

A qualitative study of the childbearing experience of women living with multiple sclerosis

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A QUALITATIVE STUDY OF THE CHILDBEARING EXPERIENCE OF WOMEN LIVING WITH MULTIPLE SCLEROSIS.

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IMPLICATIONS FOR REHABILITATION:

- Women with MS who are considering having children express a number of medical and practical concerns, but they experience difficulty in accessing to comprehensive and reliable sources of information about MS and childbearing.
- Discouragement or disapproval of choices about childbirth by clinical staff can have a negative impact on the experience of childbearing by women with MS.
- We recommend that clinicians plan to assess the concerns about choices women with MS have and systematically address these concerns throughout pregnancy, childbirth and post partum care.

ABSTRACT

Purpose: Although at any time in the UK there are about 20,000 women with MS who may be considering having children, very little is known about the experience of women with MS in relation to childbearing. The aim of this paper is to explore the childbearing experience of women with MS to determine what support and information may be useful to this target group.

Method: Interviews were conducted with women with MS (n=9) and healthcare professionals working with MS patients (n=5). Transcripts were analysed using thematic analysis.

Results: Three major themes emerged from the interviews with women living with MS. We found women were concerned about both medical and practical issues associated with having children. Limited access to information about relationships between MS and childbearing and receiving conflicting or wrong information was recounted. Opinions of family members and clinicians regarding having children in the context of MS impacted on women's experience of making decision about having children and childbearing. .

Conclusions: Women with MS can benefit from having access to comprehensive, structured sources of information about MS and childbearing. Healthcare professionals and family members' support could be channelled more appropriately to enhance their experience of making choices about childbearing.

INTRODUCTION

Multiple sclerosis (MS) particularly affects women of childbearing age [1, 2, 3, 4]. It is estimated that at any one time in the UK there are about 20,000 women with MS who may be considering having children [4].

The NICE guidelines in England and Wales for MS [5] indicates that the healthcare system should enable people with MS to play an active part in making informed decisions about their healthcare and give them relevant and accurate information about each choice and decision. The guidelines cover MS management in relation to childbearing; however it only states that MS patients who wish to become pregnant should be advised that the risk of relapse decreases during pregnancy but increases postpartum. It does not indicate that women should be offered any further information or support to make an informed decision about starting a family.

Women often experience worsening of symptoms post partum, although numerous studies show that if one considers the years before and after pregnancy, and the pregnancy itself, having a baby does not affect the overall disease activity or progression over this period [1].

Childbearing is not associated with accelerated progression of MS and women who have children following the onset of MS are not more likely to go from a relapsing-remitting to progressive disease course [3]. Moreover recent studies provided evidence for a potential long term, favourable effect of pregnancy on MS progression. Women with MS who have never had children have significant mobility problems on average 5 years sooner than women who had children at any point in time after the onset of MS [2]. It is suggested that women who

delivered one or more children after the onset of MS may have a more benign course of disease [2].

Studies examining factors determining decisions about having children, their informational needs and the support they expect from healthcare professionals are scarce. Prunty et al [6] examined the main concerns of 20 Australian women with MS when considering childbearing. The most common concerns reported by participants were the heritability of MS, the mother's ability to look after a new baby, being sufficiently agile to protect it from harm, dealing with fatigue, and social attitudes towards being a disabled parent. In contrast, the lack of access to relevant information and being discouraged by healthcare professionals and family members to have children was also often mentioned. Payne and McPherson [7] examined the experience of nine New Zealand women with MS in becoming or being a mother. The women's greatest concerns were keeping their baby safe when taking medication prior to conception, during pregnancy and breastfeeding, finding support after the baby is born, fatigue management and failure to be and be 'seen to be' an ideal mother. Additionally women with MS reported that the decision about becoming a mother was not made in private between the woman and her partner but was considered a public experience involving healthcare professionals and other family members [7]. Albrecht and colleagues [8] conducted a study assessing knowledge and personal beliefs regarding the possible effects of MS on pregnancy, puerperium and breastfeeding. They found that patients who had no children after the onset of the disease had very low knowledge about MS and childbearing compared to those who had a child after their

diagnosis of MS, however the latter learnt mainly from their own experience rather than any formal resources.

The experiences of women with MS in relation to childbearing have not yet been studied in the UK. Our paper aims to explore the experiences, and assess the expectations and needs of women with MS, in relation to childbearing.

RESEARCH DESIGN

The design was a qualitative study of an opportunistic sample of women with MS and their clinicians. The research was approved by Coventry University ethics and Cambridgeshire 2 Research Ethics Committee (ref: 10/H0308/41)

Recruitment

Women with MS were recruited from the Neurology Clinic at Cambridge University Hospital. The inclusion criteria were women who in last three months were seen in the clinic in regard to planned, current or recent pregnancy. They received a letter from the MS nurse explaining the study and inviting them to participate. Women interested in taking part contacted the lead researcher who answered their questions and scheduled an interview. Written consent was obtained from all participants prior to the interview.

Characteristics of respondents

We interviewed an opportunistic sample of nine women with MS. Three of them were considering pregnancy, three were currently pregnant (three, five and seven months) and three recently had a baby (two, six and eight months ago). All nine participants had been diagnosed with MS, and this was on average 3.1 years ago (range 1-8 years). Eight respondents had a relapsing-remitting form of MS and one woman had a secondary progressive type. The participants' mean ages were 30.6 years (range 23-37 years). Three women already had one child (two women had a child before and one after diagnosis, and one woman had two children before she was diagnosed). The highest level of education achieved by the women varied. Six women had a college degree, three had completed secondary school. Regarding employment, seven women were currently employed (four full time and three part time; two were on maternity leave), two women were not employed. All participants lived with their partners.

We also interviewed five clinicians: one neurology consultant, two MS nurses, one midwife with a special interest in MS and one General Practitioner (GP). Secondary care clinicians (i.e. apart from the GP) had experience of working with women with MS on average 9 years (range 7-12 years). Clinicians were recruited via MS nurse involved in the study

Procedure

We conducted semi structured interviews with women with MS (mode length: 60 minutes, range 45 - 90 minutes) and clinicians (mode length: 30 minutes, range: 20-60 minutes). We

asked women about their experience of discussing having a baby with their doctor or any other healthcare professional, the information and support they would like to receive in making decisions about having children and effectively managing their MS before, during and after pregnancy. We asked clinicians about their experience of discussing having children with their patients and their view on patients' educational needs in relation to childbearing. Interview schedules are available from the authors.

Data analysis

All interviews were recorded, and transcribed and analysed independently by two researchers using inductive thematic analysis [10, 11]. Data analysis comprised six steps [10]: (1) Familiarizing with data, (2) Generating initial codes, (3) Searching for themes, (4) Reviewing themes, (5) Defining and naming themes, and (6) Reporting. After completing each stage researchers compared their findings. All disagreements were discussed until consensus was achieved. See Figure 1 for themes.

RESULTS

Theme 1: Concerns about MS and pregnancy

A major concern for study participants was around their future wellbeing, especially the potential impact of coming off their MS medications to get pregnant on disease progression, and the high likelihood of relapse post partum and how it would influence their ability to look after their new baby: A woman considering pregnancy stated: *"Before I started injections I had*

3-4 major relapses a year. I am very scared that this will happen again when I stop taking them”; Another currently pregnant woman stated: “My sister recently had a baby and I see how exhausted she is....and she is healthy. I have no idea how I will cope with my fatigue if I have to get up every 2 hours’.

They were also concerned about the wellbeing of their baby i.e. whether their condition may have a negative impact on pregnancy outcomes, as well as worry about their baby inheriting MS: A pregnant woman said. *“My maternal grandmother’s sister had MS and my husband’s cousin has it too. I’m very worried that my baby will have it too but there is no way of knowing before the baby is born, is there?”*

Five participants (three currently pregnant and two who recently had children) were also concerned about the implications of their health on their employability, and of having additional expenses associated with childcare.

Theme 2: Lack of information about MS and pregnancy

All nine women reported having difficulty finding relevant, and in their opinion reliable, information about MS and childbearing. Five women who discussed having children with their healthcare professionals described the discussions with their secondary care clinicians who work with patients with MS on daily basis as being more able to answer most questions and to refer them to some useful resources (mainly the MS Society and MS Trust websites). Four women who had discussed childbearing with their primary care with primary care professionals who were not specialised in MS reported less positive experiences. All four women were

informed that during pregnancy the disease activity is usually lower, although they can expect a relapse post partum which is in accordance with NICE guidelines [5]. None of the women was referred to other resources or informed about the potential impact of MS on pregnancy outcomes.

Women listed the internet as the main source of information, followed by books and talking to others in similar situations. Five women reported that having to look for information in diverse places was time consuming, frustrating and not always rewarding.

Five women (three who were planning children, and two currently pregnant) indicated they would like to receive information on whether Disease Modifying Therapies (DMT) could affect their ability to get pregnant or could be associated with miscarriage. Three women who were planning pregnancy wanted to receive clear guidance on how long before conception DTMs should be stopped and whether they can take any medications for MS while pregnant. For example, a woman planning her pregnancy stated: *“I know the medication I’m on now is very strong and I would like to know how long before getting pregnant I have to get off it so my body is safe for my baby”*). One woman who was planning pregnancy wanted to find out more about the impact that assisted reproductive technologies may have on MS progression. All nine women wanted to find out whether MS is a hereditary disease and what is the probability that their baby may develop MS at some future time.

Seven women wanted information about the impact of pregnancy on MS symptoms, the risk of relapse during pregnancy and treatment options in case it occurs. For example, a recent mother

stated: *“My MS started when I was pregnant with my first baby. We want another one but I need to know that if I have another bad relapse there is something they can give me to help and that it won’t harm the baby”*. All six women who were planning to be pregnant or were pregnant expected information about how their condition could impact labour and delivery and what pain relief options are recommended for MS patients during labour: *“I’ve heard that if you have MS you can’t have epidural”*; *“The midwife told me that I really should have a caesarean section as natural delivery is too risky for my baby”*.

As for the post partum period, all nine women wanted to receive information about the risk of relapse after having a baby and whether restarting treatment after the baby is born can reduce that risk. All but one woman indicated they want to breastfeed their babies and wanted to find out whether MS could impair their ability to do so, and whether taking medications for MS is contraindication for breastfeeding: A new mother stated: *“I wanted to breastfeed as I know how important it is but on every [medication] leaflet it says no no no if you’re breastfeeding”*. All women were concerned about their future wellbeing, thus they wanted information about how pregnancy can influence disease progression and whether stopping DMT to have a baby can make their disease worse.

Seven women, including two who had already given birth, stated they would like to receive information about practical issues associated with having a baby, such as where to get professional help with looking after new baby, where to find out more about and buy equipment for disabled parents, who can help if the new responsibilities are overwhelming,

what support can be expected from an employer if they decide to get back to work. Three pregnant women expected some self management advice including how to alleviate MS symptoms during pregnancy, manage fatigue, and planning before the baby arrives.

Clinicians were also interviewed about the information they talked about with women with MS. In opinion of secondary care clinicians (a neurologist and two MS nurses), women with MS who were considering pregnancy were mostly concerned with whether their child can inherit susceptibility to MS. For example an MS nurse stated *"The first question they usually ask is what are the chances their baby will also have MS"*. They also reported that women were concerned about whether discontinuing medication in order to get pregnant may result in relapse and have adverse impacts on the overall disease progression. For example neurology consultant stated: *"When I tell my patients they will have to pause the treatment to get pregnant they want to know whether having a baby will accelerate the progress of their MS"*. All five clinicians mentioned the need for information about the impact of MS medication on the developing foetus if the pregnancy is not planned: *"We must remember that not all pregnancies are planned. I had patients who came to me and asked whether they should terminate pregnancy because they were still on medications."* (MS nurse).

Both MS nurses mentioned the importance of being able to access practical information, like available social and financial support. A nurse stated: *"Patients often think that getting social {services} support is very easy but it's not. They need to be aware they have to plan in advance, make a contact with social services before the baby is born"*. The nurses also commented that

women preparing for pregnancy wanted information about self management especially in regard to fatigue management.

Theme 3: Others' opinions about childbirth choices

All nine women with MS reported that the opinions of other people whom they considered important had a strong impact on their experience of making decisions about having children. Support offered by family members and healthcare professionals facilitated making a decision about having a baby and reduced anxiety associated with MS and childbearing.

All women discussed having children not only with their partners but also with other immediate family members such as parents, in-laws and siblings. Five of them reported being very encouraged by their families to have children. Most family members also offered their support and help after the baby is born. A woman who recently had a baby stated: *"My parents were very happy when we decided to start trying for a baby. When I got pregnant my mother offered to move in with us for as long as we need her after the baby is born. She stayed with us for 5 months and it was a blessing"*. However four women had less positive experiences. One woman who recently had a baby reported that she separated from her husband because in his opinion *'having a child when you have a potentially debilitating condition is not fair on a child'*. Three other women were also discouraged by their family members to have children: A woman who had a baby stated: *'My sister told me that having a disabled mother will put my baby in a difficult position right from the word go...that it will always be different from other children. It stuck with me and when I finally got pregnant I was very worried I will be a bad mother'*.

All nine women had at some point had a discussion with their healthcare professional about having a baby: For example a new mother stated: *“I was diagnosed when I was 28. We were married for 3 years and wanted to start a family so having this conversation as soon as possible was important to me”*. Five women talked about having a child with their MS nurse or neurologist, three spoke to their general practitioner and one arranged a meeting with a midwife before they decided to conceive. In all instances the discussion was initiated by the women.

Women who consulted secondary care healthcare professionals working with MS patients on daily basis found them to be very positive about them having children and reassuring patients that having MS does not put them at greater risk of miscarriage or premature birth and is unlikely to have a negative impact on their baby’s development: For example a pregnant women said: *“I spoke to Dr. (neurology consultant) and he told me that my chances of having a perfectly healthy baby are just like any other women’s without MS”*. This opinion was confirmed in our interviews with clinicians: For example neurology consultant said; *“First I always tell my patients that I am happy for them and that it’s great that they want to start a family. I reassure them that there is no reason why they can’t have a healthy baby”*. Seven women were reassured that having a baby will not accelerate the progression of their disease, however only two were told about the potential positive influence of pregnancy on the course of MS.

However, three women reported that their primary care clinicians raised the issue of their ability to look after a child if their disease progresses. A participant who was currently pregnant stated: *“My GP told me I should not be selfish and think about what I can offer to my child if my MS progresses”*. The GP participant stated: *“For me it’s a bit of a moral dilemma...is it OK to encourage people who have potentially debilitating condition to have children? How it will be in say 10 years when if they require constant care and support?”*

DISCUSSION

The aim of our study was to explore the experience of women living with MS in relation to childbearing and determine what support and information they would like to receive when considering pregnancy or expecting a baby.

It has to be mentioned that presented themes may not reflect the views and needs of all women with MS, their partners and clinicians working with this group of patients. We interviewed only a very small, purposively selected group of women with MS and clinicians, however the convergence of the data with that of studies in other countries is striking, and lends support to the strength of the findings.

Three major themes emerged from the interviews with women with MS. Respondents expressed a number of concerns and worries associated with pregnancy and their condition. Medical concerns included the impact of pregnancy and being off medication on MS progression, the potential impact of MS and MS medication on pregnancy course and outcomes, and the heritability of MS. Practical concerns were around the women’s ability to

look after a child, the availability of help and support and finances. The second theme was around difficulties in finding information regarding MS and childbearing. Respondents rarely received sufficient information from their healthcare providers and also have not come across comprehensive and trustworthy sources of information about MS and having children. The information they found was often conflicting or turned out to be inaccurate. We also found that the opinions that healthcare providers and family members expressed about women with MS having children had adverse impacts on the women's experience of making decisions about having children and childbearing. Women who experienced negative questioning of their ability to 'properly' look after her child seemed to have caused distress and raise doubts regarding having children. However, support expressed by both clinicians and family members facilitated making decision about having children, reduced anxiety and minimized concerns about having children.

This is the first study of the experiences and concerns related to pregnancy and motherhood of women with MS conducted in the UK. Similarly to other studies conducted in Australia [6,7] the main concerns were around their and their baby's future wellbeing; especially how MS can impact MS progression and whether their baby can inherit MS. Like in the Australian studies women in the UK were also worried about how getting off MS medications to get pregnant will impact their condition and their ability to look after their baby and whether they will receive sufficient help and support after the baby arrives. Also in Payne's study [7] women reported being discouraged to have children by both healthcare professionals and family members. In our study this discouragement was often a cause of woman's concerns about not being a 'good

mother'. In our study women reported very positive experiences of discussing having children with secondary care clinicians specialising in MS. Less positive experience of discussing childbearing with primary care professionals who do not specialise in MS was associated with not receiving desired information and occasionally discouragement. Findings from the study conducted in Germany [8] showed that women with MS have very limited and often wrong information about MS and pregnancy. In our study we have not examined women's knowledge; however similarly to Albrecht's findings our study provided evidence that women with MS very rarely acquire desired information about MS and childbearing from their clinicians or any formal resources.

Since MS is usually diagnosed in women of childbearing age who may consider having children, understanding their experience, responding to their needs and providing them with relevant support in making decision about having children, throughout pregnancy and post partum period is an important issue that needs to be addressed by healthcare services. Discussing having children with women with MS requires both an individualised approach and combined knowledge of different areas of medicine and psychology. Ideally counselling for women with MS who are considering pregnancy should be provided by a multidisciplinary team of professionals who can provide information regarding different aspects of MS and childbearing. The evidence from this study of the types and range of concerns, and how difficult women found it was to gain the required information to make informed choices about childbearing may provide a basis for healthcare professionals to better plan how to respond to the expectation and needs of women living with MS who are considering having children.

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DECLARATION OF INTERESTS

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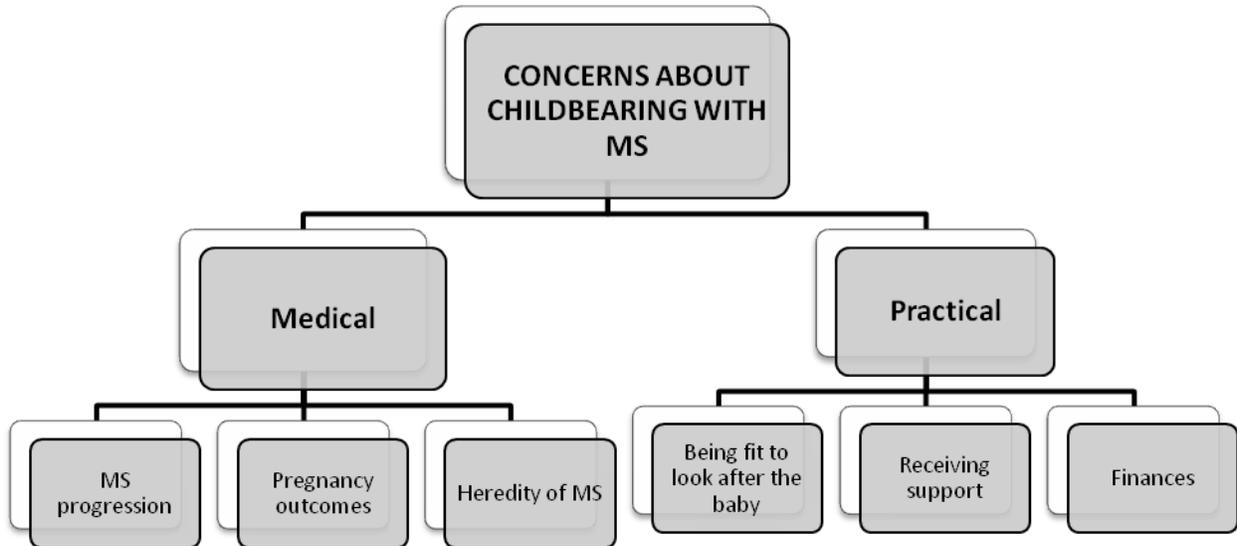
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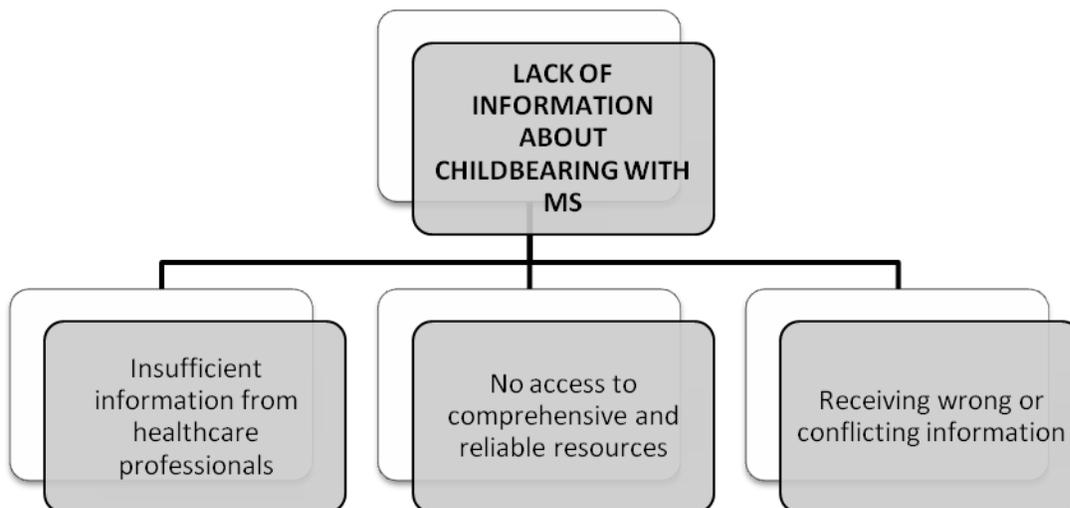
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FIGURE 1: THEMES ARISING FROM THE INTERVIEWS

THEME 1:



THEME 2:



THEME 3:

