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Amplified Ambivalence: Having a Sibling with Juvenile Idiopathic Arthritis

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ABSTRACT

Despite increased awareness of family responses to chronic illness and disability, there is still a need to understand experiences of well siblings. We begin to address this by asking “What is it like to have a sibling with juvenile idiopathic arthritis?” (JIA). Eight families with an adolescent diagnosed with JIA participated. Four members of each family, including one healthy sibling, were interviewed and transcripts analyzed using grounded theory. Analysis suggests healthy siblings see their family as different to ‘normal’ families, forfeit time with peers, share vicariously adverse experiences of their ill sibling, and feel inadequately informed. Such experiences amplify the ambivalent nature of sibling relationships and are possibly felt most strongly during late childhood and early adolescence. Support from extended family can reduce these negative experiences and facilitate social and emotional adjustment which also occurs over time as the children mature. These findings have implications for healthcare professionals and voluntary organizations.

KEY WORDS

Siblings, Juvenile Idiopathic Arthritis, Family, Childhood Disability, Chronic illness, Qualitative research.

Amplified Ambivalence: Having a Sibling with Juvenile Idiopathic Arthritis

Juvenile idiopathic arthritis (JIA) is a common childhood chronic disorder with an incidence rate within the UK (site of this research) of 1/10,000 and prevalence of 1/1,000 (Symmons, Jones, Osborn, Sills, Southwood, & Woo, 1996). Children with JIA experience disabling pain, swelling and stiffness of one or more joint as well as generalized symptoms of tiredness, weakness, and poor appetite. While evidence suggests a genetic predisposition, the aetolog(ies) remain elusive and, as yet, there is no cure. There is a growing body of knowledge on the experience of children with JIA (e.g., Barlow, Shaw, & Harrison, 1999; Shaw, Southwood, & McDonagh, 2005), however little is known about psychosocial effects on their healthy siblings. The experience of such siblings is important to understand given the children's potential to share the longest of all relationships; a relationship integrated in a family network impacting their adjustment and understanding of self and other (Dunn, 2000).

Evidence relating to JIA and siblings was sought through electronic and manual means. Meta-analyses and systematic reviews were considered as well as traditional published literature and articles were accessed through personal contact with key authors. The limited amount of research specifically relating to siblings and JIA meant some material relating to siblings of disabled children, more generally, was considered where relevant.

In their review of siblings of chronically ill children, including JIA, Sharpe and Rossiter (2002) identified predominantly negative effects. However, that such effects were reported more by parents than siblings, was interpreted as reflecting parental

sensitivity and overprotection, or alternatively, siblings' lack of awareness. Nevertheless, children are sensitive to differential treatment by parents and, when disparities are unavoidable due to chronic illness, resentment may be experienced and expressed by healthy siblings (Dunn, 2000). For example, Harding (1996) found that the emotional response of siblings could be as strong as that of their ill brother or sister and that they often felt neglected and unhappy. Moreover, Ratcliffe (2001) found that healthy siblings of disabled children will often act as carers as a way of getting noticed and loved but that they also may foster resentment. Similar findings are reported by Miller (1996) who explains how childhood disability creates a power imbalance within sibling relationships which may include a role reversal with younger children caring for their older brother or sister. In fact, Houtzager, Oort, Hoeksra-Weebers, Caron Grootenhuis and Last (2004) cite birth order and gender as influential on siblings of children with cancer and, in relation to chronic illnesses including arthritis, Silver and Frohlinger-Graham (2000) found that older sisters of males and younger sisters of both males and females displayed high levels of anxiety in comparison to matched controls of healthy siblings. However, there were no significant differences in anxiety levels noted in older sisters of chronically ill females.

Miller (1996) suggests that siblings can feel confused, angry, frustrated, isolated, and ambivalent about their disabled brother or sister due to lack of information and concern for their own vulnerability to similar illness (see also Batte, Watson & Amesss, 2006; Britton & Moore, 2002; Sloper, 2002). Indeed, Lobato and Kao (2002) found that increasing siblings' awareness of their brother or sister's disability could improve

feelings of connectedness between them and reduce problematic behavior in the well siblings. However, although not mentioned by these authors, improved behavior may also have resulted from the attention well siblings received through participating in the study which may have redressed, what they considered as, a previous imbalance.

During vulnerable developmental stages such as adolescence, siblings may also feel embarrassed by having an ill brother or sister which puts their own self-esteem at risk. For example, low self esteem was reported by Williams (1997) in her review of literature on siblings of children with chronic illness including arthritis and Britton and Moore (2002) found that siblings of children with JIA were aware of their ill sibling's adverse experiences at school and within the community, which were often not reported to parents. However, Dunn (2000) also highlights how healthy siblings can be a valuable source of support and how sibling intimacy can increase within families facing the stressful experience of a child's chronic illness and Britton and Moore (2002) offer examples of how siblings have been seen as more considerate and understanding of others due to having a brother or sister with JIA. The effects of having a sibling with JIA are, however, embedded within wider family interactions and sibling adaptation has been associated with a cohesive, expressive family environment and a positive relationship between the mother and the child with JIA (Billings, Moos, Miller, & Gottlieb, 1987). The paucity of research into the experiences of having a sibling with JIA, alongside indication of significant effects as outlined above, justified further exploration.

