# Fathers’ Views and Understanding of their Roles in Families with a Child with Acute Lymphoblastic Leukaemia: An Interpretative Phenomenological Analysis

<table>
<thead>
<tr>
<th>Journal:</th>
<th><em>Journal of Health Psychology</em></th>
</tr>
</thead>
<tbody>
<tr>
<td>Manuscript ID:</td>
<td>JHP-08-0075.R1</td>
</tr>
<tr>
<td>Manuscript Type:</td>
<td>Article</td>
</tr>
<tr>
<td>Keywords:</td>
<td>FATHERS, ROLES, FAMILIES, CHILDHOOD LYMPHOBLASTIC LEUKAEMIA, INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS</td>
</tr>
<tr>
<td>Abstract:</td>
<td>This study explored how fathers of children diagnosed with acute lymphoblastic leukaemia (ALL) perceived and understood the roles they had within their family over the course of their child’s illness and treatment. In-depth semi-structured interviews were conducted with five fathers. Transcripts were analysed using interpretative phenomenological analysis (IPA). The major themes that emerged were: adjusting to the diagnosis; the experience of maternal gate-keeping; striving for normalisation; experiences of giving and receiving support. Overall, the fathers perceived themselves as having significant responsibility in helping their child and family cope with the illness experience. Clinical implications, including the need for professionals to recognise and more openly acknowledge the fathers position, are considered.</td>
</tr>
</tbody>
</table>
Fathers’ Views and Understanding of their Roles in Families with a Child with Acute Lymphoblastic Leukaemia: An Interpretative Phenomenological Analysis

Abstract

This study explored how fathers of children diagnosed with acute lymphoblastic leukaemia (ALL) perceived and understood the roles they had within their family over the course of their child’s illness and treatment. In-depth semi-structured interviews were conducted with five fathers. Transcripts were analysed using interpretative phenomenological analysis (IPA). The major themes that emerged were: adjusting to the diagnosis; the experience of maternal gate-keeping; striving for normalisation; experiences of giving and receiving support. Overall, the fathers perceived themselves as having significant responsibility in helping their child and family cope with the illness experience. Clinical implications, including the need for professionals to recognise and more openly acknowledge the fathers position, are considered.

Keywords: fathers, roles, families, childhood ALL, interpretative phenomenological analysis
Acute Lymphoblastic Leukaemia (ALL), as a chronic childhood illness, is an extremely stressful experience that impacts upon all family members. From a systemic perspective, parents are recognised as having an important role in influencing child and family adjustment to childhood chronic illness (Kazak, Segal-Andrews, & Johnson, 1995), however most research in this area has involved only mothers of chronically ill children and has focused primarily on maternal roles and influences (Eiser, 1993). Within this context, fathers have been labelled as the ‘forgotten parent’ (May, 1996) and researchers are increasingly emphasising the need for studies of families of chronically ill children to include fathers, and to consider paternal influences (Gavin & Wysocki, 2006; Kazak et al., 1995).

The limited number of studies that have explored paternal roles and influences in response to childhood chronic illnesses, such as ALL, have produced inconsistent and contradictory results. Brown & Barbarin (1996) completed a questionnaire based study involving parents of children diagnosed with cancer (68 mothers and 56 fathers) and found that mothers and fathers assumed specific roles that conform to the ‘traditional’ gender-based division of labour i.e. mothers as the primary care-givers and fathers as the breadwinner. Supporting this, Chelser and Parry (2001) completed a qualitative analysis exploring how gender ideology influenced the experiences of fathers of children with cancer. They found that ‘traditional’ gendered beliefs shaped how fathers coped with the stress of the experience, and also influenced the nature of their involvement following their child’s diagnosis of cancer, for example fathers perceived a need to adopt a ‘strong and silent’ coping response and focused on external employment and the role of provider, while mothers assumed child care and household duties.
In contradiction to these findings however, McGrath and Chesler (2004) and McGrath and Huff (2003) describe a qualitative analysis which explored fathers’ experiences of their child’s treatment for ALL. The findings, based on interviews with fathers and mothers, suggest that fathers do assume care-giving responsibilities, and that the roles and responses of mothers and fathers to childhood cancer do not necessarily reflect traditional gender-based roles. Specifically the results portray paternal involvement as being on a continuum, with some fathers having full responsibility for the care of the ill child or well siblings, some fathers sharing responsibility with mothers, and some fathers having minimal or peripheral involvement (McGrath & Huff, 2003). Furthermore, the findings challenged the notion of stereotypical gendered coping styles, with McGrath and Chesler (2004) suggesting that coping responses were not based upon gender but rather a consideration of each partner’s strengths and weaknesses.

Finally Jones and Neill-Urban (2003) completed focus groups with fathers of children with cancer and found that although fathers tended to focus on their role as financial providers, they did not avoid or distance themselves from the direct care of children. They suggested that such findings may indicate changing gender roles in the larger society.

