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Title

“I'm walking into the unknown": Qualitative insights into how emotions and lived experience related to multiple sclerosis diagnosis impact on decisions to pursue disease modifying treatment.

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Abstract

Introduction: People with Relapsing Remitting Multiple Sclerosis (RRMS) are increasingly included as active participants in shared decision making around their treatment options. Choosing a first disease modifying treatment (DMT) is a complex process that often takes place soon after a diagnosis has been given. Patients therefore are often required to make difficult decisions at a time when they are still coming to terms with their illness. This study investigated the views and experiences of recently diagnosed patients with RRMS when they were making their initial DMT choice.

Method: This was a qualitative study involving in-depth semi-structured interviews with patients with RRMS in a National Health Service (NHS) setting in the United Kingdom. Data were collected from 6 patients and analysis was guided by an Interpretive Phenomenological Analysis (IPA) approach.

Results: Initial reactions to diagnosis were characterized by strong emotions and a feeling of despair and hopelessness. Subsequently the DMT decision was shaped by multiple considerations around maintaining normality, and restoring hope and control over one's life whilst reconciling uncertainty around efficacy. Considering the future with a DMT elicited reflections around employment and family planning.

Conclusion: Emotions and lived experience related to recent MS diagnosis can impact on the initial DMT decision in number of ways. Health care professionals need to understand the lived experience of patients making DMT decisions soon after diagnosis when engaging in shared decision making.

Keywords

Multiple Sclerosis, relapsing remitting

disease modifying treatment

treatment decision

qualitative research

1. Introduction

Management of relapsing remitting multiple sclerosis (RRMS) includes symptom management and rehabilitation alongside the use of disease modifying treatments (DMTs). An individual's RRMS prognosis depends on a variety of factors such as age, sex, relapse frequency, type of relapse, lesion load on MRI scan and extent of spinal cord involvement (Scolding et al., 2015). However, at present it is not possible to accurately predict a person's disease trajectory if left untreated, or their likely response to DMT. Generally, the more effective the DMT is in controlling inflammatory disease activity, the greater the risk of more severe side effects, such as autoimmunity (EMC, 2021) or Progressive Multifocal Leukoencephalopathy (PML), a potentially life-threatening brain infection (EMA, 2021).

As of October 2021, there are fifteen DMTs licensed for use within the NHS which have different eligibility criteria, levels of efficacy, intensities of safety monitoring requirements and routes of administration. The varying options between each DMT mean that patients face complex decisions regarding their initial choice of DMT. This complexity is documented in the published literature (Lowden et al., 2014; Reen et al., 2016; Manzano et al., 2020), and is likely to increase further as more DMTs are launched in the UK in the coming years.

Despite an increased emphasis on informed choice and shared decision-making when planning treatment with a DMT (Heeson et al., 2007; Colligan et al., 2017), evidence suggests that patient and provider perceptions of treatment preferences can be discordant (Col et al., 2017; Tintore et al., 2017; Bermel et al., 2020). Moreover, RRMS patients have been found to have poor understanding of the disease (Köpke et al., 2018), and of the risks associated with treatments following diagnosis (Giordano et al., 2018), leading to a tendency to underestimate treatment risks (Reen et al., 2016) whilst overestimating their benefits (Heesen et al., 2017). This may be further impacted by the cognitive impact of MS which can impair decision making, leading to a tendency to make risky decisions that favour immediate gain over long term outcomes (Neuhaus et al., 2018). Such work underlines the challenges of shared decision making around first treatments.

In conjunction with the requirement for shared decision making, the propensity in current clinical pathways towards early induction treatment of RRMS, with more effective yet more risky DMT (Scolding et al., 2015; Giovannoni et al., 2016), is facilitating more patients in taking an active role in their initial DMT decision during the time they are also adjusting to their recent diagnosis of RRMS. This period has been identified as a key decision-making moment in the journey of MS patients in terms of influencing decision preferences (Van Capelle et al., 2017; Van Reenan et al., 2019; Visser et al., 2020). The proximity of diagnosis and decision is an additional complexity for recently diagnosed patients (Manzano et al., 2020), and such patients are vulnerable to being overwhelmed by information regarding the disease and its treatments, which may impact treatment decisions (Vermersch et al., 2020).

