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Concealed Concern: Fathers' Experience of Having a Child with Juvenile Idiopathic

Arthritis

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Abstract

Despite increased research into families of chronically ill children, more needs to be known about the father's experience. We address this issue through asking: 'What is it like to be the father of a child with juvenile idiopathic arthritis?' (JIA). Four members of eight families with an adolescent diagnosed with JIA, including seven fathers, were interviewed and transcripts analyzed using grounded theory. This study suggests that fathers of children with JIA experience several severe losses which are exacerbated through comparisons they make between their own situation and that of fathers of healthy children. In addition, the fathers faced several constraints which reduced their opportunities to communicate with their ill child through shared activities. Fathers appeared to conceal their distress by adopting strategies of denial and distraction however their adjustment was facilitated, to some extent, by social support. They could also develop greater acceptance of their situation over time as the care of their ill child became assimilated into family life and constraints upon their life gradually reduced through the increased maturity of their son or daughter with JIA. These findings have implications for healthcare professionals and voluntary organizations.

Concealed Concern: Fathers' Experience of Having a Child with Juvenile Idiopathic Arthritis

Researchers are beginning to challenge the view that fathers of chronically ill and disabled children limit their role to supporting the mother (e.g., Pelchat, Lefebvre & Perreault, 2003). But more needs to be known about how such fathers do cope and react. The focus of the current study is the experience of fathers who have a child with Juvenile Idiopathic Arthritis (JIA). This will add to the body of knowledge already developed on the experience of children with JIA and that of their mothers (e.g., Barlow, Wright, Shaw, Luqman & Wyness, 2002; Shaw, Southwood, & McDonagh, 2005). JIA is a common childhood chronic disorder with an incidence rate within the UK of 1/10,000 and prevalence of 1/1,000 (Symmons, Jones, Osborn, Sills, Southwood, & Woo, 1996). The condition brings disabling pain, swelling and stiffness of one or more joints as well as generalized symptoms of tiredness, weakness, and poor appetite. There is currently no cure for JIA and, though causes have been attributed to an inherited pre-disposition, as yet, its origins are little understood.

Whilst most studies of parents of children with JIA, and other chronic conditions, concentrate on the child-mother dyad this is not always made clear. West (2000) argues that past research on 'parents' most often means 'mothers' with fathers, when included, often viewed as peripheral. Mothers and fathers do share significant parental experiences, such as grieving for their 'well child' and for their previous family life, however it is important to be aware that fathers may, in many ways, perceive and respond to having a chronically ill child differently to their wife. For example, Britton and Moore (2002)

found spouses to have different priorities: fathers stressed the visibility of their child's condition and long term future whilst mothers focused more on their child's ability to develop successful peer relationships and meet the challenges of daily living. Gender identity and family role may also be important with some fathers feeling their masculinity threatened by having a disabled child (Chesler & Parry, 2001) and/or doubting their own ability to provide in practical ways for their family (Baumann & Braddick, 1999).

Hegemonic masculinity is embedded in the social institutions of Western society (such as the family), associated with qualities such as physical and emotional resilience, and separated from the domestic sphere (which includes childcare) (Connell, 2002; Robertson 2006). Although there are many ways in which masculinity can be expressed, and significant challenges to hegemonic forms, the stress of having an ill child may still threaten a man's identity through exposing him as vulnerable (Courtenay, 2000; Seidler, 2007). Moreover, the extent to which a father is comfortable engaging with his ill child is influenced by the way masculinity and fatherhood are socially defined and reflected within social institutions (Chesler & Parry, 2001). For example, Baker and Lane (1994) found fathers to be more involved in caretaking activities when mothers worked outside the home. However, an ill child more often leads to increased and traditional division of labour with mothers most likely to be the partner giving up paid employment (Reay, Higold, Ball & Cribb, 1998). Hence, parental role restrictions created through the process of caring for a chronically ill child may have the affect of bolstering aspects of hegemonic masculinity and, potentially, denying fathers opportunity to integrate with the

emotional life of the family. Thus, fathers' responses, as with those of other family members, have to be seen as dynamic and in relation to forces on, and within, the family.

More research is needed into fathers' experience of having a chronically ill child and the focus of the current study is fathers who have a child with JIA. The current study is part of a larger programme of research which included members of eight families with an adolescent diagnosed with JIA.

Method

Ethical Approval

The Ethics Committee of the Institute of Psychological Sciences, University of (omitted for the purposes of blind peer review) approved the study and permission was given by the Regional Development Officer of a national charity to approach relevant families during the first author's voluntary work. All participants signed a consent form.

Researchers

We offer the following background information on the researchers to provide some context about possible influences on our approach to the study and interpretation of the material generated. Both researchers are female, are parents, and are white British nationals. As a child, the first author received a diagnosis of, what would now be classed as, JIA. She is a lecturer in a multi-disciplinary school of healthcare, has worked as a school teacher, provided care for adults disabled due to arthritis, and runs a voluntary group for children with JIA and their families. The second author guided the research and is a senior lecturer specializing in qualitative methodology and health-related research in

a department of psychology. She grew-up in a family managing the demands of chronic and acute childhood illness.