METHOD

The research reported here formed part of a larger study on the impact of JIA on family function. Eight families with an adolescent diagnosed with JIA participated. Four members of each family, including one healthy sibling, were interviewed about how JIA affected them and other family members. A semi-structured interview format was selected for data collection (Pidgeon & Henwood, 1996). Interviewing was chosen as a way of eliciting the participants' experiences in their own words and to gain insight into the social context of siblings' experiences (see Batte et al., 2006; Bluebond-Langer, 1996). This was also deemed important as the researchers did not wish to impose theoretical understandings on the data collection stage of the research prematurely. A semi-structured format provided direction to the interview through the use of a question schedule designed to cover issues of anticipated relevance but allowed flexibility to follow-up novel avenues raised by participants.

Transcripts of the interviews were analyzed using procedures based on grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) developed within sociology during the 1960s as way of tapping participant experience and bridging the gap between theory and empirical research in the social sciences. Researchers are required to put their preconceptions aside and to develop conceptual understandings from an inductive, thematic analysis of textual material. The aim is to produce theory of important social processes which is a product of, and answerable to, (that is, grounded in) empirical data. The grounded theory approach remains particularly popular in health-related research. Early articulation of procedures took a realist epistemology in that the researcher was

assumed to be able to be objective and that theory would ‘emerge’ from the data. Contemporary operationalization of grounded theory often utilizes a constructionist epistemology in which the process of analysis is considered interpretative and objectivity to be an inappropriate aim (Madill, Jordan, & Shirley, 2000). Instead, the researcher is challenged to reflect on the possible impact they had on the data collected and analysis performed. The aim is to produce an internally consistent, well-evidenced analysis which provides the reader with increased understanding of the area under investigation. The present study is situated within a contextualist constructionist epistemology which is the position that all knowledge is local, provisional, and situation-dependent (Charmaz, 1995; Jaeger & Rosnow, 1988). It is therefore important to describe the context of research well so that the reader can judge the possible impact on the information gleaned and for the researchers to discuss potential limits on the transferability of results.

In summary, this study used procedures based on grounded theory to analyze semi-structured interviews with eight families with an adolescent diagnosed with JIA to address the research question ‘What is it like to have a sibling with juvenile idiopathic arthritis?’

Ethical Approval

This study was approved by the Ethics Committee of the Institute of Psychological Sciences, University of (omitted for the purposes of blind peer review). Permission to approach families during voluntary work with a JIA support group was given by the group’s Regional Development Officer. Signed informed consent was obtained from all participants. Where the participant was under 16 years old, a parent

counter-signed their child's signature and a request from one participant sibling for a parent to be present, was respected.

Researchers

The first author is a lecturer in a multi-disciplinary school of healthcare. As a child she received a diagnosis of, what now would be termed, JIA. She has experience as a school teacher, has provided care for adults disabled due to arthritis, and has been a voluntary worker with JIA groups for several years. The research was guided by the second author. She is a senior lecturer in a psychology department and specializes in qualitative methodology and health-related research. Both researchers are white British nationals and both are parents.

Participants

Families were recruited for the study by the first author during voluntary work with a JIA support group situated in the North of England. Participant families were identified through including an adolescent (i.e., aged between 12 and 18 years) diagnosed with JIA who had at least one healthy sibling. The study included eight families with purposeful sampling of four male and four female adolescents with JIA (Table 1). An effort was also made to sample families with different structures. Hence, by the end of the study, one younger brother, four older brothers, and three younger sisters had been interviewed. As data collection and analysis were conducted iteratively (Glaser & Strauss, 1967), sample selection was also guided by categories emerging from analysis consistent with the principles of theoretical sampling. Hence, where possible, families were selected who had the potential to add detail to the developing analysis and/or to test

the developing theory. For example, one family with a single-parent father was interviewed to explore the extent to which the developing theory could account for this unusual family's experience. In all, 32 family members were interviewed: eight healthy siblings, eight adolescents diagnosed with JIA, eight mothers, seven fathers, and one grandmother (who supported her divorced daughter in absence of the ex-husband). All participants were white British nationals.

----Table 1 about here----

The first author informed potential participant families about the research verbally, taking care to ensure the ill child felt comfortable about their family being approached. If interested, families were offered further information by means of a letter and later telephoned to establish if family members were, in principle, willing to be interviewed. One week was left to allow consultation between family members and then a second telephone call was made to arrange interviews.

Data Collection

Semi-structured interviews were conducted in the home of each family and were audio-recorded with the consent of participants. Interviews with the healthy sibling of adolescents with JIA opened with the question: "Please can you tell me something about what it is like having a brother or sister with JIA?" This was followed by questions enquiring how having a brother or sister with JIA impacted upon their life, how they felt about this, how they perceived their future may be affected, and about any other information they considered relevant. Interviews with all but the youngest participant sibling lasted between 20 and 45 minutes. The interview with the youngest sibling (aged

9) lasted 10 minutes. Other family members were also asked how the life of siblings was affected, how they perceived the siblings felt about this, how it may impact the siblings' future life, and about any other information they considered relevant. Interviews with other family members lasted between 25 and 120 minutes. Consistent with grounded theory method, specific questions and prompts were reviewed and revised between interviews in order to best inform the developing theory. Interviews were transcribed verbatim by the first author.