The need for a greater understanding of paternal roles has been reinforced by growing empirical evidence demonstrating the importance of father involvement in families with a chronically ill child. Studies have found that greater paternal involvement in such families is associated with enhanced maternal adjustment, enhanced marital satisfaction and more favourable family functioning (Gavin & Wysocki, 2006).
Specifically regarding survivors of childhood cancer, positive child-father relationships are associated with the child’s enhanced adjustment across multiple domains including overall quality of life, psychological well-being and spiritual well-being, with results indicating that father-child relationships may be more influential than mother-child relationships in promoting adjustment across these various domains (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005).

Previous research has been criticised for relying heavily on mothers’ reports of the father’s role, instead of seeking the views of fathers themselves (Eiser, 1993). Research and literature has also been criticised for being based on the assumption that fathers can and should perform similar functions of caring and coping as mothers (Seiffge-Krenke, 2002). To overcome this particular limitation the research methods used to explore paternal roles need to be sufficiently flexible and open in order to allow unanticipated or unique themes to emerge. In this respect qualitative methods are appropriate, as they allow for exploratory, discovery-orientated research and hypothesis generation (Barker, Pistang, & Elliot, 2002).

As mentioned a number of studies have used qualitative methods in order to explore the experiences of fathers of children with cancer. Some of these studies did not however distinguish between different cancer diagnoses with differing treatment processes (Chesler & Parry, 2001; Jones & Neill-Urban, 2003). The treatment regime specifically for ALL incorporates four different phases: diagnosis, intensive chemotherapy treatment (lasting approximately six months and necessitating frequent hospitalisation), maintenance treatment (spanning 2-3 years in duration) and post-treatment (when the child has completed treatment but still needs to attend regular medical reviews to monitor for possible relapse or treatment related side-effects). It has been recognised that the needs of the child and family will change across these
Parents of children diagnosed with ALL therefore are likely to face different stressors and demands in comparison with other cancer diagnoses, and also differing challenges across the various stages of treatment.

Some qualitative studies have focused exclusively on childhood ALL, and on a specific stage of the treatment experience, such as the intensive chemotherapy treatment (McGrath & Chesler, 2004; McGrath & Huff, 2003), however, these studies combined both mothers and fathers views of fathers’ experiences and did not differentiate between their possible differing perspectives.

Taking these things into account, this study aimed to further the research base by interviewing fathers and exploring retrospectively their perception of the roles they played in their family across the different stages of their child’s treatment for ALL. In contrast to the other qualitative studies mentioned, this study used Interpretative Phenomenological Analysis (IPA) as the research method. This methodology allowed for a highly intensive and detailed analysis of the fathers’ accounts.

Method

Participants

Fathers of children who had completed treatment for ALL within the previous 2½ years and who were in remission of the disease were invited to take part in the study by medical consultants at the hospital where the children had been treated. Fathers who consented to take part were contacted via telephone by the lead researcher in order to arrange an interview. In total five fathers took part in the study. This sample size is in keeping with the idiographic nature of IPA (Smith, 2004). The participants were aged between 31 to 42 years old. Their children were aged between 18 months and 7 years old at the time of their diagnosis. All participants were
biological fathers and all lived in the family home with the child and the child’s mother. Four of the fathers had other children living at home at the time of diagnosis and three of the fathers had a child born during the treatment period. All of the fathers worked full time. Within three families, the child’s mother did not work. Two mothers worked on a part-time basis.

Procedure

University and NHS ethics and research governance approvals were gained prior to commencing the study. The one-to-one interviews were carried out by the lead researcher and took place at the regional hospital where all the children had been treated. Interviews lasted between 1 and 2 hours. An interview schedule was developed by members of the research team as a framework to guide discussion whilst still permitting sufficient flexibility to enable the fathers to tell their own story in their own words. Pilot interviews with fathers of children who were three or more years post-treatment aided the design of this schedule. All the participants were asked the same opening question about each stage of the illness and treatment i.e. how would you describe the roles you had in your family when your child was diagnosed? Prompts and probes were used as necessary to explore fathers’ responses further, for example, asking the fathers about similarities and differences between their role and that of the child’s mother. All interviews were tape recorded and then transcribed verbatim.

Analysis

The study employed Interpretative Phenomenological Analysis (IPA). This idiographic qualitative method focuses on the exploration of individuals’ experiences, understandings, perceptions and views of the topic under investigation (Reid, Flowers,
& Larkin, 2005). The analytic process was guided by procedures outlined by Larkin, Watts, and Clifton (2006) and, Smith and Osborn (2003). In addition guidelines for promoting quality in qualitative research were employed (Brocki & Wearden, 2006; Elliot, Fischer, & Rennie, 1999). Specifically with regard to the analytical procedure, a number of steps were taken to ensure rigor and transparency. For example, summary and self-reflective notes were kept by the lead researcher in order to document and illustrate the analytic process. Continual checks were also carried out in order to ensure that interpretations were grounded in participants’ accounts. Finally, whilst acknowledging the subjective nature of the interpretative process in IPA, members of the research team provided feedback on the analytical process and emerging interpretations in order to ensure transparency and plausibility.