Participants

Purposeful sampling of eight families, including four male and four female adolescents (i.e., aged between 12 and 18 years) with JIA and at least one healthy sibling, was conducted by the first author during her voluntary work with a JIA support group based in the North of England. An attempt was made to interview both parents in each family however this was, eventually, not possible with one family as the father did not live in the family home and other family members became reticent for him to be contacted. The maternal grandmother, who supported the family in place of the absent father, was interviewed in his place. Consistent with theoretical sampling (Glaser & Strauss, 1967), data collection and analysis were conducted iteratively so that families were recruited whose situation might help expand and/or test the developing theory on an on-going basis. Accordingly, an effort was made to sample families with different structures and the final sample includes six two-parent families, one single-parent family headed by a father, and one single-parent family headed by a mother. In all, 32 family members, all white British nationals, were interviewed: eight healthy siblings, eight adolescents diagnosed with JIA, eight mothers, seven fathers, and one grandmother. Four were fathers of male adolescents with JIA, and three were fathers of female adolescents with JIA.

Data Collection

The first author made verbal contact with potential participant families and, if interested in taking part, they were sent a letter detailing more about the study. These families were then telephoned to ascertain their willingness to take part in interviews and a second telephone call to arrange interviews was made a week later so as to allow time for consultation between family members. Semi-structured interviews (e.g., Smith, 1995) were considered the best way to gather rich information on the participants' experience and to help guard against the researchers imposing their preconceptions on the data. An interview schedule was developed which covered areas considered relevant to the topic of study but this was used flexibly and allowed the dialogue to evolve naturally and to be shaped by participants.

The research question addressed in the present paper is: 'What is it like to be the father of a child with juvenile idiopathic arthritis?'. Hence, initially, fathers were asked: 'Please can you tell me something about what it is like having a child with JIA?'. They were then asked how having such a child impacted upon their life, how they felt about this, how they perceived that their own and their child's future may be affected, and about any other information they considered relevant. Other family members interviewed were also asked how the life of the father was affected, how they perceived the father felt about this, how it may impact the father's future life, and about any other information they considered relevant. Interviews were conducted by the first author in the participants' home, were audio-recorded, and, with the fathers, lasted between 40 and 90 minutes. Between interviews, questions and prompts were reviewed and revised such as to best inform the developing theory. The first author transcribed interviews verbatim.

Data Analysis

Interview transcripts were analysed using procedures based upon constructionist interpretation of grounded theory whereby conceptual understandings are developed from an inductive, thematic analysis of textual material (Charmaz, 2006). The grounded theory approach was initially based upon a realist epistemology assuming researchers' ability to be objective and for theory to 'emerge' from data (Glaser & Strauss, 1967). A constructionist implementation of grounded theory considers analysis to be more interpretative and for researchers to consider carefully the limits on the transferability of findings (Madill, Jordan, & Shirley, 2000). Fathers' interviews, as well as reference to fathers within the interviews of other family members, were included within the data corpus. Transcripts were scrutinized line-by-line for information relevant to the research question. Meaning units (MUs) were identified, consisting of passages in the transcript which appeared to describe similar phenomena. Each MU was awarded a title which described its content and each was refined in comparison to later identified MUs. Categories with similar meaning were clustered into yet more comprehensive themes as coding continued. Relationships between themes were sought through writing memos documenting developing themes, observations, and speculations. An integrated model, relevant to the research question, was developed as result of this memo-ing and through discussions with the second author.

A credibility check by an independent researcher experienced in qualitative methods was undertaken once analysis was completed. The independent researcher was given fifteen quotes from the data alongside the title and description of the five themes

identified in the analysis and asked to place the quotes into the most appropriate theme. There was an 87% agreement with the original coding of the first author. Where coding differed (i.e., two quotes), both understood the rationale behind the other's choice and agreed that these quotes could sit comfortably within either category. Hence, the credibility check offers evidence that the coding in this study is recognizable by others and, to this extent at least, a coherent interpretation.

Results

Five themes were identified in the analysis of data relevant to the participant fathers: comparison, loss, constraints, concealment, and social and emotional adjustment. These themes were integrated to demonstrate factors impacting upon the social and emotional adjustment of fathers of children with JIA.

Theme 1: Comparison

Fathers considered their family different to other, seemingly normal, families with the child's illness dominating to the extent that Greg felt like they had "a doctor living in the house". Len described difficulties doing ordinary household jobs: "You get up and think 'I'll do a bit of DIY' but you can't cos she is asleep in bed. You can't use tools in case it wakes her up or owt in case she has been up all night." Moreover, David lamented that "normal bedtime for normal kids was like five minutes and they are in there. But it was an hour we used to take for Carl." Such experiences seemed to catalyse even more negative social comparisons: "You tend to think 'Look at him. He has no problems at all. He has a family business, nice house, nice new cars and things and how has he done that?' And I think 'why me?'" (David). Fathers felt denied 'normal family holidays'

because of their child's illness with Len explaining that "you can't really make those plans."

Fathers felt that others did not always understand the problems created by their family life. Vince explained that he had to "put up with prejudice from other people. You know 'Why should we make exceptions for him? You know if he's got problems like that he should get out of the army'." Extended family, too, were not always sympathetic: "Having seen Carl turn blue and look like a skeleton you think, you know, I think my brother has no idea and I get cheesed off" (David).