Such complexity has led to increased emphasis on the need to explore the psychosocial and emotional context of the decision process for recently diagnosed patients, and the process of adjustment to a diagnosis of RRMS (Irvine et al., 2009; Dennison et al., 2011). The unpredictability and uncertain prognosis of RRMS is associated with negative emotional outcomes and distress, making the post-diagnosis phase critical for psychological wellbeing (Kroencke et al., 2001; Janssens et al., 2003; Possa et al., 2017). Chronic illnesses such as MS are also often accompanied by changes in a person's identity, self-perception, values and beliefs, and relational changes with others (Boeije, 2002; Weinreich & Saunderson, 2003; Irvine et al., 2009). Treatment decisions can interact with this turbulent context of psychological and emotional adjustment, and identity renegotiation. In some instances, this interaction forms an important step in the process of adjustment (Lowden et al., 2014). However, where there is denial or resistance to the stigma of illness (Dennison et al., 2011), treatment onset can be delayed (Manzano et al., 2020). DMT's hence may pose as a threat or an opportunity depending on an individual's circumstances (Eskyte et al., 2019). Greater understanding of this phase is thus needed to better support the treatment decisions and adjustment of newly diagnosed patients (Topcu et al., 2020).

Research over the last decade has sought to redress the paucity of work that qualitatively explores patient perspectives on treatment decisions in MS (e.g., Van Capelle et al., 2015; 2016; Manzano et al., 2020). This work has argued that more credence should be given to the patient journey and lived experience of people with MS, in order to establish how their everyday lives and psychosocial worlds figure in decision making (Eskyte et al., 2019), particularly of those newly diagnosed with RRMS (Van Capelle et al., 2017; Van Reenan et al., 2019). This exploratory study aimed to gain insight into the lived experience of the initial DMT decision from the perspective of RRMS patients in a UK National Health Service context. The study employed an Interpretive Phenomenological Analysis (IPA) approach to explore the psychosocial and emotional experiences of people with RRMS in response to their diagnosis and subsequent treatment decisions.

2. Method

2.1 Setting and study population

This study received ethical approval from the University of Central Lancashire (STEMH447) and Greater Manchester East NHS Research Ethics Committee (16/NW/0122). Participants gave written informed consent prior to taking part. Participants were recruited via maximum variation purposive sampling from patients attending an NHS regional specialist DMT prescribing centre in the North-West of the UK. We included patients who chose highly effective, higher risk DMTs as well those who chose moderately effective, lower risk DMTs. Potential participants were approached by an MS nurse, and were given a study information sheet and the researcher's contact details.

2.2 Data collection

Participants took part in an individual in-depth interview. An interview topic guide based on the findings of a literature review provided a heuristic framework for the discussions. This guide was provided to participants in advance of the interview, to accommodate patients with cognitive impairments. None of the individuals declined to participate. Interviews were conducted within an NHS hospital, after completion of the initial DMT decision, but before initial dosing of the chosen DMT. Participants were given the option to have family or carers present during the interview, however none chose to do so. The interviewer was a qualified speech and language therapist who was highly experienced in working with similar patient groups.

2.3 Analysis

Interviews recorded with a digital recorder were transcribed verbatim and anonymized using pseudonyms prior to analysis. Analysis was guided by an Interpretive Phenomenological Analysis approach (Smith et al., 2009), suitable for exploring lived experiences, and was supported by NVivo 11 software (QSR International, USA). Starting with the first transcript, content topics and expressed emotions were identified and paraphrased, then combined into emergent themes and patterns. Each of the transcripts were subsequently analysed in turn, then all emergent themes and patterns were grouped. Attempts to 'bridle' the researcher's presumptions and to improve rigour were made throughout the interviews and analysis (Dalhberg, 2004) by completion of a reflective diary, and by duplicate analysis of a subset of transcripts by a second researcher, followed by discussion.

3. Results

A total of 6 participants were interviewed. Interview duration ranged between 56 and 83 minutes (average 66 minutes). Sociodemographic details can be found in Table 1. All participants are referred to using pseudonyms. All but one participant had received their diagnosis of RRMS within the previous 26 months. Lily was the exception to this, having received her diagnosis around 12 years prior to the interview.

