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Living with uncertainty and hope: a qualitative study exploring parents' experiences of living with childhood multiple sclerosis

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ABSTRACT

Background: There is growing recognition that multiple sclerosis (MS) is a possible, albeit uncommon, diagnosis in childhood. However, very little is known about the experiences of families living with childhood MS and this is the first study to explore this in depth.

Objective: Our objective was to explore the experiences of parents of children with multiple sclerosis.

Methods: Qualitative in depth interviews with 31 parents using a grounded theory approach. Parents were sampled and recruited via health service and voluntary sector organisations in the United Kingdom.

Results: Parents' accounts of life with childhood MS were dominated by feelings of uncertainty associated with four sources; diagnostic uncertainty, daily uncertainty, interaction uncertainty and future uncertainty. Parents attempted to manage these uncertainties using specific strategies which could in turn create further uncertainties about their child's illness. However, over time ongoing uncertainty appeared to give parents hope for their child's future with MS.

Conclusion: Illness-related uncertainties appear to play a role in generating hope among parents of a child with MS. However, this may lead parents to avoid sources of information and support that threatens their fragile optimism. Professionals need to be sensitive to the role hope plays in supporting parental coping with childhood MS.

INTRODUCTION

Being the parent of a child with a chronic illness involves developing the knowledge and skills to take on responsibility for condition management and integrate this into family life alongside coping with the emotional consequences, financial constraints and impact on family relationships (1). As the intermediary between their child and healthcare providers (HCPs), parents are a source of information for doctors, an advocate for their child and a care coordinator (2). However, there is evidence that parents do not feel well supported and experience difficulties developing collaborative relationships with HCPs (1). Understanding how parents experience their child's illness can help HCPs to better address parents' needs and develop effective partnerships with families (3). In turn, this can lead to improved illness management and outcomes (2).

This paper focuses on the experiences of parents of children with multiple sclerosis (MS). MS is a progressive neurological condition with variable outcomes that can include physical and/or cognitive impairments (4). Although MS is typically diagnosed in adults, advances in imaging technologies and research have led to increasing awareness that the onset of MS can occur in childhood (4). However, diagnosing childhood MS is difficult because of the absence of biological markers and the need to eliminate more common childhood neurological conditions before a diagnosis of MS can be made (5). There is also some evidence to suggest that families and professionals may misinterpret the typically vague and non-specific symptoms of MS leading to delays in referrals and diagnosis (6). Consequently, MS is an uncommon diagnosis in childhood.

Currently little is known about families' experiences of this uncommon and complex childhood condition. While studies have examined young peoples' perspectives (7-9), there has been no in-depth examination of parent experiences. There is some evidence to suggest that families can encounter challenges accessing condition-specific, age-appropriate information and support (10). In this paper

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we use a qualitative grounded theory approach to examine how parents experience childhood MS. This forms part of a larger qualitative study that investigated the experiences and support needs of families living with childhood MS from the perspectives of children/teenagers, parents and professionals involved in their care

METHODOLOGY AND METHODS

We designed and conducted a qualitative study using a constructivist grounded theory approach (11). Grounded theory privileges the collection and inductive interpretation of empirical data to generate meaning and theoretical insight (11). It is particularly useful for exploratory research because it can help to illuminate participants' subjective experiences and facilitate an in depth understanding of the topic being researched (11). A constructivist approach acknowledges that data are co-constructed between the researcher and the researched and thus considers how the researcher's role influences interviewer-interviewee interaction, the sharing of knowledge and meaning during interviews and the subsequent analysis and interpretation of data (11).

Sampling and Recruitment

Recruiting families to the study was challenging because it is a small and geographically dispersed population (12). We were unable to sample purposively or theoretically because of the rarity of the condition and the absence of a national patient register. We worked with 16 specialist centres providing paediatric MS services and four voluntary organisations in the UK to approach all known parents/carers of a child aged 0-17 years old with a clinically confirmed diagnosis of childhood MS.

Key contacts at participating NHS centres approached all eligible families with information about the study. Voluntary organisations displayed a study advert on webpages and in member magazines. Interested parents contacted the researchers directly if they wished to take part in the study and to

arrange a convenient date and time for the interview. Thirty-one parents from 23 families participated in the study and their characteristics are presented in Table 1.

