ABSTRACT

To address the lack of psycho-social research focusing specifically on childhood Lymphoma, this paper considers the factors unique to Lymphoma as compared with other paediatric haematological disorders and how this impacts upon the experience and coping strategies of fathers of this group. A five-year longitudinal study was conducted that explored the treatment experience for families coping with haematological disorders (including six families with a child with Lymphoma). Important issues highlighted by fathers of Lymphoma children included emotional issues such as the denial of emotions, the use of humour as a mechanism for dealing with stresses of the situation, the valuing of positive relationships with treating doctors and nurses, dealing with relationship issues (including a desire not to express their distress in order to protect their partner, a lack of time with their partner and the potential for the situation to bring about closeness or friction in the relationship), challenges dealing with people who haven’t been through a similar situation and reflection on issues of death and dying. More pragmatic concerns ranged from the desire to obtain significant, clinical information on their child’s condition, practical difficulties associated with frequent hospital visitations or extended stays (including accessing amenities and meals) and work related issues. The research is important in establishing that, despite the similarities, there are key differences that distinguish the experience of Lymphoma fathers from that of families with children with other haematological malignancies that have implications for the provision of care and support.

Key words: Paediatric Lymphoma – psycho-social – qualitative research – fathers

TREATMENT FOR CHILDHOOD LYMPHOMA: THE FATHERS’ PERSPECTIVE

Significant progress has been made in establishing the importance of research on the psycho-social aspects of childhood cancer treatments. However, the work in this area is still limited by the ongoing tendency to report on ‘cancer patients’ as if there are no distinguishing factors between the different diagnostic groups (Barakat et al. 2006; Brody & Simmons 2007; Kazak et al. 2005; Norberg et al. 2006; Ozono et al. 2007; Sawyer et al. 2000). As Norberg...
and associates (2005) report, the contextual demands of different diagnostic groups influence psycho-social domains such as coping and anxiety/depression. As Grootenhuis and Last (1997) pointed out a decade ago, there are significant difficulties in generalising findings on ‘childhood cancers’ because of the heterogeneous group of children with cancer, the difficulties in assessing illness-specific problems and the differences in reporting emotional problems by mothers and fathers. As yet, these criteria for research have still not been met. Understandably, there are now calls in the literature for illness-specific appraisals of the impact of the cancer experience (Barakat et al. 2006).

Furthermore, an understanding of the fullness of the experience of families in the context of childhood cancers is inhibited by obstacles to the inclusion in research of the perspectives of all family members. Most studies of childhood cancer that consider the experience of the parent of a child with cancer still focus on the mother, with few examining the experience of fathers (Brody & Simmons 2007). On the rare occasion that the focus is on the father, there is no refinement of the diagnostic group, with the study on the generic category ‘childhood cancer’ (Brody & Simmons 2007). There are now calls in the literature for further studies that more comprehensively document how fathers cope, to enable paediatric oncology nurses and other health care professionals to provide holistic care that addresses the unique needs of all family members (Brody & Simmons 2007).

In order to address the ongoing problems associated with the lack of research on experience of fathers with a child with a specific type of haematological disorder, the present article presents findings on the perspective of fathers with a child diagnosed with Lymphoma (hereinafter referred to as ‘Lymphoma fathers’). The findings are from a five-year longitudinal study on the experience for family members within each diagnostic group of haematological malignancies in the perspective of all family members including the sick child, parents and well siblings. Within the study the experience for family members within each diagnostic group of haematological malignancies was explored separately. Research from the study has already demonstrated clearly that there are significant differences between the leukaemia diagnostic groups of Acute Lymphoblastic Leukaemia and Acute Myeloid Leukaemia (McGrath, Patton & Huff 2005). The present discussion builds on this work by addressing the differences specific to Lymphoma families. As such, this is seminal work as there is no other psycho-social research published specifically on the concerns of fathers of children diagnosed with Lymphoma. To date, the only focus on fathers of children with Lymphoma has been on the link between their occupation and cancer aetiology, not on psycho-social concerns (Smith et al. 2006; Fear et al. 2005; Sorahan et al. 2003).

