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

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Abstract:	<p>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.</p>



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RUNNING HEAD: FATHERS' CARING ROLES AMONG CHILDREN WITH
ALL

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

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2
3 Acute Lymphoblastic Leukaemia (ALL), as a chronic childhood illness, is an
4 extremely stressful experience that impacts upon all family members. From a
5 systemic perspective, parents are recognised as having an important role in
6 influencing child and family adjustment to childhood chronic illness (Kazak, Segal-
7 Andrews, & Johnson, 1995), however most research in this area has involved only
8 mothers of chronically ill children and has focused primarily on maternal roles and
9 influences (Eiser, 1993). Within this context, fathers have been labelled as the
10 'forgotten parent' (May, 1996) and researchers are increasingly emphasising the need
11 for studies of families of chronically ill children to include fathers, and to consider
12 paternal influences (Gavin & Wysocki, 2006; Kazak et al., 1995).
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27 The limited number of studies that have explored paternal roles and influences
28 in response to childhood chronic illnesses, such as ALL, have produced inconsistent
29 and contradictory results. Brown & Barbarin (1996) completed a questionnaire based
30 study involving parents of children diagnosed with cancer (68 mothers and 56 fathers)
31 and found that mothers and fathers assumed specific roles that conform to the
32 'traditional' gender-based division of labour i.e. mothers as the primary care-givers
33 and fathers as the breadwinner. Supporting this, Chelser and Parry (2001) completed a
34 qualitative analysis exploring how gender ideology influenced the experiences of
35 fathers of children with cancer. They found that 'traditional' gendered beliefs shaped
36 how fathers coped with the stress of the experience, and also influenced the nature of
37 their involvement following their child's diagnosis of cancer, for example fathers
38 perceived a need to adopt a 'strong and silent' coping response and focused on
39 external employment and the role of provider, while mothers assumed child care and
40 household duties.
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4 In contradiction to these findings however, McGrath and Chesler (2004) and
5
6 McGrath and Huff (2003) describe a qualitative analysis which explored fathers'
7
8 experiences of their child's treatment for ALL. The findings, based on interviews with
9
10 fathers and mothers, suggest that fathers do assume care-giving responsibilities, and
11
12 that the roles and responses of mothers and fathers to childhood cancer do not
13
14 necessarily reflect traditional gender-based roles. Specifically the results portray
15
16 paternal involvement as being on a continuum, with some fathers having full
17
18 responsibility for the care of the ill child or well siblings, some fathers sharing
19
20 responsibility with mothers, and some fathers having minimal or peripheral
21
22 responsibility with mothers, and some fathers having minimal or peripheral
23
24 involvement (McGrath & Huff, 2003). Furthermore, the findings challenged the
25
26 notion of stereotypical gendered coping styles, with McGrath and Chesler (2004)
27
28 suggesting that coping responses were not based upon gender but rather a
29
30 consideration of each partner's strengths and weaknesses.
31
32

33
34 Finally Jones and Neill-Urban (2003) completed focus groups with fathers of
35
36 children with cancer and found that although fathers tended to focus on their role as
37
38 financial providers, they did not avoid or distance themselves from the direct care of
39
40 children. They suggested that such findings may indicate changing gender roles in the
41
42 larger society.
43
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45
46 The need for a greater understanding of paternal roles has been reinforced by
47
48 growing empirical evidence demonstrating the importance of father involvement in
49
50 families with a chronically ill child. Studies have found that greater paternal
51
52 involvement in such families is associated with enhanced maternal adjustment,
53
54 enhanced marital satisfaction and more favourable family functioning (Gavin &
55
56 Wysocki, 2006).
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3 Specifically regarding survivors of childhood cancer, positive child-father
4 relationships are associated with the child's enhanced adjustment across multiple
5
6 domains including overall quality of life, psychological well-being and spiritual well-
7
8 being, with results indicating that father-child relationships may be more influential
9
10 than mother-child relationships in promoting adjustment across these various domains
11
12 (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005).
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17
18 Previous research has been criticised for relying heavily on mothers' reports of
19
20 the father's role, instead of seeking the views of fathers themselves (Eiser, 1993).
21
22 Research and literature has also been criticised for being based on the assumption that
23
24 fathers can and should perform similar functions of caring and coping as mothers
25
26 (Seiffge-Krenke, 2002). To overcome this particular limitation the research methods
27
28 used to explore paternal roles need to be sufficiently flexible and open in order to
29
30 allow unanticipated or unique themes to emerge. In this respect qualitative methods
31
32 are appropriate, as they allow for exploratory, discovery-orientated research and
33
34 hypothesis generation (Barker, Pistang, & Elliot, 2002).
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39
40 As mentioned a number of studies have used qualitative methods in order to
41
42 explore the experiences of fathers of children with cancer. Some of these studies did
43
44 not however distinguish between different cancer diagnoses with differing treatment
45
46 processes (Chesler & Parry, 2001; Jones & Neill-Urban, 2003). The treatment regime
47
48 specifically for ALL incorporates four different phases: diagnosis, intensive
49
50 chemotherapy treatment (lasting approximately six months and necessitating frequent
51
52 hospitalisation), maintenance treatment (spanning 2-3 years in duration) and post-
53
54 treatment (when the child has completed treatment but still needs to attend regular
55
56 medical reviews to monitor for possible relapse or treatment related side-effects). It
57
58 has been recognised that the needs of the child and family will change across these
59
60

1
2
3 various stages (Copper, 1999). Parents of children diagnosed with ALL therefore are
4 likely to face different stressors and demands in comparison with other cancer
5 diagnoses, and also differing challenges across the various stages of treatment.
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10 Some qualitative studies have focused exclusively on childhood ALL, and on
11 a specific stage of the treatment experience, such as the intensive chemotherapy
12 treatment (McGrath & Chesler, 2004; McGrath & Huff, 2003), however, these studies
13 combined both mothers and fathers views of fathers' experiences and did not
14 differentiate between their possible differing perspectives.
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22 Taking these things into account, this study aimed to further the research base
23 by interviewing fathers and exploring retrospectively their perception of the roles they
24 played in their family across the different stages of their child's treatment for ALL. In
25 contrast to the other qualitative studies mentioned, this study used Interpretative
26 Phenomenological Analysis (IPA) as the research method. This methodology allowed
27 for a highly intensive and detailed analysis of the fathers' accounts.
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40 Method

41 *Participants*

42 Fathers of children who had completed treatment for ALL within the previous
43 2½ years and who were in remission of the disease were invited to take part in the
44 study by medical consultants at the hospital where the children had been treated.
45
46 Fathers who consented to take part were contacted via telephone by the lead
47 researcher in order to arrange an interview. In total five fathers took part in the study.
48
49 This sample size is in keeping with the idiographic nature of IPA (Smith, 2004). The
50 participants were aged between 31 to 42 years old. Their children were aged between
51 18 months and 7 years old at the time of their diagnosis. All participants were
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3 biological fathers and all lived in the family home with the child and the child's
4
5 mother. Four of the fathers had other children living at home at the time of diagnosis
6
7 and three of the fathers had a child born during the treatment period. All of the fathers
8
9 worked full time. Within three families, the child's mother did not work. Two mothers
10
11 worked on a part-time basis.
12
13

14 15 *Procedure*

16
17 University and NHS ethics and research governance approvals were gained
18
19 prior to commencing the study. The one-to-one interviews were carried out by the
20
21 lead researcher and took place at the regional hospital where all the children had been
22
23 treated. Interviews lasted between 1 and 2 hours. An interview schedule was
24
25 developed by members of the research team as a framework to guide discussion whilst
26
27 still permitting sufficient flexibility to enable the fathers to tell their own story in their
28
29 own words. Pilot interviews with fathers of children who were three or more years
30
31 post-treatment aided the design of this schedule. All the participants were asked the
32
33 same opening question about each stage of the illness and treatment i.e. how would
34
35 you describe the roles you had in your family when your child was diagnosed?
36
37 Prompts and probes were used as necessary to explore fathers' responses further, for
38
39 example, asking the fathers about similarities and differences between their role and
40
41 that of the child's mother. All interviews were tape recorded and then transcribed
42
43 verbatim.
44
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50 51 52 53 *Analysis*

54
55 The study employed Interpretative Phenomenological Analysis (IPA). This
56
57 idiographic qualitative method focuses on the exploration of individuals' experiences,
58
59 understandings, perceptions and views of the topic under investigation (Reid, Flowers,
60

1
2
3 & Larkin, 2005). The analytic process was guided by procedures outlined by Larkin,
4
5 Watts, and Clifton (2006) and, Smith and Osborn (2003). In addition guidelines for
6
7 promoting quality in qualitative research were employed (Brocki & Wearden, 2006;
8
9 Elliot, Fischer, & Rennie, 1999). Specifically with regard to the analytical procedure,
10
11 a number of steps were taken to ensure rigor and transparency. For example, summary
12
13 and self-reflective notes were kept by the lead researcher in order to document and
14
15 illustrate the analytic process. Continual checks were also carried out in order to
16
17 ensure that interpretations were grounded in participants' accounts. Finally, whilst
18
19 acknowledging the subjective nature of the interpretative process in IPA, members of
20
21 the research team provided feedback on the analytical process and emerging
22
23 interpretations in order to ensure transparency and plausibility.
24
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30 Findings

31
32 Four superordinate themes emerged through analysis of the data. These
33
34 themes, and associated subordinate themes are summarised in Table 1. They are
35
36 described in more detail below, along with verbatim quotes to exemplify the
37
38 interpretative process. Pseudonyms have been used throughout.
39
40

41 INSERT TABLE 1

42 Adjusting to the Diagnosis

43
44 'What are we in for?' - Uncertainty and lack of control. The fathers all
45
46 described the sense of uncertainty they experienced throughout their child's treatment,
47
48 but particularly at the time of diagnosis. This related to the unfamiliar nature of such
49
50 a serious illness. They had no prior experience or frame of reference from which to
51
52 understand the experience, except pre-conceived assumptions and beliefs associated
53
54 with the word cancer. The fathers experienced uncertainty about what had caused the
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3 illness, what lay ahead in terms of the treatment process, and also uncertainty about
4
5 whether or not their child would survive.
6

7
8 'Woah! What is this? What's going on? Why? What's happened? What's he done?
9
10 What's, what's you know, what's wrong with, what's wrong with him, type of
11
12 thing? You just haven't got a clue what eh, you know, what's happening next? You
13
14 know cause all these words were being used. Lymphoma, that's cancer? What's
15
16 cancer? What? What? Hold on here, what are we in for?' (Pete).
17

18
19 The question 'what are we in for?' emphasises a perceived lack of control.
20
21 This uncertainty and lack of control seemed to contribute to a sense of being helpless,
22
23 as indicated by Paul, 'My role, pretty useless (laughter), no I don't know. I think
24
25 actually the both of us were numb... You're neither here nor there... you know, and
26
27 you didn't know what was ahead of you'.
28
29

30
31 'Let's see what has to be done' - Taking control. In response to their child's
32
33 diagnosis, the fathers described the need to accept the reality of what was happening,
34
35 so that they could then begin to take control and deal with the situation. 'I think, sort
36
37 of, no matter what sort of comes up against you, you get on with it and you have to
38
39 face it really' (Tom).
40
41

42
43 Most of the fathers described their desire and efforts to gain information about
44
45 ALL. Often this was one of their very first responses upon learning about their child's
46
47 diagnosis. This may relate to the idea of *knowledge as power*. Thus making
48
49 themselves informed could be understood as one way in which the fathers tried to
50
51 achieve a sense of control over events. It enabled them to anticipate and prepare for
52
53 what lay ahead, thus providing a sense of mastery over the uncertainty.
54
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56
57 'I thought it was important for me to try and understand the position we were in
58
59 and to support my wife and family, but most importantly see that Simon [child
60

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2
3 diagnosed with ALL] and Andrea [daughter], you know what can we possibly do
4
5 here for Simon, you know what's, what's coming, but again you didn't know'
6
7
8 (Pete).
9

10 The question 'what can we possibly do?' exemplifies the focus on 'doing' that
11
12 appeared to be central in the fathers' attempts to assume control. It appeared to be
13
14 important for the fathers to have an active rather than passive role. This may have
15
16 provided a sense of personal responsibility and control. Pete describes how he
17
18 perceived this desire to 'do' as something that he, but not his wife, experienced.
19
20
21

22 'I would be, right, who do we need to talk to, what do we need to get done and
23
24 who, and Rose [mother] would be "Pete..., the doctors know what they're doing,
25
26 there's nobody else we can talk to... ..this is the place that he's meant to be, like
27
28 there's not anything else that can be done"
29
30
31

32 The fathers' thinking at this time was very orientated towards the future. Their
33
34 need to take control and *do* was underpinned by their desire to put the illness
35
36 experience in the past. The fathers made numerous references to this throughout their
37
38 interviews, for example: 'when does this start, lets get it over and done with' (Mike);
39
40 'I felt it was just ok, that's the job that has to be done you know, so lets get on with it,
41
42 this is going to make her better you know' (Paul).
43
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46 Related to the idea of actively doing, a number of fathers described how they
47
48 tended to focus on practical considerations. Mike, for example, described how he
49
50 assumed this as a role after his child was diagnosed.
51
52

53 'this is all the kind of things that was going through my head and eh... you know
54
55 just all the kind of practical things, just keeping the house running em, changing
56
57 the car, like we had a petrol car at the time, and we had to get a diesel car, because
58
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3 I knew we were going to be doing so much running, and all this crap. Like what
4
5 the hell's wrong with me, (laughs) you know what I mean?
6
7

8 In the above excerpt, Mike openly wonders why at the time of the diagnosis he
9
10 focused on practical things which, in retrospect, he didn't consider to be that
11
12 important. One reason may be that it enabled him to be actively doing, and thus
13
14 provided a sense of control at a time of uncertainty. Furthermore, having a practical
15
16 focus may have helped Mike to manage the emotional aspect of the experience. He
17
18 alludes to this when he says 'I think I kind of needed that, maybe I was doing it
19
20 selfishly, a kind of get-out'. Focusing on practicalities enabled him to remove himself
21
22 physically from emotionally overwhelming situations. Furthermore, cognitively, it
23
24 provided distraction from his feelings and emotions.
25
26
27
28

29 Overall, the following quotation from Paul exemplifies the process of
30
31 assuming a sense of control, 'See when sickness ... hits, you just you go into a
32
33 different mode, rather than Clare [mother] I would go into a mode were I know
34
35 everything'. In the excerpt above, Paul's perception of 'I know everything' is in
36
37 complete contrast to prior statements when he described himself to be 'useless', and
38
39 uncertain about what was ahead.
40
41
42

43 *'You try to play it down' - Constructing a manageable reality.* Accepting the
44
45 reality of what was happening was a difficult thing for the fathers to do. They
46
47 described how such acceptance brought with it intense feelings of fear and despair. A
48
49 number of the fathers described the emotionality they experienced when breaking the
50
51 news of their child's illness to wider family members. Telling other people seemed to
52
53 confirm the reality of the experience.
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3 'the most difficult thing we had to do was tell our parents, you know, hold on here,
4
5 Simon's not well and he's got these, you know you start using words, like they
6
7 don't, again they're very emotive, leukaemia or lymphoma' (Pete).
8
9

10 In order to accept what was happening and yet also be able to cope with this, it
11
12 seemed necessary for the fathers to construct an understanding of their child's illness
13
14 that was tolerable. The following excerpt by Roger, who was describing how he
15
16 talked to his daughter about her illness, exemplifies this process (i.e. acceptance and
17
18 the construction of a manageable view of the illness), 'you try to play it down, you
19
20 know, and I didn't want to tell her lies either'.
21
22
23

24 One of the most significant ways in which the fathers constructed a
25
26 manageable reality was by identifying and attending to positive aspects of the
27
28 experience, and being optimistic. For example, Tom described adopting the
29
30 following view, 'we're going to have to go through this and things are going to work
31
32 out well in the end'.
33
34
35

36 Two of the fathers described their motivation to make their child happy
37
38 throughout the treatment process. In part, this reflected attempts to construct a
39
40 tolerable way to understand the possibility of their child's death i.e. if their child was
41
42 happy and had a fulfilling life then their death would be more acceptable.
43
44
45

46 'I was always gearing things for, right if he dies tomorrow at least he's done this...
47
48 ... my whole thing was always to get him to Australia, which we done last year
49
50 then (laughs). You know, so like if he dies now, that's grand you know (laughs),
51
52 we've it all done you know, this was my wee thing in my head, of course it isn't
53
54 OK now, you know, but that was my wee thing always' (Mike).
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3 Mike's account again highlights how some of the fathers tended to address
4 their fears in a practical way, rather than attending to the emotional aspect of the
5 experience.
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9

10 The fathers' attempts to construct a manageable reality were compromised
11 when they experienced events that didn't fit with their constructed view. For
12 example, Roger describes how difficult it was to be positive when he and his family
13 were confronted with the reality of children dying.
14
15
16
17
18

19 'That was quite hard to take because it brought back the question again [from his
20 daughter] 'Am I going to die?' 'Is it going to happen to me?' And you had to try
21 and be positive with her and look on the bright side of things, which was quite
22 difficult to do in that situation, whenever you're playing with someone one day and
23 the next day they're not there'.
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31 The Experience of Maternal Gate-keeping

32 'I could live with not doing it, but I would have loved to have done it'. The
33 fathers discussed the parenting roles that they and their partners assumed during the
34 intensive treatment phase. Several of the fathers described how their partners'
35 preferences influenced their involvement in caring for their child in hospital. They
36 described assuming or being allocated a peripheral role because the child's mother
37 assumed the primary care-giving role for the child who was ill, 'you see when he had
38 to go in for injections, or was going in to get put under anaesthetic or that, Gillian
39 [mother] always pushed me out of the way to go and do it' (Mike).
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53 At times during interviews, some fathers expressed dissatisfaction regarding
54 this role allocation. The phrase 'pushed me out of the way' used by Mike in the above
55 quotation indicates a sense of resentment at being forcefully excluded. At other times
56 however, it seemed that fathers were reluctant to openly express any dissatisfaction.
57
58
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3 They seemed to minimise any disappointment they may have experienced in relation
4
5 to their role.
6

7
8 'I done everything else that I wanted to do but there was just those wee things
9
10 were, you know, you had to choose, it was either you or her, and I knew it would
11
12 have meant more to her to do it than, you know, I could live with not doing it but I
13
14 would have loved to have done it' (Mike).
15

16
17 'when Mary [mother] sort of says 'look no, I'm not leaving Lynn here, I'm not
18
19 leaving' and I was happy enough to accept that and I wasn't sort of saying 'right
20
21 Mary go you away I want a bit of time with her', I was getting time with her so I
22
23 was' (Tom).
24
25

26
27 This statement by Tom however contradicts another statement in which he
28
29 describes how he would have liked to have had the opportunity to swap roles with his
30
31 wife. He did not however voice this desire, or any dissatisfaction, to his wife at the
32
33 time of treatment.
34

35
36 'Sometimes now looking back I would have liked to have said to Mary [mother],
37
38 go you on home for a couple of days and I'll stay here on my own, cause I never
39
40 did that, although I think at that stage, if I had said that, Mary would have said, 'no
41
42 I'm not leaving'. You know really from an early stage that was her philosophy.
43
44 Em, so I just accepted that and em, I was sort of, I would have went home and
45
46 taken home washing, whatever had to be done'.
47
48
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50
51 The reluctance from fathers to express dissatisfaction with their role, both at
52
53 the time of treatment and also during the interview, may stem from a desire to be
54
55 positive and supportive of their partners. The fathers, in fact, described the concept of
56
57 maternal coping as one of the ways in which they made sense of, and accepted, their
58
59 peripheral role during the intensive treatment.
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6 'I could have resented that in a way you know, because I kind of felt as if I wanted
7
8 to do it as well, but I knew that it really, really meant a lot to her and that she
9
10 needed to do that, so I just kind of let her get on with it' (Mike).
11

12
13 Some fathers also understood their experience in terms of gender ideology and
14
15 societal beliefs about traditional parenting roles. For example, Mike used this frame of
16
17 reference to make sense of his role even though he perceived such views to be
18
19 outdated.
20

21
22 'She was always the one grabbing him and holding him and caring for him that
23
24 way..., but again I think it just goes back to the whole kind of traditional
25
26 upbringing where you feel it's the Mum's job and Dad kind of stands at the side of
27
28 the room, but I was always there beside him you know'.
29
30

31
32 One father, Paul, described how his beliefs about parenting roles changed
33
34 following his child's treatment. Prior to his child's illness, he perceived children
35
36 typically as having closer relationships with mothers rather than fathers, and he used
37
38 this belief to make sense of his peripheral role in hospital. Following his wife's
39
40 pregnancy however, Paul assumed primary care-giving responsibilities for his child in
41
42 hospital. He described how this experience changed the relationship he had with his
43
44 daughter, 'We got very close. Just being with her constantly' and changed his beliefs
45
46 about parenting roles, 'I don't know I think girls bond with their daddy anyway after a
47
48 wee while anyway. As I say I never believed that until now really?'
49
50
51

52
53 Finally, Mike in particular, expressed his belief that medical staff reinforced
54
55 his peripheral role. He perceived that they provided mothers with more opportunities
56
57 to assume the care-giving role, 'if they came looking for something it would have
58
59
60

1
2
3 always been kind of directed at Gillian [mother], em, it's always the Mum, always the
4
5 Mum'.
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8 As a result of their experiences, some fathers appeared to perceive their
9
10 contribution in the hospital as less helpful in comparison to the child's mother,
11
12 'you're helpless when he's getting anaesthetic and there's nothing you can do, there
13
14 was only one of you can really be there or you get in the way' (Mike).
15
16

17 To overcome this perception of *getting in the way* or being less helpful, it
18
19 seemed important for these fathers to explicitly validate their role. For example by
20
21 emphasising the roles they played in managing wider home and family life, including
22
23 looking after siblings at home. 'Maybe that's why I went and you know, done all the
24
25 kind of practical things, because there is an importance to it' (Mike).
26
27
28

29 In contrast to the experiences of the fathers outlined above, one father
30
31 perceived himself to have an equal role with his wife in caring for their child in
32
33 hospital, 'Well I thought, be there, both of us to share our time primarily, like there
34
35 was no way any of us were going to leave him in the hospital' (Pete). His experience
36
37 of involvement was in keeping with beliefs he held about the paternal role; 'You were
38
39 saying there about the role of the father, I think you need to be involved' (Pete).
40
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43 Although this father did not explicitly perceive his involvement to be
44
45 restricted, in line with other fathers, he believed that being at the hospital was an
46
47 important coping strategy for his wife, and this may have implicitly influenced his
48
49 role and involvement.
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51

52 'I felt as a father, I would have felt more comfortable when Rose [mother] was in
53
54 the hospital with Simon, because [when not at the hospital] she would have been
55
56 saying "how was Simon, how was Simon... how's he now, how's he", you know
57
58 over a two, three hour period' (Pete).
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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).

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2
3 Reflecting the perceived importance of breaks, most fathers assumed a
4
5 proactive role trying to encourage and facilitate mothers to take even short breaks
6
7 away from the experience, 'with the constant being there, you needed to sort of get
8
9 her a break really' (Tom). A number of fathers described facing resistance from
10
11 mothers when attempting to do this.
12
13

14
15 Although the fathers described it as a struggle to manage the multiple demands
16
17 associated with work, home life, and hospital life, most also described how their work
18
19 provided a useful distraction throughout the illness experience; 'it gave me a release
20
21 or it gave me another focus, you know, I wasn't thinking about Rose [*mother*] being at
22
23 home' (Pete). Most fathers described their employers as supportive. One father, in
24
25 contrast however, perceived that his employers put pressure on him to attend work.
26
27 For this participant, his job did not serve as a useful break.
28
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31
32 'Re-introducing to a proper life again' - Putting the illness in the past. While
33
34 undergoing their intensive chemotherapy treatment, the children were extremely
35
36 vulnerable to infection. Parents had to take precautions in order to protect against this,
37
38 'there was no mixing with kids, there was no nothing, he just really lived with us, it
39
40 was like living in a wee bubble for like a year and never went anywhere' (Mike).
41
42 Moving into the maintenance and post-treatment phases therefore, the fathers
43
44 considered it a priority to reintroduce their children to 'normal' life again. They
45
46 perceived it as important to encourage their children to do the same things that other
47
48 children did.
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53 'I hated that, I hated, you know making a difference for him, at that point you
54
55 know, I felt he needed it up until that point, but em at that point, you know during
56
57 maintenance when he was, was looking better you know, he looked normal and all
58
59 the rest of it, and he needed to be treated normal' (Mike).
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3 This excerpt conveys Mike's wish to no longer have to think about his child as
4 being different, or more vulnerable, than other children. Holding this view may have
5
6 allowed Mike to minimise his fears for his child, and his desire to perceive his child as
7
8 'normal' may have been one of the motivating factors behind his efforts to treat his
9
10 child as 'normal'. As discussed previously, throughout the treatment process the
11
12 fathers tended to be very orientated towards the future, signifying their desire to put
13
14 the illness experience in the past. Efforts towards normalisation in the maintenance
15
16 and post-treatment phases may reflect this desire.
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22 The fathers tended to view themselves as being the main parent to encourage
23
24 re-engagement in everyday life. They experienced and described the child's mother as
25
26 more apprehensive and fearful about it.
27
28

29 'Angela [mother] probably was more em apprehensive about letting her out than I
30
31 was, I might have been the one that was, 'I think she can go here or she can go
32
33 there'. Angela probably would have been that bit more apprehensive about her
34
35 doing things, the fact that the risk was there you know' (Roger).
36
37

38 'Gillian would always hold on to the wee warning bit that he'd [Doctor] give you,
39
40 and go "right we're not going" you know so I had to kind of, it was a constant, it
41
42 was a constant fight with her trying to take Colin places'.
43
44

45 The phrase 'constant fight' emphasises the differing positions Mike and his
46
47 partner appeared to take, but also reflects how important the issue was for him, so
48
49 important that he was willing to *fight* for it.
50
51

52 The fathers reflected an understanding of their partners not wanting to expose
53
54 their children to any risk of infection. As one father stated 'I wouldn't have been
55
56 blasé about it either' (Tom). It seemed however that these fathers were prepared and
57
58 more able to manage these risks rather than avoid them altogether.
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2
3 Experiences of Giving and Receiving Support
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5 'Feeling as if I had to be strong' vs. 'we helped each other' - Different beliefs
6
7
8 about the need to be strong. Some fathers relayed a need to be strong and understood
9
10 this in terms of supporting their partners. These fathers believed that if they expressed
11
12 their own worries it would reinforce their partners' fears. Being strong therefore
13
14 involved conveying a positive attitude and offering reassurance.
15

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17 'She was in bits at that point and I was kind of feeling as if I had to be strong and
18
19 not worrying, so I was kind of coming across as 'uck don't worry about it' you
20
21 know' (Mike).
22
23

24
25 These fathers described masking their fears and emotions. When they did
26
27 break down, it tended to be in private. For example, Mike describes how after
28
29 receiving their child's diagnosis, he withdrew from his partner in an attempt to hide
30
31 his emotion.
32

33
34 'I said to Gillian [mother] 'right I need to go out and I'll phone your Mum and
35
36 phone my Mum and tell them' and again that was me I had to get away from her
37
38 because I wanted to cry'.
39
40

41
42 Gender ideology also appeared to influence fathers' beliefs about showing
43
44 emotions.
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46
47 'it's a man's thing, men do keep things inside, maybe that is why my eyes went,
48
49 maybe I just bottled more up into myself, a man shouldn't cry in a case like that, he
50
51 should be the strong one. He is the one who works, provide...' (Paul).
52

53
54 'Maybe it's a man thing, you don't look for sympathy, if somebody finds out fine,
55
56 but you're not going to run around and say 'Guess what? Here's a bit of news',
57
58 that's a, dare I say it, it's a bit of a female trait!' (Pete).
59
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2
3 Masking fear and emotion may also reflect to some extent the strategies
4 fathers adopted to cope with the illness experience. As outlined previously, fathers
5
6 tended to respond to their fears in active, practical ways, perhaps as a form of
7
8 distraction. Some fathers, in particular, perceived that it would not be useful to dwell
9
10 on the emotional aspect of the experience. For these fathers, their own coping
11
12 strategies may have influenced their experiences of giving and receiving support.
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17
18 Contrasting this, two fathers described their experiences of greater mutual
19 support. Rather than believing that fathers had to be the strong parent, these men
20 conveyed their belief that mothers and fathers should support each other, in order to
21 support their ill child and family.
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26
27 'Anne [child] needed, she definitely needed both parents for support. Em I
28 suppose, I myself needed the support and the wife needed support, and the other
29 children as well' (Roger).
30
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34 In contrast to some of the other fathers, these men appeared to perceive it as
35 both helpful and acceptable for males to express their fears and emotions. Roger
36 relayed the following advice for fathers 'don't close yourself away from it, because
37 you're going to gain nothing by it... ... release your concerns and fears to someone
38 you can trust'.
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46 'Do you really realise what it is like?' - Neglected needs and useful supports.
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48 A lot of the fathers believed that people outside their immediate family did not
49 understand the experience they and their family were going through.
50
51

52
53 'they expected as if it was like mending a broken arm, that you know you'll have
54 the plaster off in two weeks and you'll be, you know, a bit of physiotherapy and
55 he'll be right as rain in six weeks' (Pete).
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3 Specifically, some fathers commented that people failed to consider the impact
4 on the whole family, with themselves as fathers being overlooked the most. Although
5 they expressed annoyance about this, they understood this experience in terms of
6 traditional societal beliefs about gender.
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12 'although it's Lynn that is going through the illness, it does, it does affect the
13 whole family and I think maybe outsiders don't give, people don't realise how
14 much it does affect, you know, the parents and I suppose the fathers probably are
15 the ones that might be overlooked the most, ah sure you're alright, you're a man, or
16 I don't know whether that is being sexist or what (laugh) em, you know, I got that
17 feeling anyway' (Tom).
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27 The fathers often appeared to prioritise other family members' needs over their
28 own. For example, during the interview when asked about supports that he may have
29 found helpful, Tom talked about supports for his partner and children. Thus fathers'
30 own prioritising may have reinforced other people's perceptions of fathers not being a
31 priority. The fathers' own coping strategies and their attempts to conform with socio-
32 constructed gender roles may have also indirectly reinforced the neglect of the
33 father's position. For example, by hiding their vulnerability and conveying a sense of
34 being strong, fathers may have reinforced other people's perceptions of them as not
35 needing of support. A number of fathers described the difficulty and perceived stigma
36 associated with receiving support from professionals; 'I'm sure that the hardest thing
37 in the world for someone to do is go and ask for help' (Mike). Again this may relate to
38 gender ideology and beliefs about the role of the father as the provider, as exemplified
39 by Pete's statement; 'as a father figure, it was like you try to, you know, look after
40 your own'. Such perceived stigma may have prevented fathers from openly
41 expressing their needs.
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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

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2
3 fathers' struggle but need to accept their child's diagnosis, the differing degrees of
4 involvement fathers can have in caring for the child in hospital, and also fathers'
5 concern to maintain normalcy in family life during the intensive treatment (McGrath
6 & Chesler, 2004).
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12 During the interviews most fathers emphasised their preference for actively
13 'doing' in order to cope with the illness experience rather than attending to the
14 emotional aspect of the experience. Having a practical focus appeared to enable the
15 fathers to achieve a sense of control over the experience and may have provided a way
16 to distract from emotionally overwhelming situations and thoughts. This finding is
17 consistent with results from quantitative studies which have found that fathers of
18 children with cancer tend to employ problem-focused coping strategies such as
19 gaining information and considering choices and options (Cayse, 1994; Hovey, 2005).
20 It also reflects wider empirical evidence indicating that males, in contrast to females,
21 deal with stress by using more active problem-solving coping, rather than emotion-
22 focused coping (Matud, 2004). It has been suggested that gender identity plays an
23 important role in shaping the ways in which men cope with the stresses of cancer
24 (Chesler & Parry, 2001). Socialisation theories of coping suggest that men are
25 socialised to use more active and instrumental coping behaviours while women are
26 socialised to use more emotion-focused behaviours. This stems from societal beliefs
27 and expectations regarding gender, with the traditional male role prescribing men as
28 being stoic, autonomous, self-confident and assertive. Such expected attributes can
29 make it difficult for men to accept and express feelings of fear and vulnerability
30 (Mutud, 2004). Several fathers in this study indicated that their coping responses, and
31 the roles they adopted in 'being strong' and offering support, were influenced in part
32 by their belief in this traditional male identity. Reflecting also, however, individual
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3 differences and perhaps shifting societal beliefs about gender, not all the fathers in
4
5 this study adhered to these views of male identity and coping. Some fathers perceived
6
7 it as acceptable and helpful for males, as well as females, to acknowledge and express
8
9 feelings and worries.
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12
13 A number of the fathers described how their involvement in parenting their
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15 child in hospital was influenced by the mothers' preferences. These fathers assumed
16
17 or were allocated a peripheral role because the child's mother assumed the primary
18
19 role in caring for their child. The experience of being 'pushed out' caused
20
21 disappointment, dissatisfaction and resentment, however it appeared to be difficult for
22
23 fathers to name this, perhaps because they did not want to cause upset for their partner
24
25 or perhaps because of constraints stemming from beliefs about gender and parenting
26
27 roles. Although it has not been previously emphasised within the context of childhood
28
29 chronic illness and childhood cancer, the experience of maternal gate-keeping has
30
31 been reported in general parenting literature and is increasingly being recognised as
32
33 an important factor contributing to fathers' under-involvement in childcare and
34
35 domestic tasks (Allen & Hawkins, 1999). From a systemic perspective, it
36
37 demonstrates how fathers cannot be understood apart from mothers, as parenting is a
38
39 dynamic process created through the negotiating, competing and compromising of
40
41 two people over the course of their lives (Matta & Knudson-Martin, 2006). The
42
43 fathers in this study understood their experience of maternal gate-keeping in various
44
45 ways. Some fathers understood and attributed the experience to maternal coping.
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47 Some fathers made sense of the experience in relation to traditional societal views of
48
49 women as caregivers and men as providers and protectors. This finding in particular is
50
51 in keeping with results from other studies exploring fathers' experience of childhood
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53 cancer (Chesler & Parry, 2001). It also reflects findings from studies of general
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3 parenting and fatherhood which have shown that men and women's perceptions of
4 appropriate maternal and paternal roles heavily influenced how men participated as
5 fathers (Matta & Knudson-Martin, 2006). One father from this study perceived that
6 medical staff provided more opportunities for mothers rather than fathers to assume
7 the primary care-giving role, thus reinforcing fathers' peripheral involvement. He
8 understood this to reflect the influence of societal beliefs about parenting. This
9 experience supports the suggestion that fathers wanting to have more involvement in
10 the care of their child with cancer may lack opportunities to do so and experience
11 social pressure against it because of cultural beliefs and assumptions about parenting
12 (Chesler & Parry, 2001).
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27 During the intensive treatment the fathers perceived it as important for the
28 family to get breaks away from the illness experience. They also perceived it as
29 important to maintain a semblance of normal family life. Similar views have been
30 reported in other quantitative and qualitative studies (Hovey, 2005; McGrath & Huff,
31 2003), and the importance of normalisation in families of children with chronic
32 illnesses is recognised (Knafl & Deatrck, 2002). This present study asked fathers to
33 reflect beyond the intensive treatment phase. The findings showed that most fathers
34 considered it a priority, during the maintenance and post-treatment phases, to
35 reintroduce their children to 'normal' life again, and they perceived themselves as
36 being the primary parent to encourage this. Research has shown that being able to
37 encourage children to re-establish interests and hobbies after treatment for cancer may
38 protect them against subsequent psychological difficulties (Casey, 2004). It could be
39 hypothesised that a father's role in encouraging re-engagement represents one specific
40 and important way in which fathers promote positive adjustment in children treated
41 for ALL, and may help to explain Orbuch et al's. (2005) finding that positive child-
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3 father relationships are associated with the child's enhanced adjustment following
4
5 treatment for cancer more so than mother-child relationships.
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8 The findings from this study indicate a number of implications for clinical
9
10 practice. Within the field of paediatrics, fathers tend to be the 'forgotten parent' (May,
11
12 1996). There is a need for individuals working in this area to more openly recognise
13
14 the father's position, to interact with fathers in a way that acknowledges and validates
15
16 their role, and to be aware of, and challenge, stereotypical assumptions about gender
17
18 and parenting roles, so as to ensure that both parents have the option and opportunity
19
20 for involvement.
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24 Significantly, this study found that some fathers experienced dissatisfaction in
25
26 being allocated peripheral roles, although may have found it difficult to explicitly
27
28 voice this. This finding demonstrates how gender practices and fatherhood ideals may
29
30 not coincide, and reinforces how, without conscious discussion, many couples can
31
32 revert to gender stereotypical choices (Matta & Knudson-Martin, 2006). It may be
33
34 important for those working with families to facilitate parents to have discussions
35
36 about these issues. Doing so may help to create the opportunity for more flexibility
37
38 and negotiation in parenting roles and may help parents to develop an increased
39
40 understanding and validation of their differing coping strategies and roles.
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45 Finally, the view held by some participants that their needs as a father were
46
47 neglected supports findings from empirical reviews showing that fathers are often not
48
49 included in family based interventions within paediatric psychology (Phares, Lopez,
50
51 Fields, Kamboukos, & Duhig, 2005). Increased effort and consideration needs to be
52
53 given to identify appropriate ways to support fathers. The shared understanding
54
55 between fathers going through the same experience was identified by most
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3 participants as helpful. Facilitating more opportunities for informal group discussions
4
5 and activities with other parents may be one possible way in which to support fathers.
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8 It should be recognised that the results from this study represent the
9
10 perceptions of a number of fathers at a single point in time. The fathers were
11
12 reflecting retrospectively about their experiences, three to four years after diagnosis
13
14 and in the knowledge that their child was in remission of the disease. The interviews
15
16 also took place at the hospital in which their child was treated. These factors are likely
17
18 to have influenced to some extent the resulting discussion that took place. As is the
19
20 nature of qualitative and IPA studies, the fathers' views and perceptions may have
21
22 been different at other points in time or in other contexts. Furthermore, the
23
24 opportunistic sample of the study represents fathers who were willing and perhaps
25
26 wanted the opportunity to discuss their experiences and views. Again this may have
27
28 influenced the themes that emerged. This is however a reflection of the idiographic
29
30 nature of IPA as a research method and as Smith (2004) suggests, the very detail of
31
32 the individual may also bring us closer to significant aspects of a shared humanity.
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Table 1. Summary of Super-ordinate and Subordinate Themes.

1. Adjusting to the diagnosis'What are we in for?'

Uncertainty and lack of control

'Lets see what has to be done'

Taking control

'You try to play it down'

Constructing a manageable reality

2. The Experience of Maternal Gate-Keeping'I could live with not doing it, but I would have loved to have done it'**3. Striving for Normalisation**'Not totally upset everyone and try to keep everything as normal as possible'

Minimising the impact of the illness

'Re-introducing to a proper life again'

Putting the illness in the past

4. 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.

'Do you really realise what it is like?'

Neglected needs and useful supports