples of their partners crying, such as, '(my husband) cried a lot when I told him'. At times actually during the interviews men became emotional and cried and at times the tape was stopped to allow them time to express their feelings.

Comments were made indicating that although both men and women cry there was a difference in how they did this, such as, 'I think the difference between the husband and wife is The wife will cry to someone. The husband will cry alone'. One man did talk about how he found it hard to cry, particularly in the company of others, 'I found it very difficult... like it makes me feel a little embarrassed I guess, Um, it's difficult to cry out loud just in general'.

Implications for the Wife (Female Partner)

The wives or female partners made statements indicating that they understood the father's pain and made compensation for it. This could mean shouldering the practical responsibility, 'I made a deliberate decision, Okay, I am going to be the strong one now'. However, there were statements indicating that the father can play an important support and organising role for the mother, 'Yeah, he writes everything down and he does it'.

Some fathers also played a role in relieving the mother at times from having to face certain distressing situations, for example, 'his father used to go with him. I hate watching him go to sleep (be put under anaesthesia)'.

Father's Adjustment

There were indications that many fathers adjusted to the situation as time went on. As one father stated, 'well I put it down to, well you got to live with that'. Their partners also commented on their improved coping, for example, 'he is much stronger now' or 'I think he is better with it now' or 'he's coping and I think he will be able to cope'. This adjustment included learning the language of haematology, 'dad's just great, he knows more about white cells now than he ever did'. This is important to their partners for as one wife stated, 'I'm okay because I know my husband is in control'.

In one case however the inability of the father to adjust to the diagnosis did create problems in the partner relationship, 'well my relationship with my husband is not very good because I don't think that he adjusted to (the child) being sick'. Even in this situation however the father was perceived as a support, 'I know if I ring him up and really need him, he will come'.

Family separation

Fathers noted that they found the separation caused by the hospitalisation difficult, 'I couldn't stand it on the basis of separation, I am already feeling like we have got our older child currently farmed out'. Further findings on this issue are documented in a publication on the topic of relocation from this research (McGrath 2000c).

Re-evaluation of values

There were statements indicating that the significance of the crisis challenge the fathers' attitude to work and family. As one father noted, 'I guess it is a major change. It's priority. Whereas once upon a time my career was a very high priority ... right now I couldn't give a damn'.

Discussion

The findings indicate that fathers are not only profoundly emotionally affected by the news that their child has leukaemia, but many are also able to talk about this pain. Contrary to the popular belief, crying was an important way that the men in this study expressed their distress. Their partners were aware of the acute distress and made allowances for the paternal reaction.

In this group of parents it was reported that fathers experienced and reacted to the shock of grief immediately. Mothers, on the other hand, had a delayed reaction because of their need to be 'strong' for the family. As noted in earlier research, the profound emotional reaction of fathers documented in these findings contradicts, or is atypical of, the male stereotype (Cayse 1994; McKeever 1981). These data confirm Sterken's (1996) argument that the male stereotype only persists because of lack of research in this area. With increased knowledge, Sterken argues, the fathers' emotional reaction to childhood cancer will be seen to be more a factor of individuality and life experience than gender socialisation.

In the literature, the notion of coping is used to indicate the individuals' strategy for managing stress (Holaday 1984; Sterken 1996). In acute stress, individuals can be challenged to develop new resources and strategies as a means of gaining some control over the situation (Holaday 1984). There were statements from both mothers and fathers indicating that a predominant coping style for fathers was to 'take time out from the situation'. Evasiveness as a coping style for fathers coping with a child who has cancer is documented elsewhere (Sterken 1996).

Mothers reported being understanding and supportive of this coping mechanism. However, for some mothers the responsibility of having to be the strong one was burdensome. The texts also indicated other paternal emotional reactions to the stressful situation including anger, withdrawal and escape to work: all avoidant coping activities associated with the evasive coping style (Sterken 1996). It was noted that some fathers found it difficult to express their emotions about the situation. Even when discussing crying it was stated that men tend to be tearful only in private. Such statements were set in the context of generic comments about the difficulties men have with sharing feelings and establishing close emotional ties. The inability to express feelings was sympathetically understood by the partners.

In spite of the intense grief, the fathers reported a strong desire to be with their sick child at the hospital. In the literature, however, the assumption is readily made that the mother will be the primary carer, and research tends to focus on mothers, ignoring the fathers' experience and contribution (Shapiro et al. 1998). In separate data from this research it has been shown that in the majority of families participating in this study both parents shared the responsibility for staying with the child during the hospital stay (McGrath 2000b).

For some fathers, this strong paternal desire to be there for the child was countered by an equally strong resistance to being involved with, or to witness, the painful medical procedures. There was evidence, however, that the ability to cope with involvement in the medical procedures was not gender specific, but depended on the individual dynamic of each parent. There was evidence of considerable variation within the parent duos as to which parent felt able to face witnessing the child undergoing medical procedures. This was an area where fathers could play an important supportive role. Other areas included practical assistance at home and with other family members, as well as providing financial security for the family.

Many of the fathers felt the strain of managing the additional responsibilities along with their work commitments. Fathers reported the distress of separation from their children, which included both the sick child at the hospital, and also the well siblings who were 'farmed out' during the medical crisis.

Although adjustment to the hospital drama and the new roles in the family were considered difficult, it was reported that fathers adjusted to the situation over time. In some cases, bonds between the well siblings and the father were strengthened. For some, the crisis created a re-evaluation of personal values and a renewed commitment to family relationships. These findings resonate with earlier studies where it has been documented that fathers of non-oncological, chronically ill children do manage to cope by curbing negative emotions, mobilising hope, and maintaining a clear sense of self-worth (McKeever 1981).

Recommendations

The findings from this research clearly indicate the emotional pain that fathers face in their struggle to accept the diagnosis of a serious, life-threatening illness such as ALL in their child. The shock of diagnosis, the emotional pain of coping with the illness, the desire to be with the child, the struggle to cope with the medical interventions, and concerns about other family members are not gender specific, but are rather issues common to both parents. The devastating impact of the ordeal of coping with paediatric ALL will be felt acutely by fathers as well as mothers.

By combining the insights of professional experience from working with families coping with a haematological malignancy and the findings from this research, a number of suggestions can be made to health professionals to ensure sensitivity to the fathers' plight. It is important for health professionals to be cognisant of the following.

- The importance of acknowledging the father as a valued member of the team caring for the child.
- The need to affirm the fathers concern about, and commitment to, the child by sharing information on the child's illness and treatment at all times when needed with the father.
- The significance of maintaining eye contact with the father so that clear non-verbal messages are communicated about his valued inclusion in discussions.
- The appropriateness of comments that validate and normalise the father's distress.
- The helpfulness of creating opportunities for fathers to meet and share experiences with other fathers going through the same situation.
- The importance of respecting the personal space of fathers who seek to deal with their emotional distress in privacy.
- The importance of offering the opportunity for fathers to be involved in dealing with treatment procedures, particularly if the mother is finding such interventions difficult to cope with.

Conclusion

The findings from this research build on and resonate with the scant work that has previously been completed on the fathers' experience with chronic illness. It is hoped that these findings begin to challenge the stereotype about how fathers deal with serious life challenges, such as the diagnoses of a life-threatening condition in their child. The expectation is that with fresh insights as to the fathers' experience more appropriate and helpful responses can be made within the health care system. It is hoped that the outcome of fostering this area of research will be to make a contribution to refocussing away from the exclusive concern with the mother-sick child dyad, to a holistic strengthening of the total family unit.

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