CHILDHOOD LYMPHOMA

Lymphomas account for some 10 to 12% of childhood malignancies (Somjee et al. 2005; Windebank 1998) and are the third most common group of malignancies in children and adolescents (Somjee et al. 2005; Shad & McGrath 1997). There are two major types of childhood Lymphoma, Hodgkin’s and non-Hodgkin’s Lymphoma, with the latter comprised of four sub-groups: B-cell non-Hodgkin’s Lymphoma and Burkitt’s; diffuse large B-cell Lymphoma; Lymphoblastic Lymphoma; and Anaplastic Large Cell Lymphoma (NCI 2007). Hodgkin’s disease is slightly less common than non-Hodgkin’s Lymphoma (Windebank 1998). Unlike Lymphomas in adults, paediatric Lymphomas are diffuse, aggressive neoplasms with a propensity for widespread dissemination (Shad & McGrath 1997). Thus, diagnostic strategies and treatment for these childhood cancers are different to treatment for adult sufferers of these conditions (NCI 2007) and are largely determined by protocols established by large, multi-institutional cooperative groups (White 2001). Treatments for childhood Lymphomas now have excellent therapeutic success with almost all cases of Hodgkin’s disease cured and survival rates in excess of 70 to 80% for childhood non-Hodgkin’s Lymphoma (Somjee et al. 2005; Windebank 1998). Over the past three decades, empirical chemotherapeutic management has transformed survival figures and, more recently, greater understanding of the biology is offering hope for improved management of resistant disease (Kempeneers et al. 2005). Intensification of conventional treatment approaches along with improvements in supportive care have resulted in dramatic improvements in outcomes, with event-free survival rates of close to 90% in patients with B-cell Lymphomas and only slightly lower success rates in patients with T-cell Lymphomas (Shad & McGrath 1997).

THE RESEARCH

The material in this article has been gathered from the first stage (T1) of a longitudinal study that considered the psycho-social issues associated with the treatment of paediatric ALL and associated haematological disorders including AML and the Lymphomas. The Royal Children’s Hospital Foundation and the Financial Markets Foundation for Children jointly funded the study. The multi-disciplinary study was conducted by a psycho-social researcher at the Central Queensland University (CQU) in association with research clinicians from the Paediatric Haematology and Oncology Unit of the Royal Children’s
Hospital (RCH) and the Mater Children’s Hospital (MCH), Brisbane, Australia. The study explored the experience of treatment from the perspective of the child patient, their parents and well siblings.

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

Methodology

The experience of treatment was documented through qualitative research using open-ended interviews with the child patients, their parents and well siblings at key points in the treatment trajectory. The key points differed for the different diagnostic groups, depending on the treatment protocol. For Lymphoma families there were three points of contact within the treatment protocol: two months from the beginning of treatment (T1); the end of Treatment (T2); and one year post-treatment (T3).

Child patients (aged from birth to sixteen years) diagnosed with ALL or related haematological malignancies were consecutively enrolled from the Banksia Ward at the Royal Children’s Hospital (RCH) and the Oncology/Haematology ward at the Mater Children’s Hospital. During the initial stage of treatment, the parents and siblings of these children were approached to ascertain whether they would consent to participating in the research. The positive response rate was 97.5% participation in the study. The findings presented here cover the first interviews (T1) with the parents of a child undergoing treatment for Lymphoma. All of the Lymphoma families approached enrolled in the study, and so the small number in the cohort reflects the incidence of Lymphoma within the larger consecutively enrolled cohort. By following these families throughout the treatment protocol, a substantial amount of data has been collected that provides a comparative group for exploring differences in the experience of treatment for different diagnostic groups.

The interviews with the parents were conducted by a psycho-social researcher with a counseling 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. The aim of phenomenology is to describe particular phenomena, or the appearance of things, 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 (Polit & Hungler 1995). All of the participants’ comments were coded into free nodes, which were then organised under thematic headings. There were 233 free nodes for T1 Lymphoma parent interviews and of those the ones specific to the fathers’ experience with treatment for their child diagnosed with Lymphoma are presented here.