Physical ability was very important to the fathers and they made comparisons before and after the onset of JIA (and when it was in remission) and between their ill child and healthy peers. For example, Edward and David described how their sons had been 'exceptional' at football and running: "It was unbelievable just how hard he could kick a ball and run long distance" (Edward). Also, Tony, Len and Craig reported their child to have been 'above average' in different sports. Even Vince said his daughter was ahead of other toddlers in running and climbing before the onset of her condition. Mothers, too, suggested that fathers felt cheated of the opportunity to enjoy their child's physical achievements. For example, David's wife explained that "Carl was really good at sport and I think maybe he (David) thinks what could have been." This is echoed in Tony's remark that "you look and think they are different to the other kids. They are busy having a good time kicking a football. Therefore I have got a problem." This disappointment was sometimes clearly articulated as a personal shortcoming: "You look at your child and your childhood and expect your son or daughter should be like you. It's

at times embarrassing when you have got someone in a wheelchair because it is not normal” (Tony).

Theme 2: Loss

The fathers experienced several severe losses. They felt a loss of their ‘ideal’ role as family provider and protector. While all, except Craig (single father), reported working long hours to earn extra money, this was never enough and applications had to be made for benefits. For example, Vince explained how he took on two extra part-time jobs as “I was on an army wage which was pretty poor at the time”. As well as being less able to provide financially, they often floundered in their dealings with the healthcare system. For example, Vince’s wife explained how he felt like a “fish out of water” when with medical professionals and thus that “with regard to Susie, what I says goes.” This could create a strain on the marital relationship as Tony explained: “Though we have got a strong relationship, you know, there are certainly times when we could easily have blown” and David referred to the ‘blazing rows’ between him and his partner.

A related loss was of a ‘normal’ family life: “You have got a constant threat to the whole family life because you have not got normality. You are going to end up with severe family strain and it has to lead to erosions of relationships, jealousies, frustrations” (Tony). Tension was exacerbated by the loss of control created by the unpredictability of illness flare-ups. For example, Edward said “you know, if a child is ill all the time you can take measure for that but when it just strikes!” and Tony explained that “there is no such thing as a normal life because you can’t plan. A flare up, you know, could mean this week is fine but next week he can’t walk.” Not only did fathers report a loss of control

over family life but also a loss of spontaneity as family outings had to be planned carefully. Greg expressed frustration due to restrictions placed on family life because of his son's illness and Tony explained that "it is far more pragmatic, far more planned, clinical, and, it is far slower....So, yes, we'll go to the seaside for the day but we have to sort the wheelchair out or take it very slow. Got to check all the drugs are being taken at the right times."

Fathers reported a loss of occasions when the whole family shared time together. This was particularly the case for Craig whose family life was extremely fragmented with his different children being cared for by himself, his estranged-wife, or her mother in different combinations and at different times. Tony explained that "it threatens the relationships within the family. It is really quite threatening because of the time". This was supported by his well daughter who said "He has had to look after me while Mum takes Robert to the hospital. Mum and Dad have to juggle commitments." Most fathers also reported restricted opportunities to share a social life with their wife. Greg described a number of occasions his wife could not attend social events and overseas trips related to his family business because Ben was ill. Also Vince explained that "we couldn't trust anybody else, even a registered childminder."

Fathers had to relinquish their dream of their 'ideal' child and the potential shared future to which they had looked forward: "As a fella you set up role models and expectations, you know, of a path that you expect them to follow" (Tony). Vince described how "it felt like the bottom of my whole world had fallen out to find out the child you had always wanted was disabled with arthritis" and David said that "you tend to

think ‘Why has it got to be like this’, you know, you have all sorts of things planned.” In particular, they felt a loss of a physically ‘normal’ child and Robert lamented that “Dads want to see their sons being strong and macho, winning wrestling matches and stuff like that.” In addition, they felt a loss of companionship through potential or previous shared activities with their child: “What I have missed with Luke, compared to what it has been like with Peter is, not that I am a sporty kind of person, but just kicking the football around with him which is the kind of thing I did with Peter quite a bit” (Edward). Also, Len’s wife described how he has lost his “little helper” as Debbie had ‘caddied’ for him when he played golf.

Theme 3: Constraints

Fathers found it hard to communicate with their ill child, whilst the relationship between mother and child appeared enhanced through shared interaction around the child’s care. For example, Edward’s wife described the special “code” she and her ill son had developed in relation to his care, from which Edward was excluded, and how this made him feel rejected. David described listening to his ill son’s telephone conversations in an attempt to find out more about him: “I was ear wiggling a little bit to see what sort of things they talked about”. At the same time, Carl, his son, admitted that “I rarely speak to my Dad” and his mother reported him saying that “I don’t speak to Dad full stop.”

Gender appears to be influential in how fathers tried to develop other ways of relating to their ill child. Fathers of daughters had the opportunity to communicate through some physical care and overt displays of affection and protectiveness, as Len’s wife explains: “With Len it is a huge protective thing” and she described him cutting up

Debbie's food and making her drinks. Also, Vince's wife described how he was very protective of his daughter and information offered by Craig and his daughter suggested that he was both physically and emotionally attentive to Gina. However, fathers were inhibited from adopting the 'playmate' role they might normally use to foster relationships with their children, especially their sons. Edward could "kick a ball round" with his well son, and David described how he and his well son went running together, whilst Tony's wife lamented that there was "no male bonding" between Robert and his father. Moreover, fathers of ill sons felt the need to foster independence and moderate the additional care their illness required and Edward explained that "you have also got to try and be firm as well because, you know whilst it is very difficult for him, he has got to learn to live with it and it is no good being soft with him." This was acknowledged by Robert within his relationship with his father: "Mum, but she's been the most lenient with it. I guess that is one of the reasons why Dad is so expectant of me. You know. He expects me to do all these sorts of things".