Findings

Four superordinate themes emerged through analysis of the data. These themes, and associated subordinate themes are summarised in Table 1. They are described in more detail below, along with verbatim quotes to exemplify the interpretative process. Pseudonyms have been used throughout.

INSERT TABLE 1

Adjusting to the Diagnosis

‘What are we in for?’ - Uncertainty and lack of control. The fathers all described the sense of uncertainty they experienced throughout their child’s treatment, but particularly at the time of diagnosis. This related to the unfamiliar nature of such a serious illness. They had no prior experience or frame of reference from which to understand the experience, except pre-conceived assumptions and beliefs associated with the word cancer. The fathers experienced uncertainty about what had caused the
illness, what lay ahead in terms of the treatment process, and also uncertainty about
whether or not their child would survive.

‘Woah! What is this? What’s going on? Why? What’s happened? What’s he done?
What’s, what’s you know, what’s wrong with, what’s wrong with him, type of
ingredient? You just haven’t got a clue what eh, you know, what’s happening next? You
know cause all these words were being used. Lymphoma, that’s cancer? What’s
cancer? What? What? Hold on here, what are we in for?’ (Pete).

The question ‘what are we in for?’ emphasises a perceived lack of control.

This uncertainty and lack of control seemed to contribute to a sense of being helpless,
as indicated by Paul, ‘My role, pretty useless (laughter), no I don’t know. I think
actually the both of us were numb… You’re neither here nor there… you know, and
you didn’t know what was ahead of you’.

‘Let’s see what has to be done’ - Taking control. In response to their child’s
diagnosis, the fathers described the need to accept the reality of what was happening,
so that they could then begin to take control and deal with the situation. ‘I think, sort
of, no matter what sort of comes up against you, you get on with it and you have to
face it really’ (Tom).

Most of the fathers described their desire and efforts to gain information about
ALL. Often this was one of their very first responses upon learning about their child’s
diagnosis. This may relate to the idea of knowledge as power. Thus making
themselves informed could be understood as one way in which the fathers tried to
achieve a sense of control over events. It enabled them to anticipate and prepare for
what lay ahead, thus providing a sense of mastery over the uncertainty.

‘I thought it was important for me to try and understand the position we were in
and to support my wife and family, but most importantly see that Simon [child
diagnosed with ALL] and Andrea [daughter], you know what can we possibly do here for Simon, you know what’s, what’s coming, but again you didn’t know’ (Pete).

The question ‘what can we possibly do?’ exemplifies the focus on ‘doing’ that appeared to be central in the fathers’ attempts to assume control. It appeared to be important for the fathers to have an active rather than passive role. This may have provided a sense of personal responsibility and control. Pete describes how he perceived this desire to ‘do’ as something that he, but not his wife, experienced.

‘I would be, right, who do we need to talk to, what do we need to get done and who, and Rose [mother] would be “Pete…, the doctors know what they’re doing, there’s nobody else we can talk to… …this is the place that he’s meant to be, like there’s not anything else that can be done”’

The fathers’ thinking at this time was very orientated towards the future. Their need to take control and do was underpinned by their desire to put the illness experience in the past. The fathers made numerous references to this throughout their interviews, for example: ‘when does this start, lets get it over and done with’ (Mike); ‘I felt it was just ok, that’s the job that has to be done you know, so lets get on with it, this is going to make her better you know’ (Paul).

Related to the idea of actively doing, a number of fathers described how they tended to focus on practical considerations. Mike, for example, described how he assumed this as a role after his child was diagnosed.

‘this is all the kind of things that was going through my head and eh… you know just all the kind of practical things, just keeping the house running em, changing the car, like we had a petrol car at the time, and we had to get a diesel car, because
I knew we were going to be doing so much running, and all this crap. Like what the hell’s wrong with me, (laughs) you know what I mean?’

In the above excerpt, Mike openly wonders why at the time of the diagnosis he focused on practical things which, in retrospect, he didn’t consider to be that important. One reason may be that it enabled him to be actively doing, and thus provided a sense of control at a time of uncertainty. Furthermore, having a practical focus may have helped Mike to manage the emotional aspect of the experience. He alludes to this when he says ‘I think I kind of needed that, maybe I was doing it selfishly, a kind of get-out’. Focusing on practicalities enabled him to remove himself physically from emotionally overwhelming situations. Furthermore, cognitively, it provided distraction from his feelings and emotions.

Overall, the following quotation from Paul exemplifies the process of assuming a sense of control, ‘See when sickness … hits, you just you go into a different mode, rather than Clare [mother] I would go into a mode were I know everything’. In the excerpt above, Paul’s perception of ‘I know everything’ is in complete contrast to prior statements when he described himself to be ‘useless’, and uncertain about what was ahead.

