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Article:

Waite-Jones, JM orcid.org/0000-0003-3996-5371, Swallow, V orcid.org/0000-0001-8504-4704 and Madill, A orcid.org/0000-0002-9406-507X (2020) From ‘neurotic’ to ‘managing’ mother: The ‘medical career’ experienced by mothers of a child diagnosed with Juvenile Idiopathic Arthritis. British Journal of Health Psychology, 25 (2). pp. 324-338. ISSN 1359-107X

https://doi.org/10.1111/bjhp.12409

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RUNNING HEAD: NEUROTIC TO MANAGING

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Accepted for publication in **British Journal of Health Psychology** 13th February 2020

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From ‘neurotic’ to ‘managing’ mother: The ‘medical career’ experienced by mothers of a child diagnosed with Juvenile Idiopathic Arthritis

Abstract

Objective: Despite increased research into how caring for a child diagnosed with Juvenile Idiopathic Arthritis (JIA) affects mothers, more needs to be known about ways in which such experiences transform their lives. Insight into the experiences of such mothers was sought through analysis of interviews with eight mothers and one father caring for a child with JIA.

Design: The study is situated within a larger project involving families with a child with JIA. A social constructionist approach was adopted and grounded theory including a ‘negative case,’ guided gathering and analysing data. Individual, semi-structured interviews were conducted based on the research question: ‘What is it like to be the mother of a child with juvenile idiopathic arthritis?

Results: Findings suggest that, mothers find difficulty living up to the ‘ideal mother’ expected within Western society when forced to provide competing demands of age related, yet illness relevant care. The unpredictable nature of JIA means mothers face a lack of understanding from professionals so become hyper-vigilant, ‘battling’ on behalf of their ill child. A self-perpetuating loop develops if this is misperceived as being over-protective, leaving mothers vulnerable to being judged ‘neurotic’. However, with experience, often at an emotional cost, such mothers’ confidence in managing the competing demands of caring for their ill child increases such they can navigate a positive journey from ‘neurotic’ to ‘managing’ mother.

Conclusions: Understanding this process could help healthcare professionals reduce stressful experiences faced by mothers when caring for a chronically ill child.

KEYWORDS: motherhood; childhood chronic illness and disability; medical career; juvenile idiopathic arthritis; qualitative research.

From ‘neurotic’ to ‘managing’ mother: The ‘medical career’ experienced by mothers of a child diagnosed with Juvenile Idiopathic Arthritis

Introduction

Mothers of a chronically ill child, such as with Juvenile Idiopathic Arthritis (JIA), are often diagnosed with anxiety and depression (van Ooers, Haverman, Limperg, van Dijk-Lokkart, Maurice-Stam, & Grootenhui, 2014), feel ‘chronic sorrow’ (Coughlin & Sethares, 2017) and experience ‘surplus suffering’ through negative experiences within the healthcare system (Livermore, Eleftheriou, & Wedderburn, 2016). In order to understand their experiences, we present an analysis of interviews with eight mothers of children with JIA and with one husband who is the main-carer of the couple’s children.

We focus on caring for a child with JIA as, in many ways this is a typical chronic illness of the relapse-remitting type in which the severity of symptoms can vary over time in an unpredictable manner. JIA is characterized by inflamed joints, pain, limited mobility, delayed physical development (Moorthy, Peterson, Hassett & Lehman, 2010), often continues into adulthood (Selvaag, Aulie & Lilleby, 2016), and can lead to permanent disability. Similar to the experience of families of children with other chronic illnesses, learning that their child has JIA can be a huge shock for parents given the often protracted period between symptom onset and diagnosis and which may have involved multiple diagnoses and medical interventions. Moreover, as with, other relapse-remitting forms of chronic illness, the often invisible and unpredictable symptoms of JIA can leave parents feeling guilty for not having recognised their child's difficulties earlier (Livermore et al., 2016). Chausset, Gominon, Montmaneix, Echaubard, Guillaume-Czitrom et al., (2016) describe the experience of such families as living 'disease driven' lives, hovering between 'sick and not sick' and resulting, often, in a loss of confidence in healthcare professionals.

Although fathers are affected by, and involved in the care of, their chronically-ill child (*reference omitted for blind peer review*), mothers are usually the main-carer, responsible for monitoring, preparing and administering treatments (Venter, 2011). Ideals of motherhood within northwest European, broadly Anglophone, cultures include the expectation of supporting their children towards independence by early adulthood (Hays, 1996; Williams, 2002). This ideal may be difficult to fulfil for the mother of a chronically ill child, and Yuwen, Lewis, Walker, and Ward (2017) report how such mothers often feel helpless and judge themselves to be a 'bad parent' who is responsible for their child's condition and medical side effects. Moreover, being the main-carer of an ill child can reduce opportunities for the mother to meet her own needs, and those of other family members (Ryan, Mullins, Ramsey, Bonner, Jarvis et al., 2013) and intensify the relationship with her ill child - not only for the better (Knafl, Leeman, Havill, Crandell & Sandelowski, 2015).

Having a chronically ill child impacts the working lives of both parents, but, as main carers, mothers more often reduce their paid hours or withdraw from the labour market. Cunningham- Burley, Backett-Milburn, and Kemmer (2006), for example, identify the conflict between the roles of 'mother as carer' and 'mother as earner,' with working mothers striving to store up good will and a good reputation at work in preparation for absences if their child is ill. Moreover, the additional marital strain of caring for a chronically-ill child often results in divorce and a predominance of single-mother-led families with these women, therefore, more likely to be scrutinized by professionals (Venter, 2011). Hence, it is important to appreciate the role of mothers when their child has a chronic condition such as JIA.

Mothers vicariously and, on occasion, literally share many of their child's illness experiences and may follow the same trajectory of constant adjustment, required by those diagnosed with a chronic condition (Moss-Morris, 2013). Moreover, after struggling with their child's initial symptoms and diagnosis, many mothers acquire skills and knowledge normally associated with that of healthcare practitioners, such as drug administration and exercise supervision, to manage their child's chronic symptoms and flare ups (Mulligan et al., 2013). They also negotiate the operationalisation of interventions in response to illness stage and phase, as well as balancing the needs of others within the family (Knafl et al., 2015). A mother's journey may also involve relinquishing career plans and as well as accepting this unanticipated, unpaid 'medical career' involving long hours, medical upskilling, and intense emotional work.

To gain insight into how caring for a child with JIA impacts on the lives of mothers we address the research question: What is it like to be the mother of a child with juvenile idiopathic arthritis?

Materials and Method

Ethical Approval

The study was approved by the University of (*omitted for the purposes of blind peer review),* School of Psychology Ethics Committee and permission received from a relevant national charity to approach mothers and their families. Participants gave signed informed consent.

Researchers

All researchers are white British nationals and mothers with personal and professional experience of the impact of chronic childhood illness on family life. The first author experienced juvenile arthritis herself and has worked with families of children with JIA in a professional capacity. She is also an experienced qualitative researcher. The second author's professional experience of child and family nursing, and related research, provides us insight into how the current study relates to extant research on mothers of children with chronic illness. Research rigour was facilitated by the third author's extensive experience of qualitative inquiry, personal experience of chronic illness, and experience as a mother of a child with a medical condition**.**

Recruitment and Participants

The present study is situated within a larger project in which interviews were conducted with four members of eight families with a child with JIA (32 participants in total, including mothers, fathers, siblings and ill children: *citations omitted for the purpose of blind peer review*).

Purposive sampling for participant diversity was utilized commensurate with the procedures of grounded theory (Glaser & Strauss, 1967). Participants were recruited by the first author during information days run by a voluntary group in the North of England which supports families of children with arthritis. Eight families including an adolescent diagnosed with JIA for more than three years, (four males and four females), at least one sibling and parents were identified and all agreed to take part in the study. Adolescents were selected as their families were most likely to have experienced the impact of JIA over a lengthy period of time. An equal number of male and female adolescents with JIA were sought. After individual interviews with the first two families (with one male and one female adolescent with JIA), specifically analysis-informed theoretical sampling was undertaken iteratively with analysis to recruit families with whom we could explore the impact of specific contexts such as family structure.

As analysis of the experiences of fathers and siblings has been reported previously (*see omitted for blind peer review*), the sample reported in this article consists of eight mothers of a female or male adolescent with JIA aged between 13 and 18 years old and the husband of one mother. All participants were white British nationals. Six mothers were from two-parent families of varying composition and one was from a mother-led single parent household. The final mother and her husband had previously spent considerable time living apart and the husband was the main-carer of their children. Given the relatively long interviews and depth of the analysis, nine interviews is considered sufficient data (Baker & Edwards, 2012). Given the length and richness of the interviews it was possible to pursue a number of themes (here, 'neurotic mother') until saturation was achieved: that is, analysis of the final two or three interviews with mothers provided no further substantial detail.

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

Data Collection

Potential participants were sent a letter detailing more about the study and then contacted by telephone to ask about their willingness to participate and to provide an opportunity to ask questions. Arrangements for interview were made through a second telephone call a week later to allow time for reconsideration. An individual, semi-structured interview format was used (Smith, 1995) consisting of questions and prompts considered relevant to addressing the research question. However, this was used flexibly to ensure that the interview was directed as far as possible by the participant. Interviews took place in the participant's home and commenced with the question: 'Please tell me something about what it is like having a child with JIA?' They were then asked how a child with JIA impacted their life, how they felt about this, how they saw the future, and to offer any other relevant information. Questions and prompts were reviewed and revised between interviews. One interview lasted 30 minutes and the others were between one and two hours. The first author transcribed audio-recorded interviews verbatim ensuring that participants were given pseudonyms.

Data Analysis

Interview transcripts were analysed using procedures based upon constructionist version of grounded theory whereby conceptual understandings are developed from an inductive, thematic analysis of textual material (Charmaz, 2006). This iteration of grounded theory was selected in order to acknowledge the impact of context, as well as of the personal experiences of mothers of children with JIA. Grounded theory is based on symbolic interactionism which posits that people seek to co-ordinate their actions with those of others with respect to contextually-relevant social roles. Originally grounded theory was developed within a realist epistemology in which theory is considered to ‘emerge’ relatively directly from data (Glaser & Strauss, 1967). In contrast, Charmaz’s (1995) social constructionist version, views analysis to be an interpretation of the data, while answerable to it, and potentially transferable to similar, carefully proscribed, contexts. In general the process involved: iterative collection and analysis of data; development of codes, categories and themes; the creation of a middle-range theory to explain relevant social processes; memoing to explicate and complete themes; theoretical sampling to test, check and refine concepts; and Strauss and Corbin’s (1990) method of negative case comparison.

The first two transcripts were scrutinized by the first and third author and meaning units (MUs) identified which appeared to describe relevant phenomena. Each MU was ascribed a label which described its content which was refined iteratively when compared to other MUs. MUs with related meaning were then clustered into themes. Memos were created which documented developing themes, potential relationships between themes, observations and speculations. Themes were identified and agreement reached on what could be investigated further.

Subsequent transcripts were subjected to the same analytic procedure, with the researchers reviewing findings and memos after analysis of each transcript and jointly agreeing directions for future exploration.

On completion of the thematic coding, an independent healthcare researcher with past experience of family nursing and qualitative research methods undertook a credibility check. She was provided with 15 quotations from the data alongside the title and description of the five themes identified and asked to link the quotations to a theme. There was an excellent 93% agreement between the independent researcher and the original coding. The quotation that differed was acknowledged to sit comfortably within either of two themes. Through discussion and scrutinizing of written material between authors, a model addressing the research question was developed. The model was noted to fit all but one of the mothers – Dawn who was distinct from other mothers interviewed in having spent some time previously living apart from her family. The opportunity was therefore taken to re-analyse the interview of her husband, Craig, as a deviant case test of the genderedness of the model.

Results

Five themes were identified: social comparison, role conflict, battles, hypervigilance misperceived as 'neurotic,' and socially- and emotionally-adjusted 'managing' mother. These themes suggest that main-carer mothers of children with JIA experience a medical career from 'neurotic' to 'managing' mother. This career commences with the perception of being different from mothers of healthy children in terms of being less able to promote their child's independence and suffering role conflict through feeling unable to fulfil the needs of other family members. They find themselves 'battling' with health professionals, the 'hyper vigilance' necessary for the care of their child, making them vulnerable to being perceived as 'neurotic.'

Over time, through assimilation of the ill child's needs into family life, and increased confidence in their ability to act as their child's advocate, mothers come to inhabit a more positive identity as a socially-and emotionally-adjusted 'managing' mother.

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

Theme 1: Social Comparison

Through comparison with mothers of well children, participants felt they were less able to promote physical, social and emotional independence in their child. This is clearly stated by Pauline who said '*natural progression has halted and it has sort of flipped. It has gone back. It is measured by what you do and what you don't do for your kids as you gradually move away from doing everything for them'.* All described having to help dress, bath and sometimes toilet their children, even during adolescence. For example, Dawn explained that '*We have to put her knickers and trousers on and then she lifts them up'*. However, Sheila pointed out how hard it became to offer such care: '*When they are little you can carry them but when they get to seventeen and you cannot move. It is not that simple*.'

Just as the women compared themselves to other mothers, Craig judged his abilities in relation to fathers of well children. However, he appeared to see housework as his primary concern in contrast to the mothers who prioritised the care of their ill child. On the other hand, he did echo the mothers' complaint that the other parent had made less sacrifices: '*It hasn't really affected Dawn 'cos she still goes to work'*.

Theme 2: Role Conflict

The mothers reported role conflicts they faced in terms of caring for their ill child. Conflicts involved trying to be also a good mother to their other children, a good partner, and maintaining a career and contributing to the family income. Carole explained: '*I was being pulled into many* *different directions because I would have Vince- not making demands but he would be working anything up to twelve hours a day and he would come home and want a meal on the table. Then of course Mat would want sorting out or Susie would want this or that'.*

To be a 'good mother' to their ill child could mean feeling 'less than a good mother' to their other children. For example, Jane described trying to explain to her seven-year old daughter why she had to make yet another visit to the hospital: '*I said Robert needs me at this minute so I have to go and see him and she said "But I need you too Mummy!" And, oh, that was a wrench*!' Most also reported having less time and energy to spend with their partner. Sheila said: '*There was one time when I thought that was it and the marriage was going to be over.'* Moreover, time taken to protect and promote the well-being of their child often meant sacrificing personal interests and career aspirations. For example, Joanne described having to use her holiday allowance to look after her ill child and take her to hospital because '*Being a single mum, if you ever want to get a new job and you've had a lot of sick leave then you will never get a new job*.' Nannette said: '*At one time I was going to the hospital four times a week*,' and Jane explained how she '*was holding down a job and nursing Robert and doing all this physio every day and going to town for acupuncture every day*.'

Dawn had continued full-time paid work because her husband, Craig, had given up his job to care for their ill daughter and her siblings. Although, Craig too experienced role conflict it was a different to the women. He described avoiding 'intimate' care of his daughter, Gina, for fear of being accused of '*molesting*' her: an anxiety not reported by any of the mothers. Craig explained how Gina had to manage by herself if her mother or grandmother were unavailable and, in stark contrast to the mothers, reported receiving considerable help also from hospital staff in relation to her intimate care and emotional needs.

Theme 3: Battles

To protect and promote the well-being of their child, the mothers described how they had not only to 'battle' with their child's condition, but also sometimes with other family members and professionals. Nannette said: *'I can't make people understand and that is the hard part,'* and Carole expressed a similar frustration: *'They didn't understand it. I mean I had problems understanding it.'* Even their husbands did not always understand their concerns. For example, Jane explained that '*I really wanted to say "Back me up. I'm not losing it am I?" Because he didn't understand. It was very, very, difficult. My husband did not understand it all and he left it very much to me*.' Extended family members were also described as expressing disbelief and Jill described how, during the onset of her son's illness, his grandfather had accused her of '*Just making a fuss! You know, fussy mother.'*

The mothers also described battles with professionals. For example, Joanne explained that her daughter's headmaster '*wasn't very helpful at all. He did not understand'* and Jane described how her son's teachers only began to believe her after a health professional accompanied her to a school meeting: '*taking her in suddenly gave it a lot more credence and they all sat up and took notice.'* However, participants also recounted battles with health professionals. Many had experienced difficulties obtaining a diagnosis for their child. Sheila described how, when her child was an infant, she had *'been to the doctors a couple of times and they said there was nothing wrong with him.'* Joanne described a four-year search to find a cause for her daughter's symptoms: '*We used to get so frustrated at going because there was nothing conclusive and they just said to us "Oh well it takes a long time to ascertain arthritis"'*. In fact, Joanne was so frustrated at not being believed by healthcare professionals that she asked her estranged husband to accompany his daughter to an appointment: '*I said to him "Look you go.*

You go through what we go through every day in that place and see what we go through" and he went, and he just couldn't believe it. He was astounded.' However, Pauline felt that when her husband accompanied his daughter to clinic visits he did not receive the same level of disbelief as she faced: '*…it carries more weight from the man than it does the woman and many times I say I consciously make sure I say "me and my husband" when we are in authority situations'*.

All mothers, except Dawn, indicated that they had to learn to adopt a fighting spirit. Jane explained that: '*You become the lioness. You know trying to protect your child,'* Joanne said: '*We were fighting against the system because you are trying to convince doctors there is an illness*,' and Sheila's experience was that '*as far as I was concerned he was dying before my eyes. You have just got to be a fighter. You have got to fight.'*

In contrast, Craig reported only positive encounters with healthcare professionals, seeing his daughter's care as their responsibility, but accounting for the delay obtaining a diagnosis in terms of Gina's refusal to engage during early appointments. Moreover, whereas the mothers advised developing a 'fighting spirit,' Craig advocated a more passive acceptance: '*I'd say just say take care of them and look after them because you can't do much else.'*

Theme 4: Hypervigilance misperceived as 'neurotic'

Sharing prolonged and emotionally-charged experiences appeared to forge a strong relationship between mothers and their ill child with Jane explaining how there is '*a special bond there because like when he was in hospital we were there together for twenty hours a day.'* Moreover, Nanette described a secret code she and her son had developed to meet his needs when visitors were present and how '*He was terrified anything would happen to me.*' In response the mothers appeared to develop a kind of 'hypervigilance', particularly given the often unpredictable and painful symptoms experienced by their child. Carole explained that '*I know what she has been* *through when it's been bad [...] I'll nag until the cows come home, if I feel it is going to be of benefit.'* However, disconcertingly, the intensity of the mother's care could be interpreted as problematic. Pauline felt that professionals thought '*You have got a mum here who wants to wrap her up totally in cotton wool- isolate her from the world*'; Nanette explained that '*At one stage they thought I was a bit overprotective with him'*, as did Joanne: '*I think they thought I was a very overprotective mother*'; and Jill felt judged as a '*fussy parent.'*

In fact, all mothers, other than Dawn, referred to times when health professionals had intimated that their behaviour was 'neurotic.' For example, Carole described a doctor as '*putting me down as overanxious and neurotic*'; Sheila related an incident in which a doctor '*would not even examine him. He just said "You are being neurotic. Your child is upset because he has seen someone in a white coat*!"'. And, Jane commented about a healthcare professional that: '*I think he thought I was some paranoid mother! [...] They thought I was some sort of whacko! Or that is how I interpreted it,'* This severely undermined their confidence and Joanne said '*I used to question myself as a mother. Was I doing a good job?'*

Craig reported being supportive to his ill daughter in some of the ways described by the mothers, such as holding her hand and distracting her during injections and blood tests. But he would also leave Gina at the hospital with money for food so that he could complete housework and bring his other children to collect her later. Moreover, although Craig said that his daughter informed him when she was in pain, he made no reference to the 'special bond' reported by mothers.

Theme 5: Socially- and emotionally-adjusted 'managing' mother

At the time of interview, participants had cared for their ill child between three and eight years. During this time, the mothers had become 'expert advocates' on behalf of their ill child and had accumulated considerable knowledge and experiences making them more confident in their own abilities and judgment. They described how they attempted to promote their child's independence within the boundaries of their condition. For example, Jill said '*I just tried very hard and still do to let him be the decision maker of what he was doing and that he is clearly involved in medication and decisions and what have you.'* They adopted a pragmatic approach, Nannette explaining that '*there are children who are a lot worse off and that is how I deal with it*' and Jane describing how she had '*been on the internet. I'd been doing my own research.*' Sheila also indicated that, at times, mothers could push their child further during treatment than was possible for some health professionals: '*when you are trying to get a joint mobile you know that if you don't they will lose that mobility for the rest of their life. You have to be cruel [...] I think a lot of people expect the medical profession to do it and the fact remains you can't. You have to do it.*' The 'fruits' of Sheila's labour were evident when she recounted a meeting with a social worker many years later who said '"*who would have believed he would have ended up where he is today? And I said "Exactly*!"' In fact, all the mothers - except Dawn - expressed a sense of achievement in the quality of care they gave with, for example, Jane saying *'I smile when I see him doing bits and pieces. It brings that warm feeling you know inside because I think "Crikey" you know at one point I didn't think we would get to this.'*

There is no indication that, as main carer, Craig underwent a similar journey. Rather than seek out information, develop and learn from his experiences, and advise professionals in the ways described by the mothers, Craig believed that: '*You can't do nowt. I can't. All I can say to her is "Well you will feel better tomorrow love".*'

Discussion

This study addresses the research question: What is it like to be the mother of a child with juvenile idiopathic arthritis? We found that mothers responsible for the care of a child with JIA can adopt a ‘medical career’ during their journey from ‘neurotic’ to ‘managing’ mother. This journey commences with *social comparisons* through which mothers felt they were less able to promote independence in their child than mothers of a healthy child and *role conflict* in meeting the needs of their ill child and other family members. These mothers described how they had not only to ‘*battle’* with their child’s condition, but with other family members and professionals who could *misperceive their ‘hyper vigilance’ as ‘neurotic*.’ However, over time, the women developed a more positive identity as a ‘*managing mother,’* able to support her child’s growing independence whilst providing appropriate care.

Our study is unique in presenting an empirically-grounded, integrated model and in offering evidence that this ‘medical career’ is gendered: that is, experienced by *main-carers* who are *women*. Moreover, because JIA is a typical chronic illness of the relapse-remitting type, we argue that our model has potential transferability to mothers with a chronically ill child, at least of a similar kind and involving lengthy periods between symptom onset and diagnosis. This is supported by o*mitted for the purpose of blind peer review,* who report how the relationship between mothers of children with kidney disease and healthcare professionals tends to develop through a series of stages from naïve trust, disenchantment, and eventually into a guarded alliance.

Existing research supports our findings with regard to *social comparisons*. For example, Green (2007) reports how mothers of children with chronic conditions feel stigmatized by parents of well children and that this can have an even greater negative impact than the stress of providing care. Moreover, Knafl, Leeman, Havill, Crandell and Sandelowski, (2015) found the most stressful aspect of caring for a child with JIA to be the extent to which it impacts on family life as normatively defined.

In terms of *role conflict*, Nurullah (2013) reports parental relationship discord in families coping with developmental disability. More specifically, difficulties faced by mothers of children with JIA have been documented in meeting their own needs and those of other family members (Barlow, Wright, Shaw, Luqman, & Wyness, 2002; Sallfors & Hallberg, 2003). Role conflict can be compounded by the guilt of having had doubts about their child's illness (Sallfors & Hallberg, 2003) and of feeling responsible for their child's condition (*omitted for the purpose of blind peer review*), leading to a toxic mix of emotionally-charged experiences (Neufeld, Karunanayake, Maenz, & Rosenberg, 2013).

Within this context, perceived criticism of their ability and/or motivation can cause an immense amount of suffering for these mothers, and their anger, frustration, and sense of powerlessness with regard to healthcare professionals is well documented (e.g., Gómez-Ramírez, Gibbon, Berard, Jurencak, Green, et al., 2016; Livermore, Eleftheriou, & Wedderburn, 2016; Mulligan, Pearce & Newman, 2017; Sallfors & Hallberg, 2003). Elbinoune, Amine, Rostom, Shyen, Elbadri, et al. (2017) describe disagreements between mothers and professionals regarding care. That mothers feel a need to *battle* on many fronts is also reported by (O*mitted for the purpose of blind peer review)* who found that the skepticism they often encountered within the healthcare system, particularly with regard to obtaining diagnosis, could jeopardise their later relationships with staff.

Mothers explained how they developed a special bond with their ill child and a kind of symbiosis is reported also by Sallfors and Hallberg (2003) and McAnarney, Pless, Satterwhite, and Friedman (1974). Distressingly, though, mothers felt that this bond, and the *hypervigilance* entailed providing care, could be *misinterpreted* as '*neurotic'* by others. According to Rich (1995), within Western society, mothering includes potential for overprotectiveness from which children must be defended, illustrated nicely by the linguistic slip between 'mothering' and 'smothering' (Burman, 1995). Even so, Gerhardt, Vannatta, McKellop, Zeller, Taylor et al., (2003), found only tentative evidence that mothers of chronically ill children displayed greater protectiveness than mothers of healthy children, and this was at times when their child's condition was severe.

Although mothers can feel inadequate through internalising perceived criticism (Nancarrow & Clarke, 2012), over time, and with increased experience, their expectations of 'normal' family life changes (Sallfors & Hallberg, 2003). Moreover, they can come to terms with the complex, often ambivalent, positioning of mother and carer (Baraister & Noack, 2007), which includes reassessing what constitutes good enough mothering, making fewer comparisons with other people (Sallfors & Hallberg, 2003), and accepting that uncertainty is part of everyday life (Mulligan, Pearce & Newman, 2018). At the same time, the mothers developed into confident experts regarding their child's needs and recognised their role as major knowledge holder about their child's condition (O*mitted for the purpose of blind peer review).* They guided their child, advising and working with healthcare professionals (O*mitted for the purpose of blind peer review)*, so that, eventually, the three-way relationship can develop into a partnership between child and professional. That is, they become a *managing mother.*

Our study offers novel evidence that the mothers experienced a 'medical career' within their journey from 'neurotic' to 'managing' not as the main-carer of their child with JIA, but as the *main-carer* who is also a *woman*. Neither the main-carer father who was included, nor his wife who had previously lived apart from her family for some time, experienced this journey. Caring for children is seen as the responsibility of women (Venter, 2011) and the main-carer father in our study appeared to benefit, in contrast to the mothers, from multiple sources of (female) support. Moreover, Western expectations that a ‘good’ mother is also a self-sacrificing mother (Hayes, 1996), placed our mothers in a double-bind in which their intense effort was felt to be held against them in a way in which the father’s greater passivity with regard to his ill daughter was not. Both parents can suffer stress due to the demands of caregiving (Gamwell, Mullins, Tackett, Suorsa, Mullins et al., 2016) which impacts negatively on their sense of identity (O*mitted for the purpose of blind peer review)*. However, while high levels of depression is associated with parenting a chronically ill child, our study might throw some light on why mothers are more likely to be diagnosed with clinical depression (van Ooers, Haverman, Limperg, van Dijk-Lokkart, Maurice-Stam, et al., (2014).

Behaviour and attitudes that health professionals may perceive as pathological, from the mother’s viewpoint may be consistent with good mothering as culturally defined and there is evidence that, in contrast, fathers are less inclined to ‘ruffle feathers’ (McNeil, 2004). The ‘battles’ in which the mothers engage with health professionals can be understood as an attempt to exert influence in a system in which, for her, the stakes are overwhelming and her power often experienced as minimal (Bourdieu, 1990; Legrow, Hodnett, Stremler, Mckeever & Cohen, 2014). For example, o*mitted for the purpose of blind peer review,* point to the dominance of the current paternalistic medical model within healthcare which means that professionals can refer parents to social services, with potential for the removal of children from the family.

Mothers can, therefore, be seen to have to take up a ‘medical career’ as they follow a similar trajectory to that of their chronically ill child, adjusting to and managing their care. In this regard, Moss-Morris (2013) stresses the need for multi-dimensional, adaptive outcome measures for patients. The current article indicates this is appropriate also for those whose lives are affected by the patient, particularly mothers. Greater understanding of such mothers' 'medical career' could help healthcare practitioners become more aware of the skills and knowledge they develop and the important role they play in the care of their chronically ill child.

Although our study has a relatively small sample size, it is commensurate with in-depth interviews and grounded theory analysis (Glaser & Strauss, 1967). Also, given the consistently reported difficulty in recruiting fathers (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005), we were fortunate in being able to include a man whose experiences reflected those of the other fathers interviewed, while also being, singularly, the main-carer of his ill daughter. Specifically, no father in our larger study reported being judged overprotective by professionals (*reference omitted for blind peer review*). In fact, this offered the opportunity to include a deviant case analysis (Strauss & Corbin, 1990) to test the genderedness of the posited model. Further exploration of the validity – and transferability - of this finding would be valuable.

Although all participants were recruited via one voluntary organisation, we used purposeful sampling for diversity and theoretical sampling to flesh-out gaps revealed in the developing analysis. It is possible data collection was influenced by the fact that the interviewer and first author is a slightly older woman with a diagnosis of JIA as a child (Potter & Hepburn, 2005). However, prior experience of JIA could also have provided additional insight given the interpretative approach to analysis involves empathetic engagement with the data (Gillett, 1995). Potential bias is counterbalanced through the monitoring of the research process and content by the second and third authors based on their professional experiences, the continued discussions between authors as analysis progressed, and the credibility check reported above [p.8].

Although, single interviews with mothers caring for a child with JIA over a lengthy period has helped gain awareness of the ‘medical career’ they have to adopt, further work, monitoring continuing experiences of mothers of newly diagnosed children could help further confirm if their journey from ‘neurotic’ to ‘managing’ mothers is, indeed, a linear process and offer further insight into relevant means of support.

Future research could also, consider more fully the implications of family structure, mothers’ age, ethnicity, educational level and occupational status and the impact of healthcare system from a wider geographical region. It is also important to test the transferability of findings beyond JIA (Bannister, Bunn, Burman, Daniels, Ducket et al., 2011), although we have made a case for considering the journey from ‘neurotic’ to ‘managing’ inherent to the role of being a main-carer mother of a chronically ill child, at least of the relapse-remitting type.

In conclusion, we found that main-carer mothers of a chronically ill child adopt a ‘medical career’ within their journey from ‘neurotic’ to ‘managing’ mother which may be an essential element of the process of continual adjustment they face. Understanding how and why she can feel easily undermined, can help healthcare professionals to communicate with mothers constructively and to find in her the strongest of allies in support of children with chronic illness.

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Table 1: Pseudonym of mothers, pseudonym and age of child with JIA and family composition

	Pseudonym of parent	Pseudonym of child	**Child's age at interview (yrs)**	**Child's age at onset (yrs)**	**Family composition**
1	Sheila	Carl	18	2	Husband and older son
2	Carole	Susie	16	1.5	Husband and younger son
3	Jane	Robert	15.5	9	Husband and younger daughter
4	Pauline	Debbie	14	11	Husband, older daughter and older son
5	Nanette	Luke	13.5	9	Husband and older son
6	Joanne	Selina	18	12	Younger daughter and grandmother
7	Jill	Ben	17	9	Husband and older son
8	Dawn	Gina	15.5	10	Husband (Craig), younger daughter and son but Dawn previously lived separately to family
9	Craig	Gina	15.5	10	Husband of Dawn

Figure 1. Model of the medical career from 'neurotic' to 'managing' mother