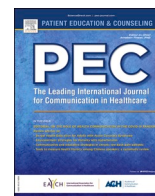




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Family planning and multiple sclerosis: A qualitative study of patient experiences to understand information needs and promote informed decision-making

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ABSTRACT

Objectives: Ambiguity exists about the impact of multiple sclerosis (MS) on fertility and pregnancy. We explored female and male patients' experiences with MS regarding family planning to understand information needs and opportunities to improve informed decision-making.

Methods: Semi-structured interviews were conducted with Australian female (n = 19) and male (n = 3) patients of reproductive age diagnosed with MS. Transcripts were analysed thematically, adopting a phenomenological approach.

Results: Four main themes emerged: 'reproductive planning', revealing inconsistent experiences about pregnancy intention discussions with health care professionals (HCPs), and involvement in decisions about MS management and pregnancy; 'reproductive concerns', about the impact of the disease and its management; 'information awareness and accessibility', with participants generally reporting they had limited access to desired information and received conflicting information about family planning; and 'trust and emotional support', with continuity of care and engagement with peer-support groups about family planning needs valued.

Conclusion: Patients with MS want consistent engagement with HCPs regarding discussion of pregnancy intent and desire improvements in quality and accessibility of available resources and support services to address reproductive concerns.

Practice implications: Family planning conversations should be a part of routine care planning for MS patients and contemporary resources are required to support these discussions.

1. Introduction

Multiple sclerosis (MS) is a chronic, neurological disease that affects the central nervous system. Approximately three million people worldwide live with MS [1]. The average age of diagnosis of the disease is 32 years (20–50 years of age) and females have a threefold higher risk of developing MS than males [1].

As the diagnosis of MS typically coincides with the peak reproductive years, the disease and its management present several unique challenges among female and male patients regarding family planning. In the context of this research, family planning relates to the areas of contraception, fertility, pregnancy and postpartum. While there is no clear

evidence that MS itself is associated with male or female infertility or adverse pregnancy outcomes [2,3] concerns about the reproductive effects of MS treatments as well as potential disease progression if treatments are ceased are common among those living with MS [4]. Disease modifying treatments (DMTs) are the mainstay of MS treatment, yet for many DMTs there is uncertainty about their potential effects on fertility or foetal development [5]. This leads to concerns about safety of use among those planning a pregnancy and in those who are currently pregnant. For female patients taking certain DMTs, guidelines commonly recommend concurrent use of contraception to prevent risk of unintended pregnancy and that the DMT be ceased during pregnancy [6]. This carries the risk of a deterioration in symptom management and

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an increased risk of relapse occurring within the first three months postpartum [7]. Less is known about the impacts of DMTs on male fertility and reproductive outcomes [8].

Recommendations and tools have been published previously to help guide HCPs and patients with MS to navigate decision-making about family planning [8–10]. Despite the availability of such recommendations and resources, there has been limited exploration of the experiences of those living with MS with respect to family planning. Such insights are critical for improving understanding of information and health service needs to supporting individuals with MS on their reproductive journey.

Previous research has focused on females and has generally reported that female patients with MS experienced inconsistent management of their MS before, during and after being pregnant [11–15]. Furthermore, female patients with MS have expressed a greater desire for counselling and support specifically related to reproductive decision-making [14]. A key limitation of previous studies is that they were undertaken prior to the availability of many of the newer DMTs and therefore do not reflect contemporary practice.

This study aimed to explore the experiences of Australian female and male patients living with MS in relation to family planning and identify information and health service needs to better support them.

2. Methods

2.1. Research design and sample

In 2021 we undertook a qualitative study involving a purposive sample of female and male patients of reproductive age living with MS.

Eligible participants were between 18 and 49 years of age, living in Australia, with any type of MS, and able to communicate in English. Participants were recruited via promotional materials advertised on the

website and social media channels of MS research and support organisations. Furthermore, the study’s flyer was advertised through a Facebook group concerning mothers who live with MS and the Twitter account of Robinson Research Institute at the University of Adelaide, with which the authors are affiliated. None of the participants were known to the research team prior to participating in the study and no members of the research team were involved in their clinical care.

Interested participants first completed a short online survey on REDCap [16] via a link that was included on the flyer. REDCap is a secure, web-based application used to collect and store data for surveys and projects. The survey link also included the participant information statement and consent form. The short survey was designed to aid in screening participants and included 11 questions including name, year of birth, postcode, type of MS, number of years living with MS, number of children, email, contact number, gender, primary language, and preferred method of contact. Following completion of the survey, participants were contacted by a member of the research team (AF) and invited to participate in an interview, either face to face or via phone or by videoconference, based on the preference of the participant. All but two interviews took place virtually. An overview of recruitment can be seen in Fig. 1.

2.2. Data collection

Semi-structured in-depth interviews were conducted by one team member (AF). An interview guide was developed that included prompts (see Table 1). The interviews encompassed asking participants to describe the following: (a) their experiences in relation to family planning; (b) the practices they utilised to obtain information on family planning; (c) the role of their HCPs in the management of the condition during family planning; (d) their comprehension of the received information around family planning; (e) their potential involvement with any

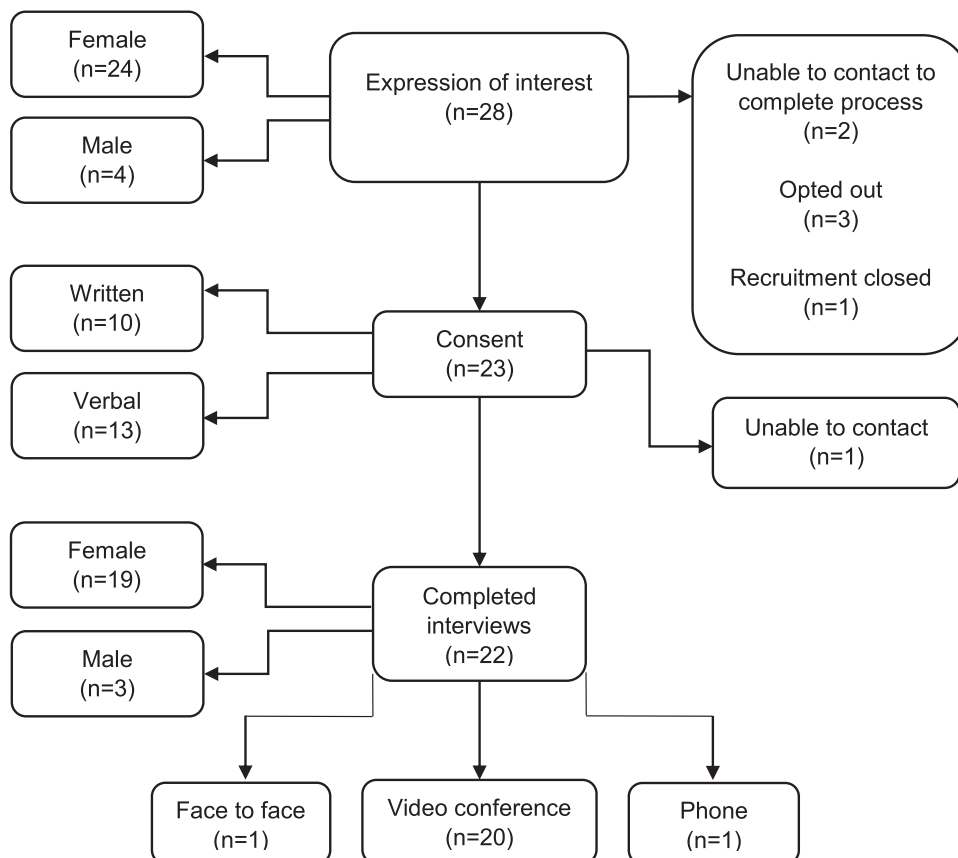


Fig. 1. Overview of recruitment and study procedure.

Table 1
Participant interviews' topic list.

Topic	Sample Question
Factors affecting decisions	Can you explain how your experience regarding family planning evolved following diagnosis? (Prompts: fertility, contraception, pregnancy, childbirth, postpartum)
Information Sources	Where did you get information from about the different aspects of family planning? How did [health care professional] respond when you expressed interest on [prompt]? (Prompts: fertility, contraception, pregnancy, childbirth, postpartum)
Comprehension of information	How easy is it for you to understand the information family planning and the impact of the treatments on (Prompts: fertility, contraception, pregnancy, childbirth, postpartum)? What would help you to understand this information better?
Community Support Networks	Are you involved in any support groups or networks for people with MS? (Prompts: If not, why? If yes, how being involved impacted you?)
Access to services	What enablers or barriers did you encounter accessing services in relation to family planning (Prompts: fertility, contraception, pregnancy, childbirth, postpartum)?
Preferences	Do you have any recommendations or suggestions for other women and men in your position?

peer-support groups for reproductive matters; and (f) the potential challenges they faced when accessing services in relation to family planning. Prior to the commencement of the interview, either written or verbal consent was collected, based on the preference of the participant. Participants were offered a \$30 electronic voucher as a compensation for their time.

Participants were also given the opportunity to review the transcripts of their interviews. No participant requested to review their transcripts. However, two participants, after the interview concluded, emailed the interviewer with additional information, which was included in the analysis.

Interviews were conducted between 29th of March to 14th of August 2021. Interviews were audio-recorded and later transcribed in full.

2.3. Data analysis

The data was analysed using thematic analysis as described by Braun and Clarke [17]. A phenomenological approach was chosen to explore in-depth the essential meanings of participants' experiences [18].

Initially, a preliminary analysis of the transcripts occurred to prepare the data for further analysis and gain an understanding and a sense of the potential emerging themes, using a data-driven coding approach. This enabled the review of the initial responses and allowed the construction of a coding scheme based on major themes that emerged. Subthemes resulted by this process were organised based on the interview topics which were previously developed, and which reflect the aims of the study. The generated subthemes can be seen in Table 2.

Ongoing discussion with, and feedback from other research team members helped to define the scope of the phenomenon under study, to discuss and agree potential approaches to data collection and analysis and to confirm interpretation of the qualitative analysis that was undertaken. The COREQ list was used to report on the study [19] (See supplementary material 1). The transcripts were analysed using NVivo version 12 Plus [20].

2.4. Ethical approval

Ethics approval was received by the University of Adelaide's Human Research Ethics Committee (approval number: H-2021-013).

Table 2
Definition of subthemes and structure.

Themes	Subtheme	Definition
Reproductive planning	Discussing pregnancy intention	Comments around discussion of reproductive matters and the disease management, and the time point this occurred with HCPs.
	Participant involvement in decision-making on reproductive matters	Comments around how much participants felt involved in decisions about reproductive matters and the management of their disease.
Reproductive concerns	Passing the disease to the offspring	Comments around the impact that MS might have on reproductive choices.
	Reproductive effects of DMTs	Comments around the impact DMTs might have on fertility and offspring.
	Disease progression and management	Comments around the disease activity and progression in case of a pregnancy and the impact that might have on reproductive choices.
Information awareness and accessibility	Coping as a parent	Comments around the ability to cope as a parent and/or being a burden to others.
	Adequacy of information	Comments on the sources of information regarding family planning and whether this information was available, and met participants' needs.
	Conflicting information	Comments around the consistency and inconsistency of information.
Trust and emotional support	Continuity of care	Comments around the type of care participants receive and want with their HCPs while managing reproductive health.
	Engagement with peer-support groups	Comments around the impact of being involved and engaged with peer-support groups through the MS organisations and social media regarding reproductive matters.

3. Results

In total, 24 females and four males expressed interest to be involved in the study, from which 19 females and three males with a mean age of 34.8 (range 27–49) completed the interview. Of those, eight participants reported that they already had children (six females and two males), and four participants were pregnant at the time of the interview. The interviews on average lasted 69 min (range 35–110 min). Participant characteristics are presented in Table 3.

The analysis of the transcripts revealed four main themes in relation to the experiences of family planning in the context of MS. These included: 1) reproductive planning, 2) reproductive concerns, 3) information awareness and accessibility, and 4) trust and emotional support. The themes and subthemes are further described below and indicative quotes to support each theme are listed in Table 4.

3.1. Reproductive planning

Participants in most instances reported that they were the ones to initiate discussion with their neurologist about pregnancy planning, with mixed experiences of how considerations regarding pregnancy intention were incorporated in decision-making about treatment of their MS.

Table 3
Participant characteristics.

Variables		N - Range	Mean - %
Gender	Female	19	86.4
	Male	3	13.6
Age	All	27–49	34.8
	Female	27–49	36.4
	Male	28–37	33.3
Type of MS	RRMS	22	100
Year of diagnosis*	Pre 2011	6	27.3
	Post 2011	16	72.7
Children	Yes	8	36.4
	No	14	63.6
Pregnant (female)	Yes	4	21.1
	No	15	78.9
Setting	Public	3	13.6
	Private	19	86.4
Geographical area	Urban	15	68.2
	Rural	1	4.5
	Regional	6	27.3

3.1.1. Discussing pregnancy intention

Regardless of pregnancy intentions, some reported that contraception was not something that was actively discussed with their neurologist in any of the consultations. Usually, contraception was a subject discussed with their general practitioners (GPs), but not in the context of the management of their MS.

Female participants commonly spoke of being responsible for initiating conversations about pregnancy intention with their neurologist. When pregnancy intention was discussed, females commonly reported receiving advice from their neurologist about staying off their medication for a certain period of time before trying to conceive. Further, participants commonly reported neurologists advising them of the importance of stabilising their disease activity prior to falling pregnant to reduce the risk of disease exacerbation post birth.

Some female patients who already had children, reported that they wished that had received better information about pregnancy and MS prior to becoming pregnant. Participants reported that having had access to better information would have alleviated concerns and anxieties they had related to the safety of continuing or ceasing their DMTs and could have provided greater reassurance related to decision-making.

In contrast to female patients, males did not report having conversations with their neurologist or other HCP about their desire to have a family.

Several participants reported that they had use of assisted reproductive technologies (ART). However, very few reported any discussion of use of ART with their neurologist, or conversely, discussions with fertility specialists about the implications of MS for fertility and pregnancy health.

3.1.2. Participant involvement in decision-making on reproductive matters

In general, decisions about planning a pregnancy were heavily dependent on the type of DMT used by participants and also their disease activity. They reported that while neurologists infrequently asked about pregnancy intent, once raised by participants, in general they felt that neurologists supported informed decision-making regarding which DMT best suited their situation. This usually required a careful balance of weighing up reproductive concerns and optimal disease management.

3.2. Reproductive concerns

Participants expressed several concerns that played a key role in influencing decisions relating to disease management and family planning. These are described below.

3.2.1. Passing the disease to the offspring

While nearly all participants reported experiencing concerns about

Table 4
Participants' voice.

Theme	Subthemes	Quotes
Reproductive Planning	Discussing pregnancy intention	<p>"I don't think they asked me that [pregnancy], I think I would mention to them about having children and if it would affect my ability to have children, but I don't think they would have asked me if I was interested in having children." F13</p> <p>"As far as the management of the MS, that was kind of completely independent of any wishes for starting a family and going down the IVF path as well. I didn't come off treatments yeah. Continued it through out" M26</p> <p>"The only time we [neurologist and participant] discussed it [contraception] was with Tysabri and especially Lemtrada, with Lemtrada you couldn't, it wasn't recommended you could fall pregnant within four months of the treatment and so he just confirmed with me 100% that I was still on the pill". F07</p>
	Involvement in decision-making on reproductive matters	<p>"I just accepted that they are the professional and they know what they are doing and (chuckles) accepted the decisions... I don't think I would not be involved ... but yea, I trusted that...they are the ones that you know have the education, I trusted that they were doing the right thing... I guess." F02</p> <p>"I feel very involved because I feel like in a way I had to be an advocate for myself... I feel like had I not advocated for myself, I would be going into this feeling not very involved at all and not very educated on it." F09</p> <p>"I was told...by my neurologist 'You have to make your own decision about the medication', I was like 'I don't have the level of expertise that a specialists has'". F10</p>
Reproductive Concerns	Passing the disease to the offspring	<p>"I've always worried about if the kids will have the MS down this track or not". F01</p> <p>"Issues around the likelihood of a baby/offspring developing MS has been a common concern. Call it guilt or hyper vigilance, the idea of passing this condition on, causes big emotionally loaded questions." F10</p> <p>"The main concern obviously, is that living with a pre-existing condition, you know, ... you wouldn't be in a position where your child is going to inherit it. That was probably the main concern, I guess." M26</p>
	Reproductive effects of DMTs	<p>"I was worried that, the medication might have done something to trigger infertility." F01</p> <p>"Across all the different treatments that I had um one of the first questions I asked was "Should I freeze my eggs?" especially with Lemtrada,</p>

(continued on next page)

Table 4 (continued)

Theme	Subthemes	Quotes
		<p>which is a chemo-therapy drug, "Should I be freezing my eggs and considering that?". F07</p> <p>"I remember at the time I did talk about pregnancy, and you know, cause it is a chemo drug [Lemtrada], "Would it affect my fertility?" F09</p>
	Disease progression and management	<p>"It was really sort of challenging I think, because you know I am 33 years old... 'Oh Gosh, what happens if we can't have children?'" F06</p> <p>"I was constantly worried about postpartum relapse, but yeah, I was, I think the MS nurse has also said to me, if I breastfeed [child's name] that it also has a protective effect on my body similar but not the same similar to pregnancy and I had that going in my head as well." F23</p> <p>"...as a man that, you know, the things that I need to consider like, you know, not, not being able to ejaculate that kind of been a really big part of my MS journey... the only option that was going to be available was going to be IVF for us." M26</p>
	Coping as a parent	<p>"I guess once I was pregnant, I was a bit worried about how I would cope and I got lot tireder, because fatigue for me has been a big issue anyway" F01</p> <p>"That would be the biggest consideration, am I going to be well enough for my kids and is it the right thing to do?" F17</p> <p>"I was just worried about having a relapse and everybody else having to drop everything in and help me, I think it's more the yeah, I suppose that the helplessness that comes with having a relapse and having to rely on other people so much. I think that's where a lot of the worry comes from." F23</p>
Information awareness and accessibility	Adequacy of information	<p>"There is not a lot of information out there and not all General Practitioners are across what MS is and what the drugs are and things like that." F01</p> <p>"I just don't feel that information is readily available, and nobody really shares it with you." F19</p> <p>"Maybe the information that you need is not always as accessible...I find the information they might present about a topic like this [MS and family planning] to be really kind of just skimming the surface, and not really getting into a lot of detail." M26</p>
	Conflicting information	<p>"Oh, is having biological children a good idea?" ... you do read conflicting opinions on that." F06</p> <p>"I think that's one of the facts that when you get the information from the neurologist and then with the interaction with other people via social media, a conflict is created let's say." F07</p>
Trust and emotional support	Continuity of care	<p>"I think it's not even having someone...seeing someone twice a month, cause I see probably my</p>

Table 4 (continued)

Theme	Subthemes	Quotes
		<p>neurologist once every six months, but also having the availability and also having, knowing that you have a separate number you can call them or just knowing that they are there and they have all your information in front of them all the time kind of thing." F01</p> <p>"Whenever I'd spoken to them about my concerns with MS and pregnancy and what it could mean for the baby and I, things like that, they've always has been really reassuring and whatever challenges that could come up throughout this process, they've always been very confident that they can handle it and they will be fine." F09</p> <p>"I always referred back to my neurology team. They were the ones looking after me and the obstetric team, or the paediatric team at the hospital..." F22</p>
	Engagement with peer-support groups	<p>"For the most part, I feel like it's a positive experience to talk to people who are like me but, you know, it can also be really hard. So, it just depends on how I'm feeling on the day or, you know, how advanced someone might be in their disease." F05</p> <p>"I think it's something that's needed for mums because...if you have MS and people who have kids or trying to conceive, so it sorts of covers everything and this, this a broad range of experience in the mothers that they are there on the website. And I think it's good to have a safe place to be able to talk about things." F23</p> <p>"I was part of a under 30 s teleconference group that ran for six weeks a couple of months ago, so that was really good. And since then, the rest, some of the group and myself we're doing monthly meetings as well." M25</p>

heritability of MS, none reported that this resulted in a decision not to have children. Concerns about heritability were addressed through participants raising this with their neurologist or consulting other information sources such as the internet.

3.2.2. Reproductive effects of DMTs

When female patients reflected on their experiences of either entertaining the possibility of a pregnancy or actively planning a pregnancy at the time of the interview, they often spoke about receiving advice to change or cease their DMT. This enhanced their concern about potential negative impacts their DMT may have on their fertility, pregnancy and health and wellbeing of a child.

No male participants expressed concerns about the potential impacts of using DMTs when attempting to conceive.

3.2.3. Disease progression and management

Female patients commonly expressed concerns in relation to the unpredictability of their MS course during and following pregnancy. They often mentioned the increased risk of relapses post childbirth and their concern that this might have an impact on their wellbeing and ability to care for their child. Similarly, the "unknowns" of stopping

using a DMT to get pregnant coupled with the high risk of postpartum relapses, which may lead to disability, were key concerns when contemplating a pregnancy.

Common advice received from neurologists to stabilise their disease prior to falling pregnant raised concerns with some participants that they may not be able to fall pregnant due to age-related infertility.

Male patients reported concerns about the impact of MS on sexual function. Of those, only one participant raised concerns that this may affect their ability to conceive naturally, which could necessitate use of ART.

3.2.4. Coping as a parent

Female participants frequently reported that they were worried whether they would be able to care for their children. This was most often discussed in the context of postpartum relapses resulting in increased disease activity and possible disability. Following this concern, some female participants said that they might have to rely on members of their family, which led them feeling as being a “burden” to others.

No male participant expressed concerns regarding their ability to cope as a parent or about feeling like a burden to others.

3.3. Information awareness and accessibility

Participants spoke about wanting easily accessible and reliable information, with common experiences reported about information received being insufficient in content and often conflicting.

3.3.1. Adequacy of information

Most participants reported actively seeking information on MS and family planning from what they called ‘trustworthy sources’, such as their neurologist. However, they were not often satisfied with the information around pregnancy and breastfeeding in relation MS they received. The majority of the participants listed limited consultation time as a reason for not having extended conversations with their neurologists about family planning. This led them to seek information from a variety of other sources, including MS nurses, GPs, the internet (i.e., MS organisation websites, Google, social media etc.) as well as from product information pamphlets given to them about DMTs.

The participants who had access to an MS nurse highlighted the value of in-depth discussions and the information they received from them. Some participants suggested that GPs could benefit from additional training about MS and family planning.

Participants’ ability to understand the information provided around MS and reproductive matters was also discussed. Most participants mentioned that the information, although not adequate in content, was easy to understand. One participant mentioned having cognitive issues that made it challenging to understanding or retain information on these topics.

3.3.2. Conflicting information

Seeking information from various sources led to conflicts about MS and reproductive issues, which was a common concern expressed by participants. Common topics where conflicting information was received included the length of time considered to safely conceive after ceasing a DMT, and likelihood of parents passing on MS to their children. Receiving conflicting information was more common among those engaging with information sources other than HCPs, such as the internet or peer-support groups. This, in most cases, did not impact decisions around having children, but the receipt of conflicting information was often a source of decisional conflict or unnecessary anxiety, which participants felt could be alleviated through improved information.

3.4. Trust and emotional support

This theme illustrates key elements of participants’ experiences

when utilising services regarding family planning.

3.4.1. Continuity of care

The participants who had already had a pregnancy reported that they wanted consistency of HCPs and a desire to not repeat themselves at each clinical encounter with their neurologist. Participants felt reassured when their HCPs were communicating with each other generally about their MS management, but this did often not occur when they were transitioning between specialist neurology care and other services relevant to family planning including fertility providers, antenatal care providers and GPs. Some participants viewed private specialist care as more favourable to public care as it often provided improved consistency in interactions with neurologists. This was associated with improved feelings of trust and reassurance in the quality of care they were receiving.

3.4.2. Engagement with peer-support groups

Participants reported a high level of engagement with reproductive-focused peer-support groups, either via MS support organisations, or social media groups for mothers with MS. A number specifically reported having focused discussions around family planning and pregnancy within these groups, but reflections and experiences were mixed. Often, participants reported interacting with people with more severe MS disease states which in some cases had a negative impact on their own emotional state. This experience was more commonly reported among those newly diagnosed with MS or with mild disease activity. Others found that the interaction with such groups helped them greatly as it allowed them to draw on other people’s experiences and provided them with a degree of emotional support and reassurance that pregnancy and parenting with MS is possible.

4. Discussion and conclusion

4.1. Discussion

Our study provides a detailed contemporary understanding of the experiences of those living with MS in relation to family planning. The findings identify opportunities to improve conversations between patients and HCPs about pregnancy intention and a need for improved access to contemporary information about common reproductive concerns related to MS and its management. This provides critical evidence to inform strategies to better support informed decision-making about commencing or ceasing certain MS treatments and about timing or avoiding a pregnancy.

In our study, patients with MS wanted HCPs to engage them in conversations about pregnancy intention, however, they reported that this did not often occur in a proactive manner. Instead, participants were often the first to initiate these conversations. This may suggest there are missed opportunities for HCPs to discuss and understand a patient’s pregnancy intention and tailor their clinical management with this information in mind. Research undertaken with female participants with other chronic conditions (e.g., epilepsy, type 1 diabetes etc.) has also identified the need for HCP to have more proactive discussions about pregnancy intentions to help female patients avoid unplanned pregnancies and to optimise health during conception [21]. This suggests that there may be common barriers among HCPs caring for females with chronic conditions that prevent them from routinely asking about pregnancy intention. Barriers reported in previous studies examining rheumatoid arthritis and kidney disease include limited time during the clinical encounter [22,23] and lack of confidence and knowledge among HCPs regarding discussions of reproductive health topics (i.e., contraception, IVF, managing pregnancy) [23]. These challenges highlight the potential value of tools for HCPs to facilitate conversations about family planning in the context of managing a chronic disease [24,25].

Due to concerns about potential teratogenicity, the use of effective methods of contraception are recommended for MS patients taking

newer DMTs [26]. However, participants in this study reported that neurologists rarely discussed contraception and preferred to defer such conversations to other HCPs, such as the individual's GP, consistent with previous research [27]. Furthermore, the interviews revealed that there was often limited communication between neurologists and GPs about MS management plans, which often resulted in repetition of participant's medical history and the feeling of concern around disease management consistency.

A lack of communication between HCPs caring for female patients with chronic conditions currently pregnant or planning a pregnancy has been reported previously. For example, in their study of female patients with auto-immune rheumatic conditions, Philips et al. found that there was little or no perceived communication between the different disciplines involved including rheumatologists, nephrologists, GPs, midwives etc. [28]. This is consistent with the findings of our study. Importantly we also found that participants reported feeling reassured in circumstances where they could see that HCPs were actively communicating with each other regarding their clinical care. The importance of having support provided by HCPs to help people with MS making family planning decisions is highlighted in the literature [14,29]. Participants also valued continuity of care, in particular, seeing the same clinicians and receiving more consistent information about family planning. This may relate to a greater sense of trust when care is delivered by a known health care provider, which may in turn help to facilitate proactive discussions around pregnancy intentions.

The current study builds on previous research examining the experiences of female MS patients in Australia concerning decisions about actively planning a pregnancy [15]. The themes that emerged from the previous mentioned study emphasised a variety of factors, such as lack of information around pregnancy in the context of MS, and concerns about mother's and offspring's wellbeing, that influence decisions concerning family planning and MS, and are consistent with our study. In our study, participants frequently reported they have difficulty accessing information about a range of issues related to family planning and MS. The difficulties related to a lack of access to information on certain topics such as pregnancy and safety of DMTs during pregnancy, as well as a lack of consistency in the information they received or found (e.g., about heritability of MS). This is consistent with the findings of studies outside of Australia [14,25,30] indicating that there are persistent gaps in access to comprehensive information about family planning in the context of MS.

Previous research demonstrates that inadequate access to high quality family planning information can create or exacerbate reproductive concerns among MS patients who are contemplating pregnancy [12–15,31]. These concerns can be focused on the disease itself and the uncertainty surrounding it as well as the safety of DMTs, findings that also emerged from our study. The concerns expressed about the safety of DMTs, both in our study and in others highlights the need for further research addressing current gaps in evidence about the safety of contemporary DMTs in pregnancy [5].

Studies exploring the experiences and perspectives of pregnancy in female patients with MS indicate that the most common source of information was their neurologist [15,32]. However, patients often also seeking seek information from other sources due to inadequate consultation time with their neurologist [14,15]. This is consistent with the findings of our study. In addition, difficulty in finding the information they desired relating to family planning and MS led many participants to utilise multiple information sources. In some cases, using multiple information sources also created conflict related to receiving inconsistent information. As such, it was clear that participants wanted adequate, reliable, readily available, and comprehensive information addressing their concerns around family planning to better inform decision-making.

The desire for more consistent information and engagement with HCPs surrounding family planning suggests that existing tools developed to improve reproductive decision-making among female patients with MS may be underutilised [33]. Steinberg et al. recently report on

the development and piloting of a tool to assess self-reported measures of knowledge and concerns regarding MS and motherhood [34]. Tools such as this could be used to identify individuals most likely to benefit from reproductive focused interventions or evaluate the impacts of such interventions in improving knowledge and reducing concerns.

4.1.1. Strengths and weaknesses

Our study has a number of strengths. We comprehensively examined a broad range of topics around reproductive health decision-making and included participants utilising contemporary DMT treatments. As such this is the first study to examine experiences of Australian MS patients, both female and male patients, related to family planning across the reproductive life course, from contraception to postpartum. We used a phenomenological approach to explore the lived experiences of the participants in depth.

However, our study has a number of limitations. We failed to recruit a greater number of male patients; an experience common across other studies examining reproductive health matters relevant to male patients. All participants had one specific type of MS (relapsing-remitting MS); therefore, it is unclear whether experiences may differ based on other MS types. As the collected data was self-reported, there may have been a degree of recall bias due to cognitive issues, or recollection of events that occurred many years ago.

4.2. Conclusion

Our findings show that people with MS want to have proactive or early conversations with HCPs about pregnancy intention so that concerns can be addressed. These conversations should be incorporated into routine clinical care of MS patient's main HCP. People with MS also want to be actively involved in decisions that influence their reproductive health choices. There is also a consistent demand for clearer and coherent information regarding MS and family planning, including safety of DMTs, that is easily accessible.

While our study sheds light on consumers experiences related to family planning, there is a need for accompanying research exploring the experiences and perspectives of HCPs to better understand how consumer information needs can be better addressed in practice.

4.3. Practice implications

Health care professionals should take the opportunity to routinely ask about pregnancy intention and facilitate conversations that address reproductive concerns common to individuals of reproductive age living with MS. This necessitates the need for improvements in the development and dissemination of resources that can be used to assist in prompting and guiding conversations about family planning. There is also a need to improve interdisciplinary collaboration and information transfer relating to family planning, while supporting greater continuity in care.

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CRediT authorship contribution statement

Anna Fragkoudi: Conceptualization, Visualization, Methodology, Preliminary and Formal analysis, Writing – original draft, Writing – review & editing. **Luke E. Grzeskowiak:** Methodology, Analysis, Writing – review & editing, Validation, and Supervision. **Alice R. Rumbold:** Methodology, Analysis, Writing – review & editing, Validation, and Supervision.

Declarations of interest

The authors have nothing to declare.

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Appendix A. Supplementary material

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.107673](https://doi.org/10.1016/j.pec.2023.107673).

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