‘You try to play it down’ - Constructing a manageable reality. Accepting the reality of what was happening was a difficult thing for the fathers to do. They described how such acceptance brought with it intense feelings of fear and despair. A number of the fathers described the emotionality they experienced when breaking the news of their child’s illness to wider family members. Telling other people seemed to confirm the reality of the experience.
‘the most difficult thing we had to do was tell our parents, you know, hold on here, Simon’s not well and he’s got these, you know you start using words, like they don’t, again they’re very emotive, leukaemia or lymphoma’ (Pete).

In order to accept what was happening and yet also be able to cope with this, it seemed necessary for the fathers to construct an understanding of their child’s illness that was tolerable. The following excerpt by Roger, who was describing how he talked to his daughter about her illness, exemplifies this process (i.e. acceptance and the construction of a manageable view of the illness), ‘you try to play it down, you know, and I didn’t want to tell her lies either’.

One of the most significant ways in which the fathers constructed a manageable reality was by identifying and attending to positive aspects of the experience, and being optimistic. For example, Tom described adopting the following view, ‘we’re going to have to go through this and things are going to work out well in the end’.

Two of the fathers described their motivation to make their child happy throughout the treatment process. In part, this reflected attempts to construct a tolerable way to understand the possibility of their child’s death i.e. if their child was happy and had a fulfilling life then their death would be more acceptable.

‘I was always gearing things for, right if he dies tomorrow at least he’s done this… … my whole thing was always to get him to Australia, which we done last year then (laughs). You know, so like if he dies now, that’s grand you know (laughs), we’ve it all done you know, this was my wee thing in my head, of course it isn’t OK now, you know, but that was my wee thing always’ (Mike).
Mike’s account again highlights how some of the fathers tended to address their fears in a practical way, rather than attending to the emotional aspect of the experience.

The fathers’ attempts to construct a manageable reality were compromised when they experienced events that didn’t fit with their constructed view. For example, Roger describes how difficult it was to be positive when he and his family were confronted with the reality of children dying.

‘That was quite hard to take because it brought back the question again [from his daughter] ‘Am I going to die?’ ‘Is it going to happen to me?’ And you had to try and be positive with her and look on the bright side of things, which was quite difficult to do in that situation, whenever you’re playing with someone one day and the next day they’re not there’.

**The Experience of Maternal Gate-keeping**

‘I could live with not doing it, but I would have loved to have done it’. The fathers discussed the parenting roles that they and their partners assumed during the intensive treatment phase. Several of the fathers described how their partners’ preferences influenced their involvement in caring for their child in hospital. They described assuming or being allocated a peripheral role because the child’s mother assumed the primary care-giving role for the child who was ill, ‘you see when he had to go in for injections, or was going in to get put under anaesthetic or that, Gillian [mother] always pushed me out of the way to go and do it’ (Mike).

At times during interviews, some fathers expressed dissatisfaction regarding this role allocation. The phrase ‘pushed me out of the way’ used by Mike in the above quotation indicates a sense of resentment at being forcefully excluded. At other times however, it seemed that fathers were reluctant to openly express any dissatisfaction.
They seemed to minimise any disappointment they may have experienced in relation to their role.

‘I done everything else that I wanted to do but there was just those wee things were, you know, you had to choose, it was either you or her, and I knew it would have meant more to her to do it than, you know, I could live with not doing it but I would have loved to have done it’ (Mike).

‘when Mary [mother] sort of says ‘look no, I’m not leaving Lynn here, I’m not leaving’ and I was happy enough to accept that and I wasn’t sort of saying ‘right Mary go you away I want a bit of time with her’, I was getting time with her so I was’ (Tom).

This statement by Tom however contradicts another statement in which he describes how he would have liked to have had the opportunity to swap roles with his wife. He did not however voice this desire, or any dissatisfaction, to his wife at the time of treatment.

‘Sometimes now looking back I would have liked to have said to Mary [mother], go you on home for a couple of days and I’ll stay here on my own, cause I never did that, although I think at that stage, if I had said that, Mary would have said, ‘no I’m not leaving’. You know really from an early stage that was her philosophy. Em, so I just accepted that and em, I was sort of, I would have went home and taken home washing, whatever had to be done’.

The reluctance from fathers to express dissatisfaction with their role, both at the time of treatment and also during the interview, may stem from a desire to be positive and supportive of their partners. The fathers, in fact, described the concept of maternal coping as one of the ways in which they made sense of, and accepted, their peripheral role during the intensive treatment.

‘I could have resented that in a way you know, because I kind of felt as if I wanted
to do it as well, but I knew that it really, really meant a lot to her and that she
needed to do that, so I just kind of let her get on with it’ (Mike).

Some fathers also understood their experience in terms of gender ideology and
societal beliefs about traditional parenting roles. For example, Mike used this frame of
reference to make sense of his role even though he perceived such views to be
outdated.

‘She was always the one grabbing him and holding him and caring for him that
way…, but again I think it just goes back to the whole kind of traditional
upbringing where you feel it’s the Mum’s job and Dad kind of stands at the side of
the room, but I was always there beside him you know’.