Table 1

Sociodemographic characteristics

Characteristic	Result
Age (mean)	38
Age (range)	24-49
Sex	
Female	3
Male	3
Time from diagnosis (mean months)	16.25
Time from diagnosis (range in months)	4 - 144
EDSS score (range)	1.0 – 3.5
Initial DMT choice	
Tysabri (natalizumab)	2
Lemtrada (alemtuzumab)	1
Copaxone (glatiramer acetate)	3

Key themes were related to 1) The RRMS diagnosis and emotional reactions of shock and hopelessness; 2) The DMT decision; 3) considering the future with a DMT. Representative quotes are presented in Table 2 to illustrate each theme and sub-theme.

3.1 Theme one: The RRMS diagnosis: Emotional reactions of shock and hopelessness

All participants described strong emotional reactions to receiving the diagnosis of MS which included expressions of shock, despair and hopelessness. Emotions during this period appeared turbulent and changeable. For James, initial hopelessness was accompanied by a sense of loss of control and helplessness in the face of the disease, which challenged one of his fundamental beliefs that good health could be protected by living a healthy lifestyle.

3.2 Theme two: The DMT decision

Following diagnosis, participants were confronted with the need to make decisions around initiating a DMT. The prospect of starting a DMT elicited multiple complex reactions in participants that broadly reflected a sense of restoring hope and emotional adjustment, albeit shadowed by uncertainty. This theme is presented as a number of sub-themes to capture the complexity around considering DMTs.

3.2.1 Fear and uncertainty around DMT

Some participants expressed fear at the prospect of starting their chosen DMT as a result of uncertainty over its outcomes. The fears of commencing the DMT related to their awareness of risks and serious side effects, and in particular focused on considerations of the uncertain benefits and efficacy of taking the DMT when weighed against these risks. The exception here was Lily, who had lived with her diagnosis for far longer than other participants. Lily appeared less anxious about the decision process, and expressed more pragmatic considerations of commencing a DMT (e.g., taking needles on a flight).

3.2.2 Role of initial DMT decision in acceptance of RRMS

The DMT decision had a role in participant’s confrontation with and acceptance of RRMS. Sophie was clear about the interaction between her emotions and the initial DMT decision, indicating that the introduction of the DMT decision prompted an unavoidable confrontation of the diagnosis of RRMS. This appeared to be a painful process for Sophie. Interestingly, although Lily had lived with her diagnosis for a long time, the prospect of commencing regular medication for the first time was also functional in her adjustment to her diagnosis. Unlike Sophie, Lily was more sanguine in this acceptance, and appeared more prepared for it.

3.2.3 DMT as way of restoring control and hope

Some participants described viewing the opportunity to commence a DMT as an opportunity to increase a sense of control and hope in the face of uncertainty and fear. Both Sophie and Yvonne appeared to mobilize their developing positivity in managing their fear relating to starting a DMT.

Some participants described the development of a more positive outlook as part of their emotional adjustment following their DMT decision. This helped them positively reframe other everyday situations and areas of their lives unrelated to the disease. Rather than restoring hope for a brighter future, Lily tied her decision more to her immediate symptoms, and feeling it was the right time to start treatment.

3.2.4 Normality

Maintaining normality was a key motivation for deciding to start a DMT. All of the participants discussed the negative impact their physical MS symptoms had on their ability to conduct their normal lives, including participation in hobbies and sports, relationships with others, and normal daily activities. These changes to normal functioning challenged the self-perception and identity of some, particularly those who had previously been very active. However, despite the frustrations imposed by disease symptoms in terms of normal functioning, Yvonne reflected on how she had changed the parameters of what she considered to be normal in order to accommodate the disease, suggesting an acceptance and emotional adjustment to the diagnosis. A desire for normality was also reflected in the DMT mode of administration and helped to shape choices. For James, daily oral medication acted as constant reminder of the disease and abnormality, hence monthly infusions were preferable. Conversely for Tom, daily oral medication helped to normalize his MS through incorporation of the DMT into an established daily care routine, and helped him to remember to administer the treatment.

3.2.5 Aiding the decision

Participants reflected on factors that would have helped aid their decision process. Most referred to the volume of information they were given by health professionals in the form of leaflets, and described consulting online resources. Although information from health professionals was considered important and helpful, participants sometimes appeared overwhelmed by it, or felt abandoned by health professionals to navigate it alone. Suggestions to aid the decision process included more