Having to work longer outside the home - "I was working long hours and travelling either side of it" (Vince) - offered fathers less opportunity to gain the same level of understanding about their child's condition and treatments displayed by mothers. However, most fathers described helping with housework as well as the care of their well children and, where possible, their ill child. For example, Len described how he often washed up, vacuumed, and tidied up as his wife and daughter were so tired from sleepless nights. Fathers indicated that undertaking household duties could feel constraining: "I think it restricts you. Yes it restricts you" (Greg).

Fathers were required to develop a vicarious 'medical career' as, whilst all fathers, except Craig, described the mother as key knowledge holder regarding the child's illness, medical staff were often perceived to give the father's opinion more credibility. For example, Vince's wife commented that "I know, no matter how wrong I feel it is, I think there is still that it carries more weight from a man than it does from a woman." And Michael's ex-wife explained that, despite the little contact he normally had with his family, she had to ask him to accompany them on a hospital visit to add credibility to her account of her child's symptoms.

Despite their supporting role fathers conveyed some knowledge about the medical experiences and treatments of their ill child. David said: "I know a bit about the arthritis world", and Tony was able to explain that "he has been on drugs that have affected you know, his liver, his kidneys, his stomach. He has had haemorrhages, you know, blood in his urine." Moreover, some fathers appeared to have developed specific caring skills. For example, Vince would use packs of frozen peas to reduce pain and swelling in Susie's joints, Len would supervise and cajole Debbie into taking her tablets, and David described, with great pride, how he had been complimented on his 'bandaging skills' "cos I've done it you see, putting the splints on. In hospital, the nurses used to come round and say 'Who has done this?' and 'Will you teach me how to do that?'" However, fathers faced some limitations and difficulties offering personal care to their daughters. Whilst Gina had no objections to receiving his help with the most intimate forms of care, Craig explained that "it's awful for me with her coming into her teens you see. So, when she

comes out of the hospital she can't do nowt. When she has this operation they are on about giving her a bed bath. I'm not giving her a bed bath."

Theme 4: Concealment

Fathers responded to their loss of a 'normal' family and child, and the new constraints on their family role, by concealing their feelings. For example, Vince explained that "you know put on a front" and Craig commented that "you can't really show a lot to them because they get upset". Debbie said she thought that her Dad hid his feelings because, as a man, if he showed them he would "be seen as pathetic." Gina also described how her father, Craig, hid his emotions and added "I've only ever seen him cry when somebody has died." However, Craig's explanation suggests that, as well as protecting his own masculinity, he was also trying to protect his daughter: "When she is crying I feel like sitting down and crying with her like ... You can't explain what your feelings are because if you show too much to Gina she thinks she is doing it all to you. She thinks she is hurting you."

Not only did the fathers appear to hide their emotions from others, they attempted to conceal their distress from themselves using strategies such as denial and distraction. One possible expression of denial was the fathers' suspiciousness that their child's pain might not be real. For example, Tony explained: "You look and you think 'Oh are they swinging the lead?' and 'Is this really pain? Is this an excuse?' You have a Jekyll and Hyde character because one side of you is really 'What can we do?' and the other side is 'Hey bull. Are you pulling the leg on this one?' and you can't help it because it is non-visible." Forgetting seemed another way in which denial was used to deal with unwanted

emotions as the fathers were often unable to recall much detail about their child's condition. Greg said: "I can't remember exactly when and what is it like at its best and worst" and David explained that "you tend to forget... you cannot remember how you felt really. You forget." The success of denial could, at times, be limited as it could be misinterpreted by their wife as evidence of 'not caring' and exacerbated some of the tensions within the marital relationship. For example, Tony explained that attending a workshop designed to help parents cope their child's illness caused arguments between him and Jane because "I saw the extremes and I could not cope with that. You know because I am seeing a sixteen year old girl and she is crippled and, having it in your face is really difficult."

Whilst working long hours was necessary to support their family, fathers also used this as a distraction. For example, when asked how he coped with his son's illness Edward replied: "It is work really. I mean I am just away from it". Greg's wife described him as a "workaholic" and Ben suggested that his "Dad hides behind his work", while his brother was unsure about how their father felt about Ben's illness as "work and the office is his life." An illuminating example of how fathers used work as a distraction was offered by Craig, the single unemployed father. When asked about the effects on routine housework, all mothers indicated that this was fitted in around the care of their ill child. In contrast, housework was a central part of Craig's life: "It is a full-time job and all. I'll tell you. You say 'Right get it all done'. Get my windows done and get everything done." And when Craig was asked what helped him most cope with having a child with JIA he laughed and said: "Work. Vaccing up. I take it out on the vac."

Fathers continued to enjoy a social life outside the family and use this as a means of distraction from emotional pressures created by having an ill child. For example, Greg explained that “Last night I was down at the pub” and even Craig got out: “I’m not stuck in house all time. Don’t get me wrong. I go out for a drink with our kid and our Len. There is a few of us who go out on a Friday night. Go round town and have a laugh and a joke like. So I do get a bit of a break and a bit of a chat with our kid like.” Whilst David felt that he had sacrificed a lot because of his son’s illness, he acknowledged that “my wife will tell you it has not affected my leisure at all, but the running was a great release as such. I probably needed that to get out and just think about it and get away from it.”