Data Analysis

Transcripts of interviews with siblings and references to well siblings within the interviews of other family members were analyzed by the first author using the procedures based on contextual constructionist operationalization of grounded theory suggested by Charmaz, (1995). In general, this involved an iterative cycle of data collection and analysis; inductive creation of codes and categories from data; development of middle-range theories to explain behaviour and identify processes; sampling for theory construction rather than to represent given populations; and delay of literature review. More specifically, transcripts were scrutinized on a line-by-line basis for information relevant to the research question and meaning units (MUs) identified defined as a number of words describing the same phenomena. Each MU was awarded a title descriptive of its content. Titles were refined as later MUs were compared to earlier MUs and those with similar meaning were clustered into single categories. As coding progressed, categories with similar meaning were clustered into yet more comprehensive themes. The first author wrote memos documenting the development of the themes and

her observations and speculations about how the themes might relate to each other in a conceptual understanding of the data. These memos were used to develop an integrated model relevant to the research question. Coding and theme integration were discussed with the second author at regular intervals. This provided a forum for interrogating the basis of the evolving theory so that weak categories or themes, or links between themes, could be identified and reanalyzed.

After completion of analysis, a credibility check was conducted by an independent researcher experienced in qualitative methods. Fifteen quotes from the data corpus were presented to the independent researcher alongside the title and description of the five themes identified in the analysis. The researcher was then asked to identify which theme the quote best matched. There was 80% agreement with the coding conducted by the first author. Where there were differences (i.e., three quotes) both agreed that it depended on how the quote had been interpreted and each could understand how the other had placed the quote under a different theme. The credibility check therefore provides evidence that the basis on which the coding was conducted in this study is, at least, recognizable by others.

RESULTS

Five themes were produced from the analysis of the siblings' interview transcripts and reference made to siblings within interview transcripts of other family members. These themes are social comparison, social contagion, emotional contagion, amplified ambivalence, and social and emotional adjustment. Figure 1 illustrates how the themes were integrated in a model demonstrating the factors impacting upon siblings and how,

over time, they can achieve social and emotional adjustment to having a brother or sister who has JIA.

Through social comparison (theme 1), siblings consider their family different to other, seemingly normal, families and time is demanded of them which could have been spent doing similar things to their peers. Experience of family difference entails social contagion (theme 2) due to association with a visibly disabled brother or sister as well as emotional contagion (theme 3) through experiencing some of the distress created by JIA. Such tensions amplify the ambivalent nature of many sibling relationships (theme 4) with ambivalence and feeling different to peers greatest during late childhood and early adolescence. Support from extended family can reduce the extent to which siblings feel different from peers. Ambivalence towards their ill brother or sister was also reduced, and a greater sense of social and emotional adjustment (theme 5) achieved, over time as both children matured. A more detailed description of each theme supported by quotes now follows.

Theme 1: Social Comparison

‘Normal’ family life, as they perceived it to be experienced by peers, was used by siblings as a standard by which to evaluate their own family life and the extent to which it differed due to including a child with JIA. For example, Jack was aware that his family was seen as different, commenting that: “You always think, what are other people thinking?”. Moreover, Chris explained that: “When I see normal families and things, like my mates and their families and things, there is like the interactions between brothers

normally you know, happiness, good fun, or a fight or things like that and you know ribbing each other a bit more. But between me and Carl it is not like that at all”.

Siblings were conscious that the roles within their family differed to those of their peers. For example, twelve year old Kirsty explained that, unlike her friends, she often made her older brother’s breakfast and had to find his crutches for him when he could not walk and her father described how being denied family outings was “like a ball and chain for the well child”. However, such differences in family life were not always perceived negatively. Chris considered his family to be different because “there’s more pressure on us” but he also added that “the relationship is probably better than normal people ‘cos you’ve just got to look after him.”

The extent to which experiences of family life for siblings with a brother or sister with JIA was perceived as atypical related to issues of gender, birth order, and the age-gap between siblings. Whilst all younger brothers and sisters adopted caretaking duties for their older siblings with JIA, girls were more likely to be involved with personal care such as helping them to dress. However, older boys often cared for younger brothers in a way not normally associated with traditional male roles. For example, 19 year-old Peter continued to help lift his 13 year-old brother out of the bath and carry him downstairs as he had done since Luke was nine. The larger the age-gap between healthy siblings and their ill younger brother or sister, the fewer restrictions they experienced compared to younger, healthy siblings. For example, younger sister Kirsty described how her overnight stays with friends were restricted by her older brother’s illness; “I had set times round Robert’s trips to the hospital when I could stay with them.”