DEMOGRAPHICS

There were six childhood Lymphoma families involved in the study. All came from two parent families and three of the fathers participated in the interviews. Only two of the families resided in the metropolitan areas, with the remaining families travelling from other towns in the state (n=3) or a town just over the Queensland/New South Wales border (n=1). Two of the families were staying in hostel accommodation provided at the hospital and one family was unaware of the hospital accommodation and so was staying in a local private hotel. At the point of enrolment in the study, the age of the child patients ranged from two years to thirteen years (2 years: n=1; 9 years: n=1; 10 years: n=1; 11 years: n=1; 13 years: n=2). The types of Lymphoma with which the children were diagnosed included Non-Hodgkin B-cell Lymphoma (n=2), Anaplastic Large Cell Lymphoma (n=1) and Burkitt’s Lymphoma (n=3). One of the children was an only child, while the remainder had siblings (one sibling: n=4; two siblings: n=1). The siblings ranged in age from infancy to sixteen years. All of the fathers were employed on a full-time basis and all of the mothers were not in paid employment and were caring for the sick child in hospital.

FINDINGS

In order to set the context for understanding the findings it is important to note that, as reported elsewhere, the Lymphoma families did see themselves as having different concerns to deal with than the other haematological diagnostic groups. The predominant differences noted in regards to children with Lymphoma centre around issues of the intensity of treatment, the relatively rare occurrence of paediatric Lymphoma and the high curative success rate of
Lymphoma as compared with other childhood haematological conditions. The parents of children with Lymphoma perceive that their journey is relatively more arduous than that of other haematological paediatric groups. Although the average treatment protocol is comparatively short, spanning six to nine months, there is scant respite from the point of diagnosis to the completion of treatment. Indeed, from the time at which their child is diagnosed and relocated for specialist treatment until the cessation of treatment, the child and carers are only rarely able to return home or take a break from intense treatment. In addition, Lymphoma represents a small proportion of childhood haematological conditions. Accordingly, parents consider their child’s condition to be rare, with the consequence that children suffering from Lymphoma are in the minority and so are set apart from the other children. This is exacerbated by the fact that most of the information provided to the parents of children with Lymphoma predominantly focuses on childhood leukaemia and makes only cursory mention of the Lymphomas. This has the consequence that parents often feel that they are not provided with sufficient information that focuses specifically on their child’s condition. However, although they perceive that there are a greater number of children being treated for ALL, the Lymphoma parents do not perceive their children’s treatment to be of lesser status than the ALL. This stands in contrast to the research findings on AML families in the study (McGrath, Patton & Huff 2005), whose perception was that they were considered to be of lesser importance. Unlike AML, which is another type of leukaemia, Lymphoma is a different diagnostic group with a high curative success rate and is thus not seen as a subgroup, albeit less important, of ALL. However, because of their high curative success rate, the angst suffered by the parents as a consequence of their child’s condition is seen as being somewhat trivialised by other parents at the hospital.

To simplify the description of the findings, where direct quotations from participants in the study are cited in the following discussion, the category of the speaker will be identified as follows: mother (m) and father (f).

**GENERIC FATHER ISSUES**

Table 1 outlines the experiences generic to fathers that emerged from findings on the ALL and AML families from the study, as documented in other publications of the findings from the study (the numbered references cited in the second column denotes articles listed below). Accompanying each generic issue is a statement from a Lymphoma parent that affirms the similarity of the experience for them in respect of that issue.

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<th>ISSUE</th>
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<tr>
<td>Experiencing extreme emotional pain – ‘(f) Three months of hell actually,’; ‘(f) You never forget about it. And the shock is there all the time. It just there all the time.’; ‘(f) I know I’ve been depressed that is for sure.’; ‘(f) We were in shock. I think the seriousness of her illness was overwhelming.’</td>
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<td>Men do cry – ‘[Talking about crying in the hospital] (m) I’ve done it before (f) I think we all have.’; ‘(m) Crying I know he (father) does.’; ‘(f) Cause you just got to find the times when you can break down and cry.’</td>
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<td>Withdrawal – ‘(m) Even though he is sometimes quite frightened of the situation and won’t speak to anyone.’ ‘(f) I didn’t want to talk to anyone I didn’t want to know about it.’</td>
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<td>Time out and physical activity to reduce stress – ‘(f) That is the best part of being able to do what we are doing you get to go and get a little bit of time on your own. Like we need time together but you need a bit of time on your own.’; ‘(f) I go out in my boat for a couple of hours by myself. I used to take someone but I go by myself.’; ‘(m) When the child’s in hospital he (father) tends to get up early and go over at 6.30 in the morning and spend the early part of the day with him. And he enjoys that but come 11 he got to go out and do something. He finds he can only tolerate it for so long. I mean he is physical and does physical work.’</td>
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<td>Keeping busy as a way of coping with the distress – ‘(m) My husband is another story he has thrown himself into work completely. He’s terrible and that is just the way he is. Jogging. Runners club. But I can understand it is just his way of working it out.’; ‘(m) He is still run run…’</td>
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### Appreciation when others reach out