Theme 5: Social and Emotional Adjustment

Fathers were helped, to some extent, to adjust to having a child with JIA by the social and emotional support offered by their family and friends. Fathers indicated that their wife was their main source of emotional support and described how the lead role she adopted helped them cope with having an ill child. In particular, the fathers were often reliant upon their wife to help them maintain a close relationship with their ill child. For example, Len’s wife explained how she “had to keep him involved.” Interestingly, even though Craig’s estranged-wife did not live with the family, she was still his main source of support: “Even though we are split up like, she still helps a lot so... she is the most helpful to me.” Extended family in the form of grandparents also proved helpful, in some cases, particularly in providing practical help. For example, Edward commented that “we are very fortunate with Nanette’s mum and dad” and Craig explained that “sometimes her Nanna will look after them for me.”

To some extent, friends facilitated the fathers' adjustment to having an ill child through providing activity-based companionship or practical help. For example, David explained that "we started a running club. I got good support from them and from the sporting side of it and, like I said, I had some good lads who became good friends at the garage who I could trust down to the ground to carry things. I'm lucky in that I've had lads who have helped me out and such, and not ripped me off, but just been there."

Over time, with increased experience, the needs of the child with JIA were assimilated into fathers' lives. For example, Greg commented that: "You have got to try and accept it" and Tony explained that "as a father you expect, you know, especially with a son, loads and you don't get it so, you have to do a massive re-set, you know, on your expectations for the child." Adjustment included modifying the previously envisaged future they had for their child: "Hopefully most of them grow out of it like. I'm hoping she does. Hope for the best. If she doesn't then we will just have to take things one day at a time like. Like I say, if she ends up like she can't work, I don't think it will come to that, but if it did she has always got a home with us" (Vince).

The increased maturity of their son or daughter with JIA also helped fathers to feel less different to fathers of well children as the young adult with JIA needed less time and attention from fathers in the form of physical and emotional care. Edward described how Luke could now be left on his own for short periods whilst he and Nannette went out and Vince said that Susie "can judge herself now like when she walks." Moreover, the child's increasing maturity enable fathers to develop new, shared interactions and thus new ways of communicating with them. For example, David's wife explained that Carl

had previously found it hard to be a spectator of sports he desperately wished to play but, as a young adult, had developed greater acceptance of his situation and spent time watching and discussing televised football with his father. Also, Tony's wife described how, over time, he and his ill son communicated through developing a shared sense of humour. Learning to drive also helped adolescent sons with JIA develop new interactions and forms of communication with their father. For example, whilst Craig referred to the physical freedom Gina's future driving would give him, fathers of sons referred to driving also as a shared topic of conversation.

Eventually fathers adjusted such that their family life became 'normal'. For example, Greg said that "By then you have changed anyway" and Len explained that "It has been there that long now it is part of your routine." Also, Vince's comment that "you don't actively think about it because it has become second nature because it has been so long" was supported by his daughter who explained that her illness was just a "normal part of Dad's life."

Discussion

Through comparison (theme 1), fathers saw themselves as less able to create a 'normal' family life or feel the same pride in their child and his or her achievements as fathers with a healthy child. Comparison heightened fathers' experience of loss (theme 2), including the loss of 'normal' family life and the loss of the 'normal' child they had envisaged fathering. They felt constrained in their role (theme 3) which restricted communication with their child, meant they had to compensate through earning extra money, adopt a supporting role, and accept a 'medical career.' Fathers concealed their

emotional response (theme 4) through adopting strategies of denial and distraction. However, the extent to which they had to conceal their response to feelings of loss and to constraints was mediated by the amount of social and emotional support they received from their family and friends. Their emotional concealment also decreased over time as greater social and emotional adjustment was achieved (theme 5) through increased assimilation of the child's needs into family life. Such adjustment also became easier with increasing maturity of the ill child.

Whilst these themes express a process of gradual adjustment, the extent to which fathers of children with JIA conceal their emotions suggests that the challenges they face may not be fully appreciated. Fathers and mothers display similar biologically-based reactions to babies (Schaffer, 1994) and cross cultural studies suggest that, when given the opportunity, fathers want to spend time with their offspring and can fulfil caretaking activities similar to that of the mother (e.g., Mackey, 2001). Hence, an appreciation of the socially constructed nature of parenting roles, in which hegemonic masculinity is embedded, could be useful in understanding why the fathers studied felt inhibited from expressing their troubles and benefiting from the improved communication and support this might have facilitated.

A father's sense of identity will be influenced by culturally available forms of masculinity. Specifically, within Western society, males are ascribed *instrumental* (functional and active) gender roles in comparison to the *expressive* (emotional and supportive) roles ascribed females (Connell, 1995). Models of behaviour are provided by parents, within men's social networks, and displayed in public arenas (Chesler & Parry,

2001; Maurer & Pleck, 2006). Fathers were particularly susceptible to comparisons that revealed their child's physical limitations, particularly those of a son, and described missing shared sporting activities (Sallfors & Hallberg, 2003). Sport provides training in instrumental masculinity made visible in the athletic male body (Connell, 1995; Robertson, 2006), is the normative way boys develop a masculine identity (Watson, 2000), and can contribute to the 'male bonding' of father and son (Seidler, 2007). The fathers' expectations appear rooted in their own childhood sporting experiences and their frustration at restrictions cultivating athleticism in their sons seemed heightened by the visibility of their child's physical disability. Hegemonic masculinity subordinates less powerful males, including those who are disabled (Courtenay, 2000), and it is likely that the fathers experienced a complex reaction to the perceived emasculation of their sons and more insidiously, by implication, of themselves (Gerschick & Miller, 2004). Hence, the fathers' loss of their 'ideal' child (Britton & Moore, 2002) is likely mixed with a sense of culpability for the child's suffering, but the child as 'product' may also be an unsettling embodiment of parental failure (Reay, Bignold, Ball & Crib, 1998).