Also, the siblings felt that time was demanded of them in relation to their ill brother or sister that could have been spent doing things similar to their peers. For example, when asked if accompanying his sister on hospital visits meant missing school, 9 year-old Mat answered “Definitely!” and offered examples of times he missed school and playing out. Kirsty and Lucy often spent a number of days each week during holidays sitting in hospital waiting rooms whilst their ill sibling received treatment. Older siblings, too, gave up their time as Alex explained: “I have had to sort of stay in when it’s been like ‘Well can you stay in because Ben is in splints’ sort of thing, if they go out.” Chris mentioned a number of times that, had his brother not been ill, he could have done other things and he stated that “That gets me a little bit thinking that it’s not really fair.”

Theme 2: Social Contagion

Siblings were subjected to a form of social contagion during childhood and early adolescence as they received adverse treatment from peers due to being associated with someone who was different: “It was like ‘Oh Alex, Ben’s brother, you know ‘Ner, ner, ner, ner, ner,’ as if they were having a go at me as well”. However, the siblings could never quite predict peers’ responses. Kirsty reported variable reactions: “Well sometimes ‘poor you’ and sometimes ‘ha, ha’ because we have fallen out.”

All the siblings experienced a feeling of social contagion through having a visibly different brother or sister. For example, Lucy explained that people would stare at her sister because she “walked funny” which meant that when they were together it felt as if they were staring at her too. Her mother also described how children at school would use her sister’s physical difference as a taunt to hurt Lucy by “going round saying your

sister's a spastic and stuff like that." Age appeared an influential factor on how siblings felt about being seen with their visibly different sister or brother. The experience of Chris and Lucy suggest that during late childhood and early adolescence siblings' status within their peer group was affected by being linked to visible disability, particularly when schools and peer groups were shared with their ill sibling. In contrast, those who were older by a larger age gap, such as Peter and Jack, felt little impact on their social lives. However, comments from other family members hinted that Peter and Jack did not talk to friends or workmates about their sibling's illness. This suggests that even they experienced, or feared that they would experience, some social contagion related to their sibling's disability.

Also, spending time at hospitals, knowing something of their brother or sister's condition and treatments, and witnessing their pain and distress meant that all interviewed siblings had developed a vicarious medical career: "He had to go to hospital a lot. I mean I could have done without that a lot in my life... I hate going to hospitals and things" (Chris). However, siblings were not always aware of what was happening, particularly during medical visits. For example, Kirsty mentioned that "He would never let me go in. I always sat in the waiting room". Even so, siblings sometimes witnessed distressing events. For example, Mat's mother described his anger and distress, when as a toddler, he witnessed his sister's joints injections and heard her "scream blue murder".

Theme 3: Emotional Contagion

As well as their own concerns for their ill sister or brother, siblings witnessed the distress of other family members, but could do little to help. Such experiences, combined

with the unpredictability of flare-ups associated with JIA, lack of understanding and even a fear of a proness to such an illness (for example, Chris's mother explained that he was terrified of getting arthritis), meant that siblings often felt angry and frustrated. For example, Chris expressed the sentiment that "Maybe I'd be a happier person if Carl was normal" and Jack explained that "You get a bit wound up about it."

All siblings expressed concern at seeing their brother or sister in pain and distress. For example, Kirsty said: "It's quite hard, yes, especially when it is hurting" and Lisa felt embarrassed for her sister who had to attend hospital clinics geared towards young children: "They had like blackboards and play stations and stuff rather than like you were a teenager they could have had like magazines and things." Jack expressed concern at his sister's continued school absence and Lucy understood only too well the bullying her sister received there: "I feel like it shouldn't be happening to her, that she is still a normal human being like everybody else, so she shouldn't get treated badly." All except Mat (the youngest sibling interviewed) knew their mother got very upset and felt their father was equally hurt but did not always show it. For example, Lucy said: "I think he feels awful when she (her sister) is crying because it is as if he has made her start crying." In response, they tried to avoid causing parents any further concern as "You don't want to give too much headaches to your mum and dad because they have got too much already." (Chris). However, the stress was contagious and Lucy's mother confided that her daughter "has got a temper now through her, 'cos she has got it off her. She used to be right quiet did our Lucy 'till our Gina got this."

Theme 4: Amplified Ambivalence

Healthy siblings were often placed in a position of competing with their ill brother or sister for parental time and affection, and yet felt concern and affection towards their ill sibling. They praised but also, in some cases, blamed and resented their ill sibling. For example, Lisa was very upset at seeing her sister in pain, but had also “freaked out” at her grandmother’s house saying her sister had “faked” it for attention. Siblings with JIA were physically and emotionally dependent on their brothers and sisters and Kirsty’s mum explained that her son dare not upset his sister in case she let go when pushing his wheelchair. On the other hand, the ill sibling had greater power in terms of parental protection. Such power dynamics were influenced by age, gender and birth order.

Younger brothers and sisters had greater power over their older, ill sibling in comparison to their peers but also had to take on additional caretaking and advocacy duties. Older brothers and sisters already had a degree of power due to age but had to limit the extent to which they used physical force to resolve disputes in comparison to their peers who had younger, well siblings, particularly those with younger brothers.

All participant siblings displayed a strong sense of what a good brother and sister should be. For example, Lucy said: “you are meant to help your brothers and sisters out.” They acted as social advocates and protectors, bringing friends home to play because “no people play with her around here” (Lucy) and offering support when there was trouble with peers: “had to step in and say ‘ hey, give it up’ you know” (Alex). However, ambivalence was still evident, and even Alex described occasions when “I was not going to stand up for him because a) he will never learn and b) why should I in a way?”

Nevertheless, siblings conveyed a strong sense of pride at how their brother or sister with JIA overcame some of their adversities.

To a greater or lesser degree all siblings reported some compensations in having a brother or sister with JIA. For example, Lucy and her younger brother received a television from family members when their ill sister was given one from a charity and Mat's mum described making sure he had extra treats. Siblings also reported that their family was closer due to their sister or brother's illness. For example, Lucy said: "I think it makes us closer because we help each other and mostly stay around each other."

Comments made by siblings, and other family members suggested that siblings experienced some form of inequitable treatment, particularly in terms of parental time. For example, Chris said "When my brother is bad they concentrate on how Carl is and stuff". There was also an onus on brothers and sisters to control their behavior towards their ill sibling. For example, Chris said that he had been told "from a young age being like told not to hit him or not to do this or do that" and Mat's mum explained how he had had to learn not to hug his sister's legs, hold her hand too tightly, or sit on her lap because it hurt her. At the same time, siblings often bore the brunt of their ill brother or sister's distress and Lucy's parents described how her ill sister would hit out at her and other family members with her crutches.

Also, siblings expressed some negative feelings about their ill brother or sister, although they often tried to hide these from their family. Whilst Alex's mother did not think he resented or disbelieved his ill brother, Alex actually described how he became annoyed because he "puts it on sometimes". However, given the unpredictable nature of

JIA, siblings could never be sure just how ill their brother or sister was and Alex added that “It makes you feel guilty, but it doesn’t help when he uses it sometimes and not others.” Lisa and Lucy often resented the fuss made by their ill sisters. Lucy explained that “I feel as if she is over-reacting and she shouldn’t be acting like that” and Jack admitted thinking that his sister may possibly use her illness to avoid school. Kirsty, also felt her brother over-reacted to gain attention and described being interrupted to help him: “Quite few a times my mum or dad will say ‘Kirsty go and do this for your brother’ and I’m busy doing my homework or something like that and I have to get up and do it.”

Theme 5: Social and Emotional Adjustment

Support from the extended family, particularly grandparents, buffered some of the adverse effects of having a brother or sister with JIA. However, siblings appeared more accepting of their family situation, and were able to maintain a sense of self-identity independent of their family, over time as their own maturity increased as did that of their ill brother or sister.

Relatives redressed some of the imbalance created by differential treatment of well and ill siblings, particularly in the cases of Lisa, Lucy, Jack and Peter and Chris. For example, Lisa’s aunt provided shopping trips and Lucy’s uncles and cousins provided practical support. Grandparents, in particular, played a key role in supporting siblings and Lucy, Lisa and Chris spent considerable time in the care of their grandmothers. Lucy’s grandmother provided sleepovers for her ill sister and accompanied her on some hospital visits which meant that Lucy and her younger brother spent less time in hospital waiting rooms and had some respite from their caretaking and social advocacy roles. Lisa could

relieve some of the pressure of having an ill sister by “freaking out” at her grandmother’s home. Similarly, Peter was able to spend more time with his parents when his grandparents temporarily took over the care of his ill brother. However, no such help had been available for Kirsty, Alex or Mat and their parents mentioned how useful it would have been to have had supportive grandparents living close by.

As siblings matured they were more able to accept and respond appropriately to the emotional and social impact of having a brother or sister with JIA. In early childhood, siblings responded by offering practical help when it suited them. For example, Mat’s parents explained how, when younger he had willingly “fetched and carried” for his older sister but at nine years old was less accommodating. By late childhood/early adolescence siblings appeared to be struggling with conflicting emotions in response to having an ill sibling with Kirsty’s ill brother explaining that she was “jealous, sad and angry all at the same time”. However, he also thought that “it will be a lot easier for her to understand when she is older.” Similarly, Peter said: “I feel a bit different about it now. I have understood it more. Because I know what the problem is then it is a lot easier to understand and help.” The increased maturity of the ill sibling was also influential. Jack explained the assimilation of his sisters’ illness into family life was: “because she is growing anyway and getting older” and Peter said that his improved relationship with his brother was because: “I am a bit older and he is a bit older now.”

-----Figure 1 about here-----

DISCUSSION

This study used procedures based on grounded theory to analyze interviews with eight families with an adolescent diagnosed with JIA to address the research question ‘What is it like to have a sibling with juvenile idiopathic arthritis?’ Analysis suggests that the healthy siblings taking part in our study see their family as different to ‘normal’ families, forfeit time with peers, share vicariously some adverse experiences of their ill sibling, and feel inadequately informed. Such experiences amplify the ambivalent nature of many sibling relationships and were, possibly, felt most strongly during late childhood and early adolescence. Support from extended family can help reduce these negative experiences and facilitate social and emotional adjustment which also occurs over time with increased maturity of the healthy sibling and child with JIA. Each theme described in the results section is now discussed in relation to the wider literature.

Social Comparison and Social Contagion

Healthy siblings viewed their family relationships in terms of their wider social experiences and judged themselves in relation to peers in ‘normal’ families (see also Dunn, 2000). The sense of belonging to a family which was ‘different’ was felt particularly keenly by siblings as they developed towards adolescence, and greater independence, as their self-esteem was still influenced by their family background. Hence, the stigma of visible disability was experienced as socially contagious as siblings felt they were associated with their disabled brother or sister and judged negatively by peers. This finding is consistent with Miller’s (1996) observation that, in families with a disabled child, shared social experiences impact on the self-esteem of well children,

particularly during adolescence and between same sex siblings. Social contagion meant that well siblings could feel 'out of place' in relation to their peers. They also risked being 'out of time' due to the vicarious medical career they sometimes had to adopt when living with, and assisting, an ill sibling as this involved responsibilities often beyond their years. Our interpretation that siblings may feel 'out of place and out of time' is compatible with examples offered by Britton and Moore (2002) in relation to JIA, and Batte et al. (2006), Dunn (2000), Harding (1996), and Ratcliffe (2001) with regard to chronic childhood illness more generally.

Emotional Contagion

Siblings were found to be more aware, often, than parents of their ill brother or sister's adverse social experiences (see also Batte et al., 2006; Dunn, 2000) and to be distressed on their sibling's behalf. This supports Harding's (1996) assertion that siblings can be as emotionally affected as the ill child and concerned that they, themselves, may be susceptible to JIA. Batte et al. (2006), Britton and Moore, (2002), Miller (1996), Ratcliffe (2001), and Sloper (2000) also found that siblings of disabled children worry about their own vulnerability, particularly when they have been given little information, and rely on what they have overheard and have imagined.

Amplified Ambivalence

The key finding of our study is that the ambivalent nature of many sibling relationships, described by Dunn (2000), was very notable within our sample of families. In comparison to their peers, the siblings were perceived to face greater tensions in their relationship with their ill brother or sister. They had to cope with competing emotional

demands; modifying their behavior in response to the obvious distress of their sibling whilst experiencing the reasonable desire to have their own needs met. Moreover, having a sibling with JIA meant that there could be a role reversal with younger children caring for their older brother or sister. Well children could be placed in the paradoxical position of having considerable power over their ill sibling while, at the same time, used as a scapegoat for their pain and frustration. Such findings confirm those of Miller (1996), Ratcliffe (2001), and Sloper (2000) on the role reversal and power imbalance in such relationships.

Stalker and Connors (2004) stress the positive views expressed by siblings of disabled children as a contrast to the pathological nature of such experiences reported in some previous research. And our participant siblings were aware that they received some, if few, compensations for having a brother or sister with JIA. Parents and other family members attempted to redress imbalances in attention and some siblings reported having closer family relationships due to illness (see also Britton & Moore, 2002; Sloper, 2000). However, Miller (1996) suggests that the ambivalent and unresolved feelings of siblings of ill children are not always recognized by parents. We found that, whilst siblings sometimes denied adverse experiences, their parents could offer many examples. This is also reported by Sharpe and Rossiter (2002) who suggest that parents may be being over protective of their children. However, our findings suggest that siblings may, indeed, be reticent to admit negative experiences and try to appear to cope in order to protect other family members (see also Ratcliffe, 2001; Sloper, 2000).

Social and Emotional Adjustment

Our study suggests that sibling vulnerability to amplified ambivalence and their associated social and emotional adjustment can be mediated by extended family support. The need to keep siblings better informed has been stressed consistently in previous studies (e.g., Batte et al., 2006; Houtzater, 2004; Sloper & While, 1996) and, in relation to JIA, Britton and Moore (2002) note that parents often had little time to keep siblings informed of the ill child's progress. Our findings suggest that the extended family could play a valuable role here. Grandparents, in particular, could help meet some of the siblings' needs, particularly as Spinetta and Deasy-Spinetta (1981) point out that, even during their sibling's healthy periods, well children may still miss out as their parents try to catch up with other neglected duties. We also found that siblings' acceptance of their family situation and ability to create and maintain an independent sense of self developed over time with increased maturity of both the sibling and child with JIA. This finding is compatible with Miller's (1996) suggestion that sibling experiences be seen as a continuum moving from positive to negative at different times during the developmental trajectory of the sibling and their ill brother or sister.

Implications for Practice

Findings from this study have implication for practice as healthcare professionals could benefit from greater awareness of siblings' experience as they are often brought to hospital consultations and can be involved intimately in caring for their brother or sister from a young age. Our participant siblings expressed a desire for greater information (see also Batte et al., 2006; Houtzager et al., 2004; Sloper, 2000) and through providing this

healthcare professionals and voluntary organizations could help minimize sibling distress. This is particularly important as Barlow and Ellard (2004) found no psycho-educational interventions for siblings of children with JIA although studies demonstrate the usefulness of such interventions in relation to other chronic conditions and disorders (Lobato and Kao, 2002 and Williams et al., 2003). However, timing of information may be important as Barlow and Ellard (2004) identified particular vulnerable periods in the trajectory of children with chronic illness, such as when a diagnosis is given. This may also apply to their siblings along with the increased sensitivities experienced around early adolescence identified in the present study. The particular vulnerability of siblings during adolescence suggests a need to seek further understanding of appropriate support which can be offered at such times, particularly for those who do not receive it from the extended family.

The tentative nature of findings from this study are appreciated, particularly given that it is situated within a contextualist constructionist epistemology which admits knowledge to be local, provisional, and situation-dependent. It is therefore important to discuss potential limits on the transferability of results. The small sample group means that we cannot claim our findings to be representative of the wider population of families with JIA. However, our sample size included family members as well as siblings and is typical of qualitative research which seeks to keep a sense of the ‘whole picture’ while being sensitive to the experience of individual participants. Moreover, available participants were selected using a mixture of purposeful and theoretical sampling to enhance the detail of the model and test the appropriateness of interpretations. Such

procedures should enhance the transferability of findings (Banister, Burman, Parker, Taylor, & Tindall, 1995). Future research could sample participants to consider more thoroughly the implication of age, gender, and birth order and use a wider geographical area (including regions or countries subject to different healthcare systems) as well as including diverse ethnic groups.

Interviewing multiple members of the same family (as recommended by Ellis, Upton, & Thompson, 2000) offers a potentially comprehensive view of siblings' experiences as some of the issues siblings may have been reticent to articulate were hinted at, or described, from the perspective of other family members. However, it is appreciated that there are unavoidable social processes involved in the act of 'doing an interview' (Potter & Hepburn, 2005). The interviewer (first author) is much older than the young people who participated in this study and may have been perceived by them as a figure of authority and/or, at the very least, an outsider. Given this, siblings and their ill brothers and sisters appeared reasonably forth-coming, and some expressed appreciation of the opportunity to 'tell their story'. Nevertheless, it is possible that the first author read some of her own experiences of JIA into the analysis and that both authors viewed the data through their own experiences as parents and as siblings. However, the credibility check demonstrated that the themes could, at least, be evidenced by the data.

In conclusion, this study suggests that siblings of those with JIA experience amplified ambivalence and we highlight the importance of extended family support and information from health providers and voluntary organizations in minimizing the negative impacts of this on siblings' social and emotional development.

References

- Banister, P., Burman E., Parker, I., Taylor, M., & Tindall, C. (1995). *Qualitative methods in psychology: a research guide*. Buckingham: Open University Press.
- Barlow, J.H., Shaw K.L., & Harrison, K. (1999). Consulting the 'experts': Children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research: Theory & Practice*. **14**, 597-610.
- Barlow J. H., & Ellard, D.R., (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child: Care, Health & Development*. **30**, 637-645.
- Batte, S., Watson, A.R., & Amess, K. (2006) The effects of chronic renal failure on siblings. *Pediatric Nephrology*. **21**. 246-250.
- Billings, A.G., Moos, R.H., Miller, J.J., & Gottleib, J.E. (1987). Psychosocial Adaptation in Juvenile rheumatic Disease: A Controlled Evaluation. *Health Psychology*. **6**, 343-359.
- Bluebond-Lagner, M. (1996) *In the shadow of illness: parents of the chronically sick child*. Princeton: Princeton University Press.
- 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., *Qualitative Research, Reflexivity and Context*. In Murray, M. (Ed.) (1995) *Rediscovering Methods in Psychology*. London: Sage.
- Dunn, J. (2000). State of the art: Siblings. *The Psychologist*. **13**, 244-248.
- Ellis, N., Upton, U., & Thompson, P. (2000). Epilepsy and the family: a review of current literature. *Seizure*. **9**, 22-30.
- Glaser, B. G., & Strauss, A.L. (1965). *Awareness of dying*. Chicago: Aldine.
- Glaser, B. G., & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine.
- Harding, R. (1996). Children with cancer: the needs of siblings. *Professional Nurse*. **11**, 588-590.
- Houtzager, B.A., Oort, F.J., Hoeksra-Weebers, J.H.M., Caron, H.N., Grootenhuis M.A., & Last, B.F. (2004) Coping and family functioning predict longitudinal psychological

- adaptation of siblings of childhood cancer patients. *Journal of Pediatric Psychology*. **8**,591-605
- Jaeger, M. E., & Rosnow, R.L. (1988). Contextualism and its implications for psychological inquiry. *British Journal of Psychology*. **79**, 63-75.
- Lobato, D. J., & Kao, B.T. (2002). Integrated Sibling-Parent Group Intervention to Improve Sibling Knowledge and Adjustment to Chronic Illness and Disability. *Journal of Pediatric Psychology*. **27**, 711-716.
- 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.
- Miller, S. (1996). Living with a disabled sibling: A review. *Paediatric Nursing*. **8**, 21-23.
- Pidgeon, N. & Henwood, K. (1996). Grounded Theory: practical implementation. In J.T.E. Richardson (Ed.). *Handbook of Qualitative Research Methods*. Leicester: BPS Books.
- Potter, J., & Hepburn, A. (2005). Qualitative interviews in psychology: Problems and possibilities. *Qualitative Research in Psychology*. **4**, 281-307.
- Ratcliffe, J. (2001). *Listening to Siblings*. Birmingham: Hansel Trust Publications.
- Sharpe, D., & Rossiter, L. (2002). Siblings of Children with a Chronic Illness: A Meta-Analysis. *Journal of Pediatric Psychology*. **27**, 699-710
- Shaw, K. L., Southwood, T.R, & McDonagh, J.E. (2005). Growing up and moving on in rheumatology: a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Rheumatology*. **44**, 806-812.
- Silver, E. J., & Frohlinger-Graham, M.J. (2000). Brief Report: Psychological Symptoms in Healthy Female Siblings of Adolescents With and Without Chronic Conditions. *Journal of Pediatric Psychology*. **25**, 279-284.
- Sloper, P. & While, D. (1996) Risk factors in the adjustment of siblings of children with cancer. *Journal of Child Psychology and Psychiatry and Allied Disciplines*. **37**. 597-607.
- Sloper, P. (2000) Experiences and support needs of siblings of children with cancer. *Health and Social care in the Community*. **8**. 298-306.
- Spinetta, J. (1981) The sibling of the child with cancer. Spinetta, J. & Deasy-Spinetta, P., (Eds.) 133-142. Mosby: St. Luis.

Stalker, K., & Connors, C. (2004). Children's Perceptions of Their Disabled Siblings: 'She's Different but it's Normal for Us.' *Children & Society*. **18**, 218-230.

Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. Second edition. London: Sage Publications.

Symmonds 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**, 1975-80.

Williams, P. D. (1997) Siblings and pediatric chronic illness: a review of the literature. *International Journal of Nursing Studies*. **34**. 312-323.

Williams, P.D., Williams, A.R., Graff, J.C., Hanson, S., Stanton, A., Hafeman, C., Liebebergen, A., Leuenberg, K., Setter, R.K., Ridder, L., Curry, H., Barnard, M., and Sanders, S. (2002) Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability *Journal of Behavioural Medicine*. **25**. 411-424.

Williams, P.D., Williams, A.R., Graff, J.C., Hanson, S., Stanton, A., Hafeman, C., Liebebergen, A., Leuenberg, K., Setter, R.K., Ridder, L., Curry, H., Barnard, M., and Sanders, S. (2003) A community-based intervention for siblings and parents of children with a chronic illness or disability: the ISEE study. *Journal of Pediatrics*. **143**. 386-393.

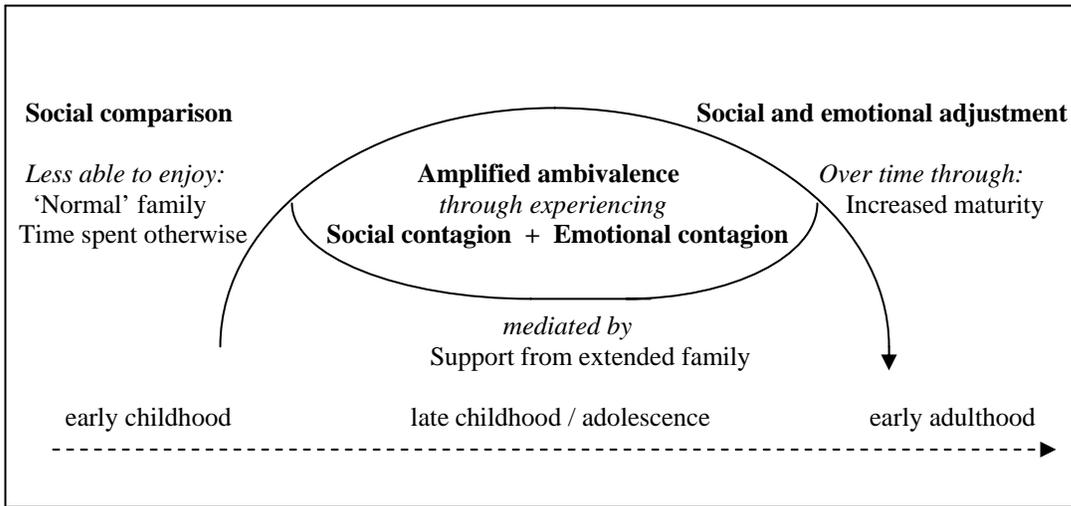
Table 1

Pseudonym and Age of Siblings and their Relationship to JIA Adolescents

Sibling's pseudonym	Age at interview (years)	Relationship to child with JIA	Pseudonym of child with JIA	Age gap (years)	Sibling's age at JIA onset (years)
Mat	9	Younger brother	Susie	7	Birth
Peter	19	Older brother	Luke	5.5	13
Chris	20	Older brother	Carl	2	4
Alex	20	Older brother	Ben	3	12
Jack	24	Older brother	Debbie	10	19
Kirsty	12	Younger sister	Robert	3.5	7
Lucy	12	Younger sister	Gina	3.5	7
Lisa	13	Younger sister	Selina	5	7

Figure 1

Model Illustrating Factors Impacting Upon Social and Emotional Adjustment of Siblings whose Brother or Sister has JIA



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