- "(f) They [other parents at the hospital] force themselves onto you and it is the right thing to do. I shouldn't say force but they make the effort (m) they say hello.;" *(f) When we were first here it was probably a good week or so before we spoke to anyone. They would come up and say hello. And you'd say hello and you don't want to talk to them. You'd go hide in the corner and this is going to be gone tomorrow. And after a while we really needed those people."

### Anger

- "(m) Everything is very tense (f) if it doesn't go right we tend to everyone here tends to find out very quickly.;" *(f) I said mate if you don't do it [access vein] properly I am going to punch you (m) very upset (f) oh I was fuming. It is just training and time I suppose. But it is stressing for both parents."

### Mothers are aware of fathers’ distress and protect them

- "(m) My husband was pathetic at the start but he admitted it. He was aware enough to know. He even said to me “I am utterly useless to you aren’t I?” He wouldn’t have coped at all if I had stayed up there and worked. I was more practical and had to be. Like I had suitcases to pack and to organise.;" *(m) [Interviewer: you were giving him that space] Oh well you have to. I actually enjoy being a female."

### Facing the situation – lack of choice

- "(f) People say to us: “how are you coping?” Well what do you do?"

### Normalcy

- "(m) I must admit when we've been up here for a long time I look forward to going home for a couple of nights and going to work. (f) Trying to forget about it for half an hour.;"

### Close involvement of father in all aspects of care of family including care of siblings

- "(f) We like to try to be as normal as we can be when we go home. One of us always got to be with the child. We try like they [siblings] love fishing. But we try to give both of them time."

### Fathers efforts at maintaining family home in wife’s absence

- "(m) I've been down here so why should I come home to a dirty house. I've had the fans cleaned and the windows cleaned. No, he is wonderful.;" *(f) At the hospital I am worried if my wife is up all night vacuuming and she is worried when there is no food in the fridge."

### Sharing the care, fathers involvement at hospital

- "(f) And the strain of managing the illness does. (m) It is very exhausting this time like with getting up in the middle of the night to give her medicine. (f) It is every three hours.;" *(m) We worked out a good routine. I am there nearly all day. Father at 3 pick sibling up from school and I give him a break which they all need. Husband home by 5 he takes care of child while I get dinner.;" *(f) Learn to live on 3 hrs per night, so sleep deprivation is no stranger to us."

### Variation from fathers deeply involved to those reluctant to care

- "(m) I can't ask my partner to be here all the time. I'd like him to be here a bit more often sometimes because his daughter needs him. I asked him to stay and he won't. I get jack of him and tell him sometimes."

### Father wants to be at hospital with sick child

- "(f) It was hard when the child was crook don't leave her bedside.;"

### Difficulty of witnessing treatment

- "(f) And I thought “Ohh… practice (cannulation) on me then don't hurt my daughter.”;"
Pam McGrath

Advocacy for child patient – ‘(f) There is no other way to be as far as I’m concerned. There is no use sitting back in the back corner and just not doing anything about it. If you don’t speak up nothing happens. You really have to be on the ball. Like my wife and I kept a journal of the first two cycles. We wrote down every single thing that happened.’; ‘(f) You know they are human and make errors in judgement or mistakes as well. Keep an eye on things.’

Work issues – ‘(m) And because he’s like well you go out and work. And I said the reality of the different pay checks.’; ‘(f) I thought about closing business down.’; ‘(f) Even though boss has been supportive I still find myself worrying about work.’

The stress of family separation – ‘(f) The separation does stress.’

Adjustment over time – ‘(f) I don’t need to bug them as much because my base level of understanding is a lot higher. And because my initial fears have been allayed. And for the time being I am happy to distance myself from the technical side. Because I feel confident and comfortable that it is all under control and squared away.’

Financial Impact – ‘(f) Everything just sky rocketed. We are lucky we have our business. If we didn’t we would be dead broke by now.’; ‘(f) Financially hasn’t affected us. If I was a contractor rather than a permanent employee than that would. I imagine that would have a serious impact.’