One father, Paul, described how his beliefs about parenting roles changed
following his child’s treatment. Prior to his child’s illness, he perceived children
typically as having closer relationships with mothers rather than fathers, and he used
this belief to make sense of his peripheral role in hospital. Following his wife’s
pregnancy however, Paul assumed primary care-giving responsibilities for his child in
hospital. He described how this experience changed the relationship he had with his
daughter, ‘We got very close. Just being with her constantly’ and changed his beliefs
about parenting roles, ‘I don’t know I think girls bond with their daddy anyway after a
wee while anyway. As I say I never believed that until now really?’

Finally, Mike in particular, expressed his belief that medical staff reinforced
his peripheral role. He perceived that they provided mothers with more opportunities
to assume the care-giving role, ‘if they came looking for something it would have
always been kind of directed at Gillian [mother], em, it’s always the Mum, always the Mum’.

As a result of their experiences, some fathers appeared to perceive their contribution in the hospital as less helpful in comparison to the child’s mother, ‘you’re helpless when he’s getting anaesthetic and there’s nothing you can do, there was only one of you can really be there or you get in the way’ (Mike).

To overcome this perception of getting in the way or being less helpful, it seemed important for these fathers to explicitly validate their role. For example by emphasising the roles they played in managing wider home and family life, including looking after siblings at home. ‘Maybe that’s why I went and you know, done all the kind of practical things, because there is an importance to it’ (Mike).

In contrast to the experiences of the fathers outlined above, one father perceived himself to have an equal role with his wife in caring for their child in hospital, ‘Well I thought, be there, both of us to share our time primarily, like there was no way any of us were going to leave him in the hospital’ (Pete). His experience of involvement was in keeping with beliefs he held about the paternal role; ‘You were saying there about the role of the father, I think you need to be involved’ (Pete).

Although this father did not explicitly perceive his involvement to be restricted, in line with other fathers, he believed that being at the hospital was an important coping strategy for his wife, and this may have implicitly influenced his role and involvement.

‘I felt as a father, I would have felt more comfortable when Rose [mother] was in the hospital with Simon, because [when not at the hospital] she would have been saying “how was Simon, how was Simon… how’s he now, how’s he”, you know over a two, three hour period’ (Pete).
Striving for Normalisation

‘Not totally upset everybody and try to keep everything as normal as possible’

- Minimising the impact of the illness. The fathers perceived it as important not to let the illness experience totally dominate their family’s lives. In trying to minimise the impact of the illness experience, the fathers described their desire and attempts to maintain a semblance of normal family life. In particular, they perceived this as an important way to support siblings of the ill child. Tom provided some examples of the lengths he went to in order to minimise disruption for his eldest son. This including making the two hour journey home from the hospital some nights, so that he would be at home when his son woke up the next day, and so that he could take him to school. He perceived this as important because he wanted to ‘keep life as normal for him really, not totally upset everybody and try to keep everything as normal as possible’ (Tom).

Fathers described the need for them and their family to have breaks from the illness experience. They described how it helped to have things to distract from the illness experience. This may be a reflection of the coping strategy outlined previously, in which it was suggested that fathers preferred to be actively doing, rather than passively ruminating on their experience. Some fathers perceived their partners as more reluctant to remove their focus from the experience, preferring instead to remain attentive to their child and the illness.

‘I just got out to clear my head, go for a walk or whatever, whereas Gillian [mother] was completely the opposite em, she would have just sat, she would have, if there was a seat outside the door, she would have sat outside it you know, waiting for him to wake up’ (Mike).
Reflecting the perceived importance of breaks, most fathers assumed a proactive role trying to encourage and facilitate mothers to take even short breaks away from the experience, ‘with the constant being there, you needed to sort of get her a break really’ (Tom). A number of fathers described facing resistance from mothers when attempting to do this.

Although the fathers described it as a struggle to manage the multiple demands associated with work, home life, and hospital life, most also described how their work provided a useful distraction throughout the illness experience; ‘it gave me a release or it gave me another focus, you know, I wasn’t thinking about Rose [mother] being at home’ (Pete). Most fathers described their employers as supportive. One father, in contrast however, perceived that his employers put pressure on him to attend work. For this participant, his job did not serve as a useful break.

‘Re-introducing to a proper life again’ - Putting the illness in the past. While undergoing their intensive chemotherapy treatment, the children were extremely vulnerable to infection. Parents had to take precautions in order to protect against this, ‘there was no mixing with kids, there was no nothing, he just really lived with us, it was like living in a wee bubble for like a year and never went anywhere’ (Mike). Moving into the maintenance and post-treatment phases therefore, the fathers considered it a priority to reintroduce their children to ‘normal’ life again. They perceived it as important to encourage their children to do the same things that other children did.

‘I hated that, I hated, you know making a difference for him, at that point you know, I felt he needed it up until that point, but em at that point, you know during maintenance when he was, was looking better you know, he looked normal and all the rest of it, and he needed to be treated normal’ (Mike).
This excerpt conveys Mike’s wish to no longer have to think about his child as being different, or more vulnerable, than other children. Holding this view may have allowed Mike to minimise his fears for his child, and his desire to perceive his child as ‘normal’ may have been one of the motivating factors behind his efforts to treat his child as ‘normal’. As discussed previously, throughout the treatment process the fathers tended to be very orientated towards the future, signifying their desire to put the illness experience in the past. Efforts towards normalisation in the maintenance and post-treatment phases may reflect this desire.

The fathers tended to view themselves as being the main parent to encourage re-engagement in everyday life. They experienced and described the child’s mother as more apprehensive and fearful about it.

‘Angela [mother] probably was more em apprehensive about letting her out than I was, I might have been the one that was, ‘I think she can go here or she can go there’. Angela probably would have been that bit more apprehensive about her doing things, the fact that the risk was there you know’ (Roger).

‘Gillian would always hold on to the wee warning bit that he’d [Doctor] give you, and go “right we’re not going” you know so I had to kind of, it was a constant, it was a constant fight with her trying to take Colin places’.

The phrase ‘constant fight’ emphasises the differing positions Mike and his partner appeared to take, but also reflects how important the issue was for him, so important that he was willing to fight for it.

The fathers reflected an understanding of their partners not wanting to expose their children to any risk of infection. As one father stated ‘I wouldn’t have been blasé about it either’ (Tom). It seemed however that these fathers were prepared and more able to manage these risks rather than avoid them altogether.
Experiences of Giving and Receiving Support

‘Feeling as if I had to be strong’ vs. ‘we helped each other’ - Different beliefs about the need to be strong. Some fathers relayed a need to be strong and understood this in terms of supporting their partners. These fathers believed that if they expressed their own worries it would reinforce their partners’ fears. Being strong therefore involved conveying a positive attitude and offering reassurance.

‘She was in bits at that point and I was kind of feeling as if I had to be strong and not worrying, so I was kind of coming across as ‘uck don’t worry about it’ you know’ (Mike).

These fathers described masking their fears and emotions. When they did break down, it tended to be in private. For example, Mike describes how after receiving their child’s diagnosis, he withdrew from his partner in an attempt to hide his emotion.

‘I said to Gillian [mother]’right I need to go out and I’ll phone your Mum and phone my Mum and tell them’ and again that was me I had to get away from her because I wanted to cry’.

Gender ideology also appeared to influence fathers’ beliefs about showing emotions.

‘it’s a man’s thing, men do keep things inside, maybe that is why my eyes went, maybe I just bottled more up into myself, a man shouldn’t cry in a case like that, he should be the strong one. He is the one who works, provide…’ (Paul).

‘Maybe it’s a man thing, you don’t look for sympathy, if somebody finds out fine, but you’re not going to run around and say ‘Guess what? Here’s a bit of news’, that’s a, dare I say it, it’s a bit of a female trait!’ (Pete).
Masking fear and emotion may also reflect to some extent the strategies fathers adopted to cope with the illness experience. As outlined previously, fathers tended to respond to their fears in active, practical ways, perhaps as a form of distraction. Some fathers, in particular, perceived that it would not be useful to dwell on the emotional aspect of the experience. For these fathers, their own coping strategies may have influenced their experiences of giving and receiving support.

Contrasting this, two fathers described their experiences of greater mutual support. Rather than believing that fathers had to be the strong parent, these men conveyed their belief that mothers and fathers should support each other, in order to support their ill child and family.

‘Anne [child] needed, she definitely needed both parents for support. Em I suppose, I myself needed the support and the wife needed support, and the other children as well’ (Roger).

In contrast to some of the other fathers, these men appeared to perceive it as both helpful and acceptable for males to express their fears and emotions. Roger relayed the following advice for fathers ‘don’t close yourself away from it, because you’re going to gain nothing by it… … release your concerns and fears to someone you can trust’.

‘Do you really realise what it is like?’ - Neglected needs and useful supports.

A lot of the fathers believed that people outside their immediate family did not understand the experience they and their family were going through.

‘they expected as if it was like mending a broken arm, that you know you’ll have the plaster off in two weeks and you’ll be, you know, a bit of physiotherapy and he’ll be right as rain in six weeks’ (Pete).
Specifically, some fathers commented that people failed to consider the impact on the whole family, with themselves as fathers being overlooked the most. Although they expressed annoyance about this, they understood this experience in terms of traditional societal beliefs about gender.

‘although it’s Lynn that is going through the illness, it does, it does affect the whole family and I think maybe outsiders don’t give, people don’t realise how much it does affect, you know, the parents and I suppose the fathers probably are the ones that might be overlooked the most, ah sure you’re alright, you’re a man, or I don’t know whether that is being sexist or what (laugh) em, you know, I got that feeling anyway’ (Tom).

The fathers often appeared to prioritise other family members’ needs over their own. For example, during the interview when asked about supports that he may have found helpful, Tom talked about supports for his partner and children. Thus fathers’ own prioritising may have reinforced other people’s perceptions of fathers not being a priority. The fathers’ own coping strategies and their attempts to confirm with socio-constructed gender roles may have also indirectly reinforced the neglect of the father’s position. For example, by hiding their vulnerability and conveying a sense of being strong, fathers may have reinforced other people’s perceptions of them as not needing of support. A number of fathers described the difficulty and perceived stigma associated with receiving support from professionals; ‘I’m sure that the hardest thing in the world for someone to do is go and ask for help’ (Mike). Again this may relate to gender ideology and beliefs about the role of the father as the provider, as exemplified by Pete’s statement; ‘as a father figure, it was like you try to, you know, look after your own’. Such perceived stigma may have prevented fathers from openly expressing their needs.
Most fathers identified informal support from other parents in the hospital as being very helpful. In contrast with experiences of not being understood, these parents were perceived as understanding because they were going through the same experience. One of the fathers in particular described the help and understanding he gained from talking with other fathers, ‘talking to other men was a good help, some of them were very good, some of them were very understanding’ (Paul). The experience of shared understanding appeared to reduce a sense of emotional isolation that fathers may have experienced; ‘you got to talk with other people who were in the same situation or similar situations, you weren’t on your own’ (Roger).

Discussion

This study explored how five fathers of children diagnosed with ALL viewed and understood the roles they had within their family across the course of their child’s illness and treatment. Using IPA as the methodology allowed for a highly intensive and detailed analysis of the fathers’ accounts. Overall, the fathers perceived themselves as having significant responsibility in helping their child and family cope with the illness experience. Specifically four overarching super-ordinate themes were identified through analysis of the data: adjusting to the diagnosis; the experience of maternal gate-keeping; striving for normalisation; experiences of giving and receiving support. As outlined, these themes were associated with more specific and detailed subordinate themes.

Although the aim of this study was to explore in detail the individual experiences and perceptions of a small group of fathers, comparing these findings with those from other studies indicates that some of the experiences and views described may be common among the wider group of fathers. For example, a qualitative study involving families with a child diagnosed with ALL described
fathers’ struggle but need to accept their child’s diagnosis, the differing degrees of
involvement fathers can have in caring for the child in hospital, and also fathers’
concern to maintain normalcy in family life during the intensive treatment (McGrath
& Chesler, 2004).

During the interviews most fathers emphasised their preference for actively
‘doing’ in order to cope with the illness experience rather than attending to the
emotional aspect of the experience. Having a practical focus appeared to enable the
fathers to achieve a sense of control over the experience and may have provided a way
to distract from emotionally overwhelming situations and thoughts. This finding is
consistent with results from quantitative studies which have found that fathers of
children with cancer tend to employ problem-focused coping strategies such as
gaining information and considering choices and options (Cayse, 1994; Hovey, 2005).
It also reflects wider empirical evidence indicating that males, in contrast to females,
deal with stress by using more active problem-solving coping, rather than emotion-
focused coping (Matud, 2004). It has been suggested that gender identity plays an
important role in shaping the ways in which men cope with the stresses of cancer
(Chesler & Parry, 2001). Socialisation theories of coping suggest that men are
socialised to use more active and instrumental coping behaviours while women are
socialised to use more emotion-focused behaviours. This stems from societal beliefs
and expectations regarding gender, with the traditional male role prescribing men as
being stoic, autonomous, self-confident and assertive. Such expected attributes can
make it difficult for men to accept and express feelings of fear and vulnerability
(Matud, 2004). Several fathers in this study indicated that their coping responses, and
the roles they adopted in ‘being strong’ and offering support, were influenced in part
by their belief in this traditional male identity. Reflecting also, however, individual
differences and perhaps shifting societal beliefs about gender, not all the fathers in
this study adhered to these views of male identity and coping. Some fathers perceived
it as acceptable and helpful for males, as well as females, to acknowledge and express
feelings and worries.

A number of the fathers described how their involvement in parenting their
child in hospital was influenced by the mothers’ preferences. These fathers assumed
or were allocated a peripheral role because the child’s mother assumed the primary
role in caring for their child. The experience of being ‘pushed out’ caused
disappointment, dissatisfaction and resentment, however it appeared to be difficult for
fathers to name this, perhaps because they did not want to cause upset for their partner
or perhaps because of constraints stemming from beliefs about gender and parenting
roles. Although it has not been previously emphasised within the context of childhood
chronic illness and childhood cancer, the experience of maternal gate-keeping has
been reported in general parenting literature and is increasingly being recognised as
an important factor contributing to fathers’ under-involvement in childcare and
domestic tasks (Allen & Hawkins, 1999). From a systemic perspective, it
demonstrates how fathers cannot be understood apart from mothers, as parenting is a
dynamic process created through the negotiating, competing and compromising of
two people over the course of their lives (Matta & Knudson-Martin, 2006). The
fathers in this study understood their experience of maternal gate-keeping in various
ways. Some fathers understood and attributed the experience to maternal coping.
Some fathers made sense of the experience in relation to traditional societal views of
women as caregivers and men as providers and protectors. This finding in particular is
in keeping with results from other studies exploring fathers’ experience of childhood
cancer (Chesler & Parry, 2001). It also reflects findings from studies of general
parenting and fatherhood which have shown that men and women’s perceptions of
appropriate maternal and paternal roles heavily influenced how men participated as
fathers (Matta & Knudson-Martin, 2006). One father from this study perceived that
medical staff provided more opportunities for mothers rather than fathers to assume
the primary care-giving role, thus reinforcing fathers’ peripheral involvement. He
understood this to reflect the influence of societal beliefs about parenting. This
experience supports the suggestion that fathers wanting to have more involvement in
the care of their child with cancer may lack opportunities to do so and experience
social pressure against it because of cultural beliefs and assumptions about parenting
(Chesler & Parry, 2001).

During the intensive treatment the fathers perceived it as important for the
family to get breaks away from the illness experience. They also perceived it as
important to maintain a semblance of normal family life. Similar views have been
reported in other quantitative and qualitative studies (Hovey, 2005; McGrath & Huff,
2003), and the importance of normalisation in families of children with chronic
illnesses is recognised (Knafl & Deatrick, 2002). This present study asked fathers to
reflect beyond the intensive treatment phase. The findings showed that most fathers
considered it a priority, during the maintenance and post-treatment phases, to
reintroduce their children to ‘normal’ life again, and they perceived themselves as
being the primary parent to encourage this. Research has shown that being able to
encourage children to re-establish interests and hobbies after treatment for cancer may
protect them against subsequent psychological difficulties (Casey, 2004). It could be
hypothesised that a father’s role in encouraging re-engagement represents one specific
and important way in which fathers promote positive adjustment in children treated
for ALL, and may help to explain Orbuch et al.’s. (2005) finding that positive child-
father relationships are associated with the child’s enhanced adjustment following treatment for cancer more so than mother-child relationships.

The findings from this study indicate a number of implications for clinical practice. Within the field of paediatrics, fathers tend to be the ‘forgotten parent’ (May, 1996). There is a need for individuals working in this area to more openly recognise the father’s position, to interact with fathers in a way that acknowledges and validates their role, and to be aware of, and challenge, stereotypical assumptions about gender and parenting roles, so as to ensure that both parents have the option and opportunity for involvement.

Significantly, this study found that some fathers experienced dissatisfaction in being allocated peripheral roles, although may have found it difficult to explicitly voice this. This finding demonstrates how gender practices and fatherhood ideals may not coincide, and reinforces how, without conscious discussion, many couples can revert to gender stereotypical choices (Matta & Knudson-Martin, 2006). It may be important for those working with families to facilitate parents to have discussions about these issues. Doing so may help to create the opportunity for more flexibility and negotiation in parenting roles and may help parents to develop an increased understanding and validation of their differing coping strategies and roles.

Finally, the view held by some participants that their needs as a father were neglected supports findings from empirical reviews showing that fathers are often not included in family based interventions within paediatric psychology (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Increased effort and consideration needs to be given to identify appropriate ways to support fathers. The shared understanding between fathers going through the same experience was identified by most
participants as helpful. Facilitating more opportunities for informal group discussions and activities with other parents may be one possible way in which to support fathers.

It should be recognised that the results from this study represent the perceptions of a number of fathers at a single point in time. The fathers were reflecting retrospectively about their experiences, three to fours years after diagnosis and in the knowledge that their child was in remission of the disease. The interviews also took place at the hospital in which their child was treated. These factors are likely to have influenced to some extent the resulting discussion that took place. As is the nature of qualitative and IPA studies, the fathers’ views and perceptions may have been different at other points in time or in other contexts. Furthermore, the opportunistic sample of the study represents fathers who were willing and perhaps wanted the opportunity to discuss their experiences and views. Again this may have influenced the themes that emerged. This is however a reflection of the idiographic nature of IPA as a research method and as Smith (2004) suggests, the very detail of the individual may also bring us closer to significant aspects of a shared humanity.
References


Table 1. Summary of Super-ordinate and Subordinate Themes.

<table>
<thead>
<tr>
<th>1. Adjusting to the diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘What are we in for?’</td>
</tr>
<tr>
<td>Uncertainty and lack of control</td>
</tr>
<tr>
<td>‘Let’s see what has to be done’</td>
</tr>
<tr>
<td>Taking control</td>
</tr>
<tr>
<td>‘You try to play it down’</td>
</tr>
<tr>
<td>Constructing a manageable reality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. The Experience of Maternal Gate-Keeping</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I could live with not doing it, but I would have loved to have done it’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Striving for Normalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Not totally upset everyone and try to keep everything as normal as possible’</td>
</tr>
<tr>
<td>Minimising the impact of the illness</td>
</tr>
<tr>
<td>‘Re-introducing to a proper life again’</td>
</tr>
<tr>
<td>Putting the illness in the past</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Experiences of giving and receiving support</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Feeling as if I had to be strong’ vs ‘we helped each other’</td>
</tr>
</tbody>
</table>
| Different beliefs about the need to be strong.
| ‘Do you really realise what it is like?’ |
| Neglected needs and useful supports |