Data collection

We used semi-structured, conversational style interviews to examine parents' experiences (13). Interviews were initially informed by a predetermined topic guide that focused on three potential areas, or periods of time, thought to be of relevance to the study: pre-diagnosis, diagnosis and post-diagnosis. Questioning was sufficiently flexible, however, to allow participants' to raise new issues of interest and to allow [author 1] to explore their responses in further detail. All interviews opened with an invitation for parents to describe the time when they first noticed that their child was experiencing issues with their health and their response informed subsequent questioning.

During the initial interviews, questioning was exploratory to try to understand the life worlds of parents, particularly the terminology they used to describe what they were experiencing (and how this might differ from medical terminology), their interpretation of medical services, and the types of issues they could encounter when caring for a child with MS. During subsequent interviews, questioning became more focused to gather detailed information that would advance categories under development (11).

All interviews were conducted by [author 1], an experienced qualitative researcher, in home settings, were digitally recorded and transcribed verbatim. On average, interviews lasted 90 minutes (range 60-180). Parents could chose to be interviewed alone or with their child present (Table 2) and we acknowledge the effect joint interviews might have on data generation (14). Data collection continued for twelve months (February 2013-2014) until we had achieved theoretical saturation and had fully developed the categories (11, 15).

Data analysis

Interview transcripts were analysed inductively in Nvivo using the constant comparative method. This approach involves concurrent data generation and collection to develop coding and theoretical insights grounded in the empirical data (11, 16). We developed initial codes via line by line coding and re-reading of the transcripts and paying close attention to participants' reported behaviour, experiences and assumptions, as well as their silences and pauses. We used coding labels that conveyed action to express the participants' physical and emotional response to described situations; such as 'searching for information', 'feeling frustrated', and 'seeking answers'. We wrote analytical memos alongside coding to record our thought process and reflect on our theoretical sensitivity to the data, and maintain an audit trail of the analysis process.

As the research progressed we used theoretical sampling to focus data collection and saturate developing categories. Intermediate coding was used to reconnect the data by fully developing the individual categories and linking those categories together. The detailed analysis of deviant cases helped to develop the properties and dimensions of the categories. During this process a core category 'living with uncertainty' was identified as central to parents' experiences of caring for a child with MS. The core category was subject to further theoretical sampling and focused coding to achieve theoretical saturation of the data (11). We coded the data independently and met regularly during the research to discuss the analysis strategy, our interpretations of the data and the development of codes and categories. We kept a record of our discussions to aid category development and theoretical saturation and to serve as an audit trail of our decision-making process (17).

Reflexivity

We maintained a reflexive standpoint throughout the study to account for our influence on the research process and the co-construction of data with research participants (18). A reflexive journal was used to record beliefs, actions and observations that might have influenced the collection and

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analysis of data. We considered how our positionality (white, middle class, professional parents) and our professional knowledge (a combination of clinical and non-clinical expertise) shaped our interaction with participants and informed our line of questioning (17). For example, [author 1] noted that her experience as a parent helped her to build rapport with participants during the interviews but care was needed to ensure participants discussed their experiences in depth rather than assuming a shared understanding of parenting. Furthermore, although we aimed to relinquish control of the interview to give interviewees the opportunity to discuss issues they felt were important, we acknowledge that this process was only partial and that participants' responses were inevitably orientated towards giving [author 1] the answers they perceived to be relevant to the research (19).

Ethical approval

The study was approved by the NHS North West (Lancaster) Research Ethics Committee and we gained appropriate approvals from each NHS site assisting with participant recruitment. All parents provided written informed consent before the interview commenced and assurances of confidentiality/anonymity given. We developed procedures for managing participant distress and disclosure.

FINDINGS

During data analysis we identified the core category 'living with uncertainty' to explain parents' experiences of living with childhood MS. Using extracts from the data to support our interpretations, we outline sources of parents' uncertainty before examining four strategies they use to manage uncertainty.

Sources of Uncertainty

Diagnostic uncertainty

Parents reported experiencing the diagnostic process as lengthy and frightening. It appeared to be difficult for parents to interpret the non-specific and variable symptoms of childhood MS, that included numbness, poor coordination and headaches, because they were 'invisible' and appeared and disappeared over time. Moreover, childhood MS was not an obvious diagnosis given its rarity.

Multiple healthcare professionals (HCPs) were involved in diagnosing the illness, increasing the potential for conflicting medical opinions, different labelling of the child's condition and delay.