Table 1: Generic father issues. * Please note: (1) refers to the article McGrath, Patton & Huff 2005; (2) McGrath & Chesler 2004; (3) McGrath & Huff 2003a; (4) McGrath & Huff 2003b; (5) McGrath 2001.

ISSUES OF DIFFERENCE

Although there were great similarities in the experience of fathers with a child with Lymphoma and fathers with child with a different haematological disorder, there were also a number of issues not previously reported.

Additional issues on fathers’ coping

In contrast to the prior findings that explained the fathers’ emotions as withdrawing into a personal space to deal with the pain, one Lymphoma father provided the insight that, for him, the process of denying the seriousness of the situation helped him cope.

• ‘(f) I deny emotions because I can’t handle them I think.’

Also, this is the first time that the role of humour as a mechanism for dealing with the stress of the situation was posited.

• ‘(m) My husband sometimes [is] too happy and easy going. I mean he is a loving dad. I think he never has a serious time with child. Maybe it is a sensitivity thing he doesn’t know child needs a serious talk. He makes a joke of the situation. I don’t think all men are like that but the majority. That is why women handle it better. Even though we have had heart to heart I’ve tried to explain it. But I don’t think he understands what I’m saying. He doesn’t want to deal with it he wants to forget it.’

However, humour can be a double-edged sword with accompanying feelings of guilt at being so light-hearted in the midst of such a serious situation, as the following statement demonstrates:

• ‘(m) … and you can like smile. I didn’t think I’d ever be able to smile or laugh or share a joke again. But after our child sort of thing you can do that. You can smile and you can have a joke (f) without feeling guilty (m) yes, you begin to feel guilty because it is so serious when child does something funny and thinks its funny she laughs and it just light up the whole thing.’

Additional insights on the hospital experience

The Lymphoma fathers spoke about their strong supportive relationship with the hospital staff. As the following father’s comments reveal, a positive relationship with the doctor and nurses responsible for the child’s care was an important factor in helping the fathers to cope with the ordeal of treatment.

• ‘(f) [Doctor’s name] is actually fantastic. And honestly if they changed him now we would not know what to do. And all of the nurses here are just absolutely fantastic and that is the only thing that has keeps us sane actually.’
The Lymphoma fathers’ attitude to information-seeking is different to that recorded in the prior research on the ALL and AML families involved in the study. The prior findings indicated that fathers from those diagnostic groups were more likely to leave the information gathering to the mother. In contrast, however, one of the Lymphoma fathers indicated that he was actively gathering information and that this assisted his coping:

- ‘(m) The difference was that my husband went into information seeker to survive. I went into compassionate mother to survive. To me it was I’ve got to get her through this. He can deal with the facts I can’t do that now. I can’t do both. (f) I took a diary of the first week in intensive care. I monitored all of her results. The more I learned about it the more I could understand. And the less fear I had. So I was understanding and to dispel the ignorance and of course the fear.’

Perhaps because they spend so much time at the hospital, practical issues were voiced as significant concerns for the Lymphoma fathers. The problem accessing food while at the hospital was noted, as follows:

- ‘(f) We take a bag of food and heat it up in the microwave but if you did that for an extended period of time you would be nutritionally deficient.’

The suggestion was made that the hospital should provide parents who are on the ward with food.

- ‘(f) If you could get a meal with the child that would be fantastic. Whoever is there full time it would be great if they could get a feed.’
- ‘(f) Parents, the moral support we provide the kid is very important part of their treatment. I think it is a small price for them to pay [supply meal to parents].’

Further evidence of practical discomfort can be seen by the following description of accessing a shower:

- ‘(f) It [hospital] just not comfortable here for the parents. Like we’ve had to shower in the kids shower. I’m too considerate I want to make sure it is available for the kids when they need it so wait until they are asleep and not going to hold anyone up. (f) You are never really completely comfortable but you get as comfortable as you can. First hate it wouldn’t touch anything now if pillow falls on floor pick it up and stick it under my head.’

Additional Relationship Issues

The Lymphoma fathers spoke about the complementarity in their relationship with their partners with whom they shared strengths and weaknesses.

- ‘(f) We had our strains and stresses obviously. And you know one of us will be stressed and the other one won’t. But we are reasonably close anyway. We’re sort of trying to hold it together.’
- ‘(f) We are both aware of our strengths and weaknesses.’