Despite Baker and Lane's (1994) assertion of new attitudes towards fatherhood, our study supports Chesler and Parry's (2001) argument that the 'father as breadwinner' still permeates Western culture. Our participant fathers appeared to judge themselves against the traditional role of the man as protector and provider and to feel their competence erode as they struggled to support their family financially and in practical ways (Britton, 2001; McNeill, 2004; Sallfors & Hallberg, 2003). Baumann and Braddick's (1999) findings that potential challenges to masculinity through fathering a

disabled child are countered by fathers' sense of their increased importance within their family were not reflected in our study. All fathers interviewed, except for the single father, appeared to be in a peripheral supporting role (see also Sallfors & Hallberg, 2003).

Constraints of increased division of labour within parental roles experienced by fathers meant they worked long hours to provide financially for their family whilst, most often, mothers undertook the main caretaking duties for their ill child. Whilst paid work may favour men in providing an identity and opportunities for self-worth outside their parenting role, fathers may not experience this as an active choice (Connell, 2002; Mac an Ghail 1996). Working outside the home meant reduced involvement in the care of their ill child and in shared activities potentially compromising the development of a good relationship already impeded by the loss a 'playmate' role they would have adopted more easily with a robust child (Britton, 2001; Sallfors & Hallberg, 2003; West, 2000).

Hence, the fathers can be understood to be positioned within disturbing tensions related to hegemonic forms of masculinity as fathering an ill child comes to embody the man's own failed (or potentially failing) masculinity in terms of provider and playmate. Moreover, they resented the reduced time and attention available to them from their partner. Our participant fathers described concealing these difficulties to avoid burdening their family. However, concealment may have functioned also to maintain a sense of masculine self esteem through hiding such conflicts from others and, possibly, from self (Seidler, 2007). This interpretation is substantiated to some extent by Gerhardt et al. (2003) who found that, although in a similar family situation, fathers of children with JIA tended to express less anxiety than mothers.

The fathers attempted to limit the impact of their distress through use of distraction and denial. Whilst employment outside the home restricts involvement with the ill child, it is important to acknowledge that work can also be a father's way of showing care (Morgan, 1992). Even so, the men admitted using their work often as a distraction and expressed guilt that this was not always available to their wife (see also Sallfors & Hallberg, 2003). Whilst fathers sometimes used denial as a coping mechanism, this has only short-term benefits and left them vulnerable during periods in which their child suffered visible physical limitations. More specifically, fathers' use of denial and, hence, particular sensitivity to the visibility of their child's condition (see also Baumann & Braddick, 1999; Britton & Moore, 2002), may help explain their reticence to be involved in their child's hospital visits as these demand engagement with medical realities (Sallfors & Hallberg, 2003). Distraction and denial certainly have their place as coping mechanisms but might delay adjustment to a chronic situation if problem-focused strategies, such as typical of mothers, are not also utilised (West, 2000).

That fathers' concealed their anxiety allows us to understand better a paradox which emerged in relation to the parents' experience of healthcare professionals. Despite the peripheral caretaking role of the fathers, mothers reported feeling that their husband's opinion was better believed by healthcare professionals (see also Britton, 2001). Interestingly, McNeill (2004) reports that fathers fear becoming unpopular with healthcare professionals if they raise difficult issues and, although such reticence may sustain the peripheral and secondary role to which they feel assigned (West, 2000), it may also avoid them appearing over-anxious. This may make fathers seem more credible to

healthcare staff than do the mothers, particularly as this reinforces gender based expectations of the 'rational' male and the 'emotional' female (Sneider, 2006).

Fluctuations particular to JIA such as extreme and unpredictable changes from 'illness' to 'normalcy', create tensions which may hamper fathers' adjustment as family life, and, in this way, contrasts the experience of families caring for a child with a life-threatening illness or permanent disability (Sullivan-Bolyai, Rosenberg, & Bayard, 2006; Towers & Swift, 2006). However, our participant fathers gradually adjusted to a lifestyle compatible with the challenge of JIA. Wives were found to be the most valued form of emotional support within this adjustment process (see also McNeill, 2004) whilst others, particularly friends, gave practical help or usefully distracting activity-based companionship. In particular, Walker (2004) describes the covert intimacy and support between male friends. Use of shared public space, such as the local pub or gym and instrumental telephone calls made, for other specific purposes, provides opportunities for men to discuss issues of concern. However, whilst this offers some opportunity for emotional expression, masculine codes have to be preserved and if fathers disclose too directly they risk making male friends feel uncomfortable.

Our findings suggest that, given the extent to which fathers conceal their emotions, the depth of their response to having a child with JIA is difficult to assess. However, there is a need to try and understand their position, particularly as previous research has had to rely on reports from mothers, with the underlying assumption that parents have similar reactions (Baumann & Braddick, 1999; West, 2000) and information gathered in our larger study indicates that mothers are not always aware of the fathers'

experiences (see also Britton & Moore, 2002; McNeill, 2004). In fact, our participant fathers mentioned that they had not previously felt able to discuss their feelings, even with their partner.

Our small sample size limits the extent to which findings might be considered representative of the wider population of families with JIA. However, drawing material from interviews with 32 participants is a reasonable data base for research using a thematic form of qualitative analysis. Participants were also selected, from the families available, by using both purposeful and theoretical sampling in an attempt to assess the appropriateness of interpretations and add further detail to the emerging model. Moreover, as recommended by Ellis, Upton and Thompson (2000), our sample included four different members of each family. Such procedures can aid the transferability of findings (Banister, Burman, Parker, Taylor, & Tindall, 1995). Interviewing multiple members of the same family offered a potentially comprehensive view of fathers' experiences and how they impacted others, and family members did offer different perspectives on the father. This strategy allowed us to speculate that there were issues about which the men were reticent to talk or, about which, they were unaware. Whilst the interviewer's age and gender (a woman, slightly older than the participant men) may have affected how each participant responded, fathers also commented on how helpful it had been to talk (see also Britton, 2001; Britton & Moore, 2002; West, 2000).

Future research could consider more thoroughly the implication of family structure, father's age and occupational status, use a wider geographical area (ensuring inclusion of different healthcare systems), and include families from diverse ethnic

groups. In particular, it would be interesting to investigate further the experiences of fathers caring for chronically ill children within the context of dual and single parent households. Another area for further research suggested by the present study is the impact of the increasing maturity of the ill child on the father's level of adjustment as this appears to be a novel finding.

Whilst this study confirms, to some extent, the supporting role of fathers of chronically ill children it indicates the extent to which fathers' concealment of their concerns influences, and is influenced by, this role and impacts their relationship with family and health professionals. A need emerged to appreciate the constraints of socially constructed gender expectations on fathers' engagement with their ill child and on their sense of masculinity and self-esteem, their use of denial and distraction, and the ambiguous role of paid work. Better understanding could mitigate health professionals' judgements of fathers as either uninvolved or as the more rational parent. Greater attempts to involve fathers in their child's care could also facilitate the father's adjustment to having a child with a chronic illness such as JIA.

References

- Baker, S. & Lane, M. (1994). The good father. *Child Health*, **2**, 28-30.
- Banister, P., Burman E., Parker, I., Taylor, M., & Tindall, C. (1995). *Qualitative methods in psychology: A research guide*. Buckingham, UK: Open University Press.
- Barlow, J. H., Wright, C. C., Shaw, K. L., Luqman, R., & Wyness, I. J. (2002). Maternal stressors, maternal well being and children's well being in the context of juvenile idiopathic arthritis. *Early Child Development and Care*, **172**, 89-98.
- Baumann, S. L. & Braddick, M. (1999). Out of their element: Fathers of children who are 'not the same.' *Journal of Pediatric Nursing*, **14**, 369-378.
- Britton, C. (2001). *Telling it how it is*. Brimingham: Hanseltrust Publications.
- Britton C. & Moore, A. (2002). Views from the Inside, Part 2: What the children with arthritis said, and the experiences of siblings, mothers, fathers and grandparents. *British Journal of Occupational Therapy*, **65**, 413-419.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Chesler, M.A. & Parry, C. (2001). Gender roles and/or styles in crisis: An integrative analysis of the experiences of fathers of children with cancer. *Qualitative Health Research*, **11**, 363-384.
- Connell, R.W. (1995). *Masculinities*. Cambridge: Polity.
- Connell, R.W. (2002). *Gender*. Cambridge: Polity.
- Courtenay, W.H. (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine*, **50**, 1385-1401.

- Ellis, N., Upton, U., & Thompson, P. (2000). Epilepsy and the family: A review of current literature. *Seizure*, *9*, 22-30.
- Gerhardt, C. A., Vannatta, K., McKellop, J., Zeller, M., Taylor, J., Passo, M., & Noll, R. B., (2003). Comparing parental distress: Family functioning and the role of social support for caregivers with and without a child with Juvenile Rheumatoid Arthritis. *Journal of Pediatric Psychology*, *28*, 5-15.
- Gerschick, T. J., & Miller, A. S. (2004). Coming to terms with masculinity and physical disability. In M. S. Kimmel & M.A. Messner (Eds.), *Men's lives* (pp.349-362). London: Pearson Education Inc.
- Glaser, B. G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Mac an Ghail, M. (1996). *Understanding masculinities*. Buckingham: Open University Press.
- Mackey, W.C. (2001). Support for the existence of an independent man-to-child affiliative bond: Fatherhood as a biocultural invention. *Psychology of Men & Masculinity*, *2*, 51-66.
- Madill, A., Jordan, A., & Shirley, S. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist, and radical constructionist epistemologies. *British Journal of Psychology*, *91*, 1-20.
- Maurer, T. W. & Pleck, J. H. (2006). Fathers' caregiving and breadwinning: A gender congruence analysis. *Psychology of Men & Masculinity*, *7*, 101-112.

- McNeil, T. (2004). Fathers' experiences of parenting a child with Juvenile Rheumatoid Arthritis. *Qualitative Health Research, 14*, 526-545.
- Morgan, D. H. J. (1992). *Discovering men*. London: Routledge.
- Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care, 7*, 231-247.
- Reay, D., Bignold, S., Ball, S.J., & Cribb, A. (1998). 'He just had a different way of showing it': Gender dynamics in families coping with childhood cancer. *Journal of Gender Studies, 7*, 39-52.
- Robertson, S. (2006). 'I've been like a coiled spring this last week': Embodied masculinity and health. *Sociology of Health & Illness, 28*, 433-456.
- Sallfors, C. & Hallberg, L. R-M. (2003). A parental perspective on living with a chronically ill child: A qualitative study. *Family Systems & Health, 21*, 193-203.
- Schaffer, H. R. (1994). *Making decisions about children*. Oxford: Blackwell.
- Shaw, K. L., Southwood, T. R., & McDonagh, J. E. (2005). Growing up and moving on in rheumatology: A multi-centre cohort of adolescents with Juvenile Idiopathic Arthritis. *Rheumatology, 44*, 806-812.
- Seidler, V. J. (2006). *Transforming masculinities*. London: Routledge.
- Seidler, V. J. (2007). Masculinities, bodies and emotional life. *Men and Masculinities, 10*, 9-12.

- Smith, J. A. (1995). *Semi-structured interviewing and qualitative analysis*. In J. A. Smith, R. Harré, and L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9-27). London: Sage.
- Sullivan-Bolyai, S., Rosenberg, R., & Bayard, M. (2006). Fathers' reflections on parenting young children with type 1 diabetes. *MCN American Journal of Maternal Child Nursing*, *31*, 24-31.
- Symmons, D. P. M., Jones, M., Osborn, J., Sills, J., Southwood, T. R., & Woo, P. (1996). Paediatric rheumatology in the United Kingdom: Data from the British Paediatric Group National Diagnostic register. *Journal of Rheumatology*, *23*, 1975-1980.
- Towers, C. & Swift, P. (2006). *Recognising fathers*. Report for the Foundation for People with Learning Disabilities.
<http://www.learningdisabilities.org.uk/page.cfm?pagecode=PUUP>. Accessed 14.03.2007.
- Walker, K. (2004) 'I'm not friends the way she's friends': Ideological and behavioural constructions of masculinity in men's friendships. In M. S. Kimmel & M.A. Messner (Eds.), *Men's lives* (pp. 389-401). London: Pearson Education Inc.
- Watson, J. (2000). *Male bodies*. Buckingham: Open University Press.
- West, S. (2000). *Just a shadow: A review of support for fathers of children with disabilities*. Birmingham, UK: Hanseltrust.

Table 1

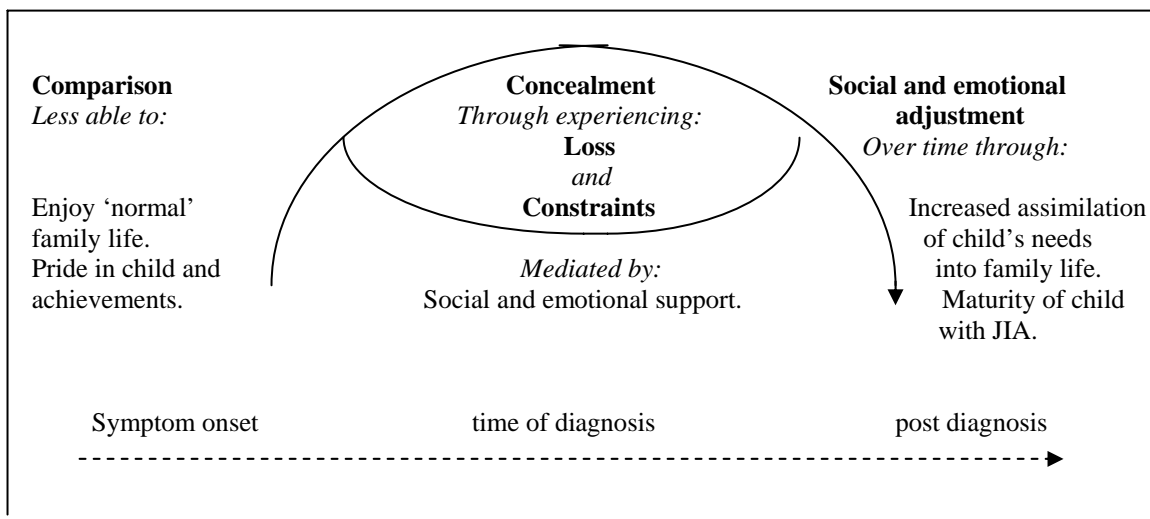
Father and JIA Child's Pseudonym, JIA Child's Age, and Other Family Members

Father's pseudonym	JIA child's pseudonym	JIA child's age at interview (years)	Child's age at onset of JIA (years)	Other family members
Edward	Luke	13.5	9	Wife and older son.
Tony	Robert	15.5	9	Wife and younger daughter.
Greg	Ben	17	9	Wife and older son.
David	Carl	18	2	Wife and older son.
Len	Debbie	14	11	Wife, older daughter and older son.
Craig	Gina	15.5	10	Younger daughter and son. His wife lived separately to the family.
Vince	Susie	16	1.5	Wife and younger son.
Michael*	Selina	18	12	Ex-wife and younger daughter. He had little contact with the family.

*This father was not interviewed but was discussed in interviews with the other family members.

Figure 1

Model Illustrating Factors Impacting Upon Social and Emotional Adjustment of Fathers who have a child with JIA



Key: **themes (bold)**, sub-themes (no bold), *type of relationship (italic)*, direction of influence → , direction of illness trajectory -->