Because of the varying viewpoints on things, you know, we could go and see two people, one may say one thing, another may say another ... Nothing is set in stone as far as this type of thing is concerned, you know and we've been in that position really for the last ten years.
(Parent 10)

Professional uncertainty appeared to intensify parent's anxiety about the child's illness. Parents expected doctors to be able to diagnose a specific illness and develop a treatment plan and so were unable to comprehend the limitations of medical expertise and professionals' subsequent reluctance to make a diagnosis. Without a definitive diagnosis, parents appeared to be unable to make sense of their child's illness and were uncertain how best to help their child.

We've got another six month wait for his appointment so [the specialist] can look at the notes, and then in six months we'll know a little bit more. Will they then say actually, no, I don't think it's MS? Now we're sitting here thinking has he, hasn't he? He's on the treatment, he must have it. But [the specialist] is saying his [vision impairments] are not related to it [MS], so what's causing his eye [problems]? (Parent 29)

Daily uncertainty

Parents experienced daily life as unpredictable and uncertain. The relapsing-remitting nature of MS made it difficult for parents to predict when their child's condition would 'flare-up' or how their child would be affected. Children's daily support needs were changeable and therefore parents' caring

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activities varied. During relapses, parents were actively involved in children's personal care needs. During periods of remission, however, children were often able to resume these activities without help. Being unable to predict children's care needs made it challenging for parents to manage the child's illness alongside paid employment, family responsibilities, social activities and 'normal' family events:

That's the hardest thing about the whole thing [MS], because one day you're alright, the next day you're not. You can't plan anything, you can't do anything, you don't know where you're going, what you can do. (Parent 23)

Parents lacked access to reliable information and professional support, which further increased their uncertainty about managing their child's illness. They described feeling uncertain how to identify and respond to perceived changes in their child's condition, resulting in a reluctance to seek medical help for fear of being labelled neurotic or incompetent by medical staff:

Nobody's actually turned round and said, right these are the symptoms and these are what you should look for. Nobody. So it's like you look at him and you think, well is it a symptom, isn't it? Then if you take him to the hospital, you feel thick, they say there's nothing wrong with him. (Parent 13)

Interaction Uncertainty

Social interactions appeared to exacerbate parents' uncertainties about their child's illness. Parents reported that when they disclosed their child's illness to HCPs, teachers, friends and peer groups, some disputed the diagnosis:

He was ill not so long ago and we went down the hospital and the doctor came down and says, he can't have [MS]! Because nobody, not many doctors, have really heard of it in kids. (Parent 24)

I mean even now sometimes when we say to people he's got MS, oh well it must have been misdiagnosed, he can't have, he's too young. (Parent 8)

Furthermore, because children and young people with MS often looked visibly well, parents reported finding it challenging to convince others that their child was ill and had specific health needs:

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Even my brother said to me, sis you told us that she is ill, she doesn't look ill to us. I said, you don't see it outside, she is really ill inside, because her problem is in the brain, you are seeing her like that because she won't tell you how she feels. (Parent 16)

The doubt expressed by other people about the MS diagnosis, and the fact children appeared to be 'healthy', heightened parents' feelings of uncertainty, leading some to question the MS label and whether their child was really ill:

I find it quite difficult to understand that she has MS, that you know, that she can have MS, because in our family there is no history, obviously it's not hereditary but still there's...everyone is very healthy in our family and everything, and she was just a normal, healthy child, to suddenly fall ill like that, and have this life-changing illness. (Parent 21)

Future uncertainty

Parents reported that the variable impact of childhood MS created uncertainty about their child's future life. Specialists could not predict the child's prognosis because they lacked detailed knowledge of the condition, leaving parents "in limbo" (Parent 9). Without a prognosis, parents feared that their child would be severely impaired with extensive support needs:

I'll walk around [the] town and I'll see somebody in a wheelchair, unless they have got a broken leg or they're obviously severely disabled I'm just thinking, this is what the poor lass has got, you know. I don't know, I just feel so useless, that's how I feel, but I've got to be strong for her. (Parent 28)

In turn, they questioned the implications for their child's academic and career aspirations. Parents' accounts suggested that they were apprehensive about their child's ability to achieve culturally-normative milestones, such as moving away from home. This created ongoing uncertainty about parents' future role and involvement in their child's illness:

That really, really worries me, I don't want her to stop carrying on with her dream but how am I going to support her when she is miles away from me? I don't know what to do. I won't have peace of mind when she goes to university. (Parent 16)

Strategies to manage uncertainty

Parents appeared to use four strategies to reduce the uncertainty they experienced.

Information Searching

Parents described information-searching in the immediate post-diagnosis period as a strategy to alleviate their uncertainty. Specialists, general practitioners, nurses, charities, friends, family, and the internet were all key sources of knowledge and advice. Learning about the condition appeared to help parents make sense of their experience and, in turn, anticipate greater control of their child's illness. What was previously uncertain and frightening had the potential to become 'known' and therefore manageable. However, parents' accounts suggest that their initial optimism was gradually replaced with disappointment and frustration when it became clear that specialist knowledge was limited and available information was undesirable and the anticipated sense of control was not realised:

I wrote to everybody, I wrote to any names I could get. I wrote to the [MS charity] but it was the same information I was getting from them all, it was very limited. Parents, some of them had told me to just read the other parents stories on line ... I suppose we're all looking for the same thing, we're all just looking for someone to say "Oh we've got a cure," that's what we're looking for and it's not there. And then I read a lot of the [MS charity] sites and adult stories and it would depress me because I don't want to think about the worst things obviously, I just have to keep hoping that the stem cell treatment that they're talking about is going to be available soon, but then it's going to take years isn't it, years and years. (Parent 1)

Rather than minimise parents' uncertainties about their child's illness, information-searching uncovered negative stories, that in turn, created further uncertainty about the child's future with MS. This led some parents to abandon their search altogether as one parent explained:

We stopped researching and we just live with it day to day and just take it as it comes. (Parent 14).

Continuous monitoring

Parents reported observing their child carefully, routinely documenting any changes in behaviour, physical features and daily activity, as a strategy to reduce the uncertainties of their child's illness. Parents discussed learning the 'signs' that indicated the onset of a relapse and becoming more certain about when to seek medical help. Knowing what to look for and how to support their child appeared to help parents experience a greater sense of control over their child's illness:

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Father: *We know the signs. He's on an open ward, every time we've said...*

Mother: *We've got open appointments at the hospital. I can just phone up and say he's not well, bring him up.*

Father: *...he's got it, guaranteed he has. 100 per cent record.*

(Parents 6 and 7)

Nonetheless, this constant monitoring appeared to exacerbate parents' uncertainties. Parents described concerns that they were misinterpreting the perceived signs of the illness and were not responding appropriately to their child's needs:

The thing that affected me is just watching out all the time. Anything different they do, you think is it that? And then you think you can't worry too much. Then if you worry too much they're going to be at the bloody doctors all the time (Parent 18)

Parents questioned what constituted 'normal' behaviour for their child and were unsure if the behaviour their child exhibited was or not related to MS. Indeed parents reported feeling uncertain if they could ever really understand their child's illness:

Maybe [MS is] why he's a bit behind in his class but then there are other [students] his teacher says that are even further behind. Don't blame it on his MS and it's true, it's maybe nothing to do with MS but you fall into a trap of just blaming everything you know. He's slower at reading than most kids, is it his MS or is it just [my son], you know, you just don't know. (Parent 1)

Implementing changes

Parents reported making modifications to their child's diet and daily routine as a means of reducing the uncertainty of their child's illness. Strategies included encouraging their child to be more active, consume nutritious foods and increase their vitamin D levels. Parents appeared to believe that helping their child to lead a 'healthy' lifestyle had the potential to improve their overall health and reduce the uncertainty of potential relapses and disability. Moreover, taking action in this way appeared to help parents feel more in control of their child's illness and foster a more positive outlook about the future:

I'm just trying to be positive. I try to keep him as much as possible away from disability until [he needs] the medication. This is my aim. And in order to get that I'll do anything possible to help him do a tiny little bit, try and drag him out when the sun shines, try to walk with him if it's possible or his mum tries to give him as much healthy food as possible. So this is really, life is based on how much we can help him. (Parent 20)

Nonetheless, parents were uncertain if these changes would have any lasting effect on their child's illness and doubted the extent to which they could encourage their child to experiment with new diets and practise healthy living routinely:

She does relaxation and just like a good diet, sleep, we try not to let her get too tired, we try to keep her up on her sleep and eating well, yeah, to keep her well, to try and keep her well because if she goes down with stuff it flares up. And that's all we can do really at our end just keep her well. Super food day would be the ideal but I don't think I could get a 15 year old to eat super food. (Parent 12)

Optimistic thinking

Although parents were understandably distressed by their child's diagnosis, parents' accounts suggested that over time they developed a more optimistic outlook about their child's uncertain future with MS. As they learned more about the uncertainties of their child's illness parents articulated hopes that their child would be minimally impacted by their condition and able to lead a 'normal' life. The variability of symptoms, the unknown outcomes and professional disputes about the diagnosis, offered parents hope that their child may recover and/or have been incorrectly diagnosed:

They [the doctors] said in the beginning and the middle she [daughter] was an enigma and they said like, you know, she didn't fit into the same categories as anybody else type thing. And we've held steadfast to that. (Parent 9)

Parents described using various strategies to sustain their optimism about their child's health, including: using alternative labels to describe their child's illness; seeking second opinions from other specialists and avoiding interactions with others, including family members, who could challenge the parents' (fragile) hope:

[A family member] basically said if [she's] got this [MS], this is what would happen; negative, negative, negative, negative, negative. And then I listened to it all and I thought, do you know, if [my daughter] hears this, it's not right. So I basically said, you know, I'm not going to tell you. So we stopped telling him. (Parent 2)

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Moreover, parents described withdrawing from potential sources of support, such as peer support groups, because they did not want to be reminded that their child faced a potentially undesirable future with MS:

I used to get [MS charity] magazine for him but I've stopped that as well now because I felt as though everyone was bed ridden and I thought I can't cope with this, I don't want to read that side of it. I know it's there, it's not as though I'm in denial, I know what can happen and I know how horrendous it can be but there are no happy stories in there, not happy stories but people living their lives to spite MS, everything seems to be bad. (Parent 1)

To maintain their optimism, parents reported focusing on the immediate present and their child's existing needs, rather than worrying about what the future might bring:

You sort of pull yourself up and pull your socks up and think right, come on, just get on with it ... You don't know what your future holds. Nobody does. You can always look on that dark side of things, but that will bring you down. I look at the here and now and think we're doing well, we're lucky, everything's good, and long may it continue. If there's a bad day comes then I'll just deal with it as and when it happens rather than chew myself up now with all the what ifs. (Parent 25)

This strategy appeared to help parents recognise their limitations; namely their inability to predict their child's future and the futility of attempting to control the uncertain outcomes of childhood MS. Parents' strategies therefore appeared to be only partially successful in managing uncertainty and might actually create further uncertainties about their child's illness.

DISCUSSION

This is the first study, to our knowledge, that has explored childhood MS from parents' perspectives. Like parents of children with other rare conditions their experiences are dominated by feelings of uncertainty (20, 21). The variability and unpredictability of MS challenges parents' everyday routines and taken-for-granted assumptions about their child's future. Parents can experience uncertainty about how to retain a sense of continuity with the past and their previous 'normal' family life (22) (23). The lengthy diagnostic process, the uncertainties of medical knowledge and difficulties

communicating the illness to others further exacerbates parents' uncertainties, as has been observed in earlier studies of rare childhood conditions (20, 24). In our study, parents appear to interpret uncertainty as limiting their control over illness-related events, relegating them to powerless bystanders in their child's illness experience and causing them distress.

Our analysis suggests that parents employed four distinct strategies to manage their uncertainties: information searching; continuous monitoring; implementing change; and optimism. Like previous studies, our research highlights parents' desire for information in the immediate post-diagnosis period as a means to understand and manage their child's illness (1, 20). Gathering information can help parents develop a framework to interpret the meaning of the illness and understand the consequences for them as parents (25, 26). Depending on the availability and perceived credibility of this information (27) parents may place a greater reliance on their experiential knowledge and intuition to mitigate the uncertainties of the child's condition (28). However, we demonstrate that parents' strategies are only partially successful in resolving their uncertainties and that information-searching may uncover unfavourable knowledge that creates new questions about the illness. Consequently, as Barbour et al. (29) observed information can actually generate *additional* uncertainties by challenging accepted beliefs about the condition and creating further questions about the diagnosis and outcomes. Indeed the parents in this study opted to avoid health information to maintain hope for the future and continue with 'normal' family life.

We therefore contend that parents' uncertainties play a conflicting role in their experience of childhood MS; uncertainties simultaneously cause parents' distress while offering them hope of a more optimistic future for their ill child. The disputed nature of an MS diagnosis in childhood enables parents to retain a sense of hope that a more positive diagnostic label might be applied to their child at some point in the future. Our work builds on the findings of Misel's (25) study, which explored the interplay between uncertainty and hope, by demonstrating that parents' strategies are not static but

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alter over time as their perceptions of illness-related uncertainties change. We demonstrate that parents' strategies are revised as their search for knowledge uncovers undesirable information, namely the potential for physical and behavioural impairments. In view of the known negative outcomes, the uncertainties of childhood MS are interpreted more positively because not knowing allows them to doubt the diagnosis and maintain hope. Other studies have noted how parents may deliberately filter or avoid new knowledge to preserve the uncertainty of the condition and sustain a more positive outlook for the future (25, 29). Indeed Kerr and Haas (20) suggest that parents information seeking may be directed at discovering new information that provides an alternative, more positive explanation of their child's condition.

Nevertheless, we contend that optimistic thinking is predicated on hope and parents' hopes appear to be inherently fragile. A negative comment from a family member, encountering an individual with physical impairments, or the onset of another relapse has the potential to shatter parents' beliefs that their child is or will remain well. Thus, we observed parents withdrawing from potential sources of support to avoid any encounters that threatened their optimism. Furthermore, we contend that parents come to rely on their uncertainty about childhood MS as a way to sustain their hope; uncertainty allows for potential recovery and normality. Thus, parents appear to be caught in a delicate balancing act; trading the negative images of MS, namely physical impairment and illness progression, against the uncertain, but more positive ideal of recuperation and health. This suggests that professionals must handle the communication of condition-specific information sensitively so that it does not shatter the illusion of hope that illness uncertainties might help parents to sustain (30).

Study Limitations

Although we used a multi-site recruitment strategy to recruit a broad sample of parents and capture the diversity of families' experiences (12), we cannot make claims for transferability to parents living

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in alternative socio-cultural contexts. We also recognise that parents' accounts of their experiences are restricted by the socially-constructed conventions of storytelling (i.e. defined by a beginning, middle and end) and the time-constraints of an interview, and thus appear as a set of seamless, linear events (19). Furthermore, parents' reports can be shaped by their perceptions of what is and what is not permissible to discuss during an interview (13), particularly when children and/or other family members are present (14), as well as the continual reinterpretation of past memories from a present-day perspective (31). Nonetheless, there are similarities between our findings and literature discussing the experiences of parents of children with rare chronic conditions (20).

Implications for Clinical Practice

While there is growing awareness that MS can occur in childhood, few children are diagnosed with the condition. Many HCPs, including paediatric neurologists, lack experience of childhood MS and may be uncertain how to support families appropriately. The findings of this study suggest that HCPs supporting a parent of a child with MS need to be sensitive to parents' uncertainties about the illness and manage the provision of information carefully. Parents require information that is appropriate to their individual needs and does not challenge their hopes, so they continue to engage with healthcare services. It is currently unclear if professionals supporting children with MS are aware of parents' support needs or how to manage parents' uncertainties.

Establishing a national network of childhood MS specialist centres would be a first step towards helping families to access professionals with experience of managing the condition. Specialists may be more familiar with and confident in meeting the individualised needs of families managing the uncertainties of childhood MS. Furthermore, HCPs with less experience of childhood MS could seek information and advice from specialist centres about how best to support families.

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HCPs, including specialists, may also benefit from specialist training on managing parents' uncertainties about childhood MS. HCPs could collaborate with families experiencing childhood MS to develop training and information resources. More broadly, the findings of this study suggest that HCPs may benefit from specialist training on managing uncertainty and hope during medical encounters to facilitate effective partnerships with parents.

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Table 1: Participant Characteristics

Characteristic	Number
<i>Parents (n= 31)</i>	
Mother	20
Father	11
<i>Family Structure (n=23)</i>	
Two parent	15
Lone parent	8
<i>Age of children at the time of the interview (years) (n=23)</i>	
≤ 12 years old	3
13-17 years old	20
<i>(Mean age = 15 years)</i>	
<i>Gender of children (n=23)</i>	
Female	15
Male	8

Table 2: Parent Interview Structure

Structure	Number
One parent	3
<i>Mother only</i>	2
<i>Father only</i>	1
Two parent	4
One parent and child	14
<i>Mother and child</i>	12
<i>Father and child</i>	2
Two parents and child	6
(Child only)*	(3)

*All children/young people were given the opportunity be interviewed with or without their parents present. Twenty-one children/young people were interviewed with three children/young people choosing to be interviewed alone and 18 choosing to be interviewed with their parents present.