The sharing and complementarity can change over time, providing ongoing support.

- ‘(m) I think I’ve been a strong person for most of our relationship. In the first week when I was breaking down a lot and I didn’t think I could cope. I was surprised going – “I can’t deal with it.” And he was coming and saying “you’ve got to be strong.” And now it’s like me going “well why don’t you join me and be strong.”’
Dealing with the outside world

The alienation from others who have not experienced a similar challenging life experience was voiced. As one participant stated:

• ‘(f) Like I can't talk to my parents about it because they just don't understand. They just don't.'

However, there were also indications that fathers could identify with the awkwardness of others not know what to say, as the following comment shows:

• ‘(f) That is understandable I wouldn't know what to do either.'

It was also noted that providing others with information about the child's illness is understandable in relation to work colleagues.

• ‘(f) [Interviewer: Talk at work?] Yeah with a few people - selective. I don't want to make it seem like it's a newspaper. I don't mind people at work knowing. Because it is a legitimate reason not to be there. If they are waiting or relying on me for something they have a reason to know why I can't get it. But you know eventually the word gets out. And pretty much everyone knows.'

Issues surrounding death and dying

The most significant difference in the findings from Lymphoma fathers as compared to previous data on the other diagnostic groups is the extensive discussion on issues of death and dying. There were insights about the fathers' psychological process of blocking the full import of the fact that their child had a potentially life threatening illness. As one father ably expressed:

• ‘(f) I feel like I'm locking part of myself off. Coping with the realities of managing time and activities I guess. I am starting to feel a part of me is just portioned off that potential for death. Cause it doesn't when I think about it, doesn't seem to feel real. I wonder if I closed that off for the wrong reasons or if I've closed that off because I can afford to.'

There is also a sense of identifying with the child patient's sense of not wanting to discuss the possibility of death and dying, as the following comments suggest:

• ‘(m) She hasn't said a lot. She sort of hasn't asked me those sort of questions. (f) She doesn't want to know.'

Experiencing the death of other children on the ward is a particularly confronting time, as one couple explained:

• ‘(f) It makes it more real when you know that that can happen (m) yes, it does, you sort of think yes cancer is. (f) The problem is he was in a bed beside us. Only a week before running around the ward.'

As with other issues, the fathers typically were reluctant to talk about their feelings about this serious issue. The reluctance to discuss this concern can be distressing for their wife and she may create the impetus to face the issue, as one mother recounts:

• ‘(m) I've made him [husband] talk about that. I actually got to a point where I said I feel like I'm going insane. If you don't talk about how you feel about your daughter dying than you and I are not in this together. Because this is our child and I feel like I'm the only one who has considered she'll die. So we have even done that together.'

A core concern is on the issue of how the father would cope if the worst was to happen and they had to face the death of their child, as the following insight reveals:

• ‘(f) I watched those people their daughter declining. And she was going to die. I asked myself, thank God I'm not in that situation. How would I cope? I thought they were coping with it in a very mature way. I couldn't imagine myself being as mature or as responsible in death as they were. Now that is a concern for me. Because I don't want to let my wife down or the side down if that happens.'

And there was evidence that some fathers did find ways of facing and dealing with this distressing issue. Honest information and the ability to talk through the issue with the medical and nursing staff were noted as factors central to the process of coping, as one participant explained:

• ‘(f) And that is why I was able by about day three or four in intensive care to know the worst case is not scarifying us and we're facing it. And I felt a bit more comfortable. Doctor and nurses in ICU cut above your average person. They were very open with explaining all the effects. The more they taught me the more I felt she wasn't on her death door. Week one we were scared witless and they were able to allay that fear.'

DISCUSSION

The findings on the fathers' experience of treatment contradict the recent research by Patistea (2005) that indicates that there is neither gender nor spousal differences in parents' coping behaviours. It has now been demonstrated through a comparison of data from all haematological diagnostic groups (ALL, AML, Lymphoma) published from the study that there are generic issues that characterise
paternal patterns of coping. Similarly, Svavarsdottir’s (2005) research demonstrates that the level of well-being was significantly different between the parents with 65% of the mothers showing clinically or problem-indicative stress as compared with 26.3% of the fathers.

However, as outlined elsewhere (McGrath & Chesler 2004), a strong caveat to this work is that such differences are based on a comparison of the general response and that individuals will differ. The authors concur with the warning by Norberg and associates (2006) that, while recognizing that there are demonstrated gender differences in support-seeking behaviours between parents with a child with cancer, in clinical practice individual variation should be acknowledged and the inflexible presumptions of gender differences avoided. As Goldbeck (2001) argues there are coping dissimilarities between fathers and mothers of children with cancer and so psychosocial interventions should support this difference when it is adaptive, and should help parents to overcome those differences when they negatively affect their child.

As outlined in Table 1, the findings from this study affirm a wide range of similarity between the experience of Lymphoma fathers and the experience of fathers in other haematological groups. The insights are important for evidence-based practice that situates the holistic response in well-informed research rather than unexplored assumptions that unreflectively cluster all diagnostic groups together. Alongside the similarities, there were also differences with important implications for practice. Some of the insights contribute to a deepening of our understanding of fathers’ ways of coping, such as the protective motive in the reluctance to express distress, the role of and problems associated with the use of humour, the importance of satisfying and supportive relationships with the medical and nursing staff and the value of honest information and insights about dealing with work colleagues and others who do not understand the experience of childhood Lymphoma.

Other insights appear to be directly related to the childhood Lymphoma experience. Lymphoma families distinguish themselves by the demanding and intense nature of the hospital experience. It is understandable that practical issues such as lack of privacy, lack of opportunity for partners to spend time together, lack of availability of food, problems with accessing amenities at the hospital such as showers and comfort at the hospital are issues for fathers.

In view of the high cure rate for childhood Lymphoma, perhaps the most surprising finding is the focus on issues of death and dying, not documented in the other diagnostic groups in the study. Again, these findings appear to be directly related to the ‘uniqueness’ of the Lymphoma experience as posited by the parents. As outlined in the introduction to the findings, because of their high curative success rate, the angst suffered by the Lymphoma parents as a consequence of their child’s condition is seen as being somewhat trivialised by other parents at the hospital. It is documented from further findings from the study (McGrath 2003) that the parents valued their involvement as participants in the study as it gave them the opportunity to discuss issues they were not able to talk about in the hospital setting. Perhaps the strong emphasis on issues associated with death and dying can be attributed to the fact that Lymphoma parents are not comfortable discussing these issues in the hospital setting and took the opportunity to ventilate these issues through their participation in the study. The important point is that Lymphoma fathers are struggling with these issues and do require a sympathetic and honest space to explore their concerns in this regard. There are indications that the opportunity for honest information and the opportunity to talk provide a firm foundation for coping with the seriousness of the child’s condition.

The difficulties reported by the fathers need to be viewed in terms of the literature that indicates a high level of posttraumatic stress in fathers of children with cancer (Alderfer et al. 2005; Barakat et al. 2006; Kazak et al. 2005). Speechley and Noh (1992) demonstrated that parents of a child with cancer were more depressed and anxious than parents of healthy children, with a higher risk of psychological distress stemming from the low levels of social support available for such fathers. As reported by Sawyer et al. (2000), during the time of diagnosis and early treatment parents of children with cancer demonstrate more psychological problems than control groups in the community. As Brody and Simmons (2007) affirm, the support from health care professionals is necessary for fathers to remain positive during their child’s illness. The need for privacy, physical comfort, honest information, understanding and support as reported by these fathers should be at the centre of a holistic response to these families.

CONCLUSION

The findings of the research emphasise the fundamental importance of an appreciation of the uniqueness of each paediatric haematological condition on the part of those caring for patients and their families in order to understand and be responsive to their specific needs. The research establishes that, while fathers experience a number of generic emotional responses when they are confronted with the diagnosis and treatment of a child with cancer, there are also significant points of different linked to the specific
condition with which their child is diagnosed that shapes the ways in which fathers cope with the diagnosis and treatment of their child and the hospital experience, and the manner in which they face the challenges such an experience poses to their relationships, work and spiritual meaning-making. It is the authors’ hope and expectation that, by beginning to document the experience of particular members of a family with a child with a particular haematological condition, in this case fathers, paediatric oncology nurses and other health care professionals will be able to provide holistic care that addresses the unique needs of that family member and diagnostic group.

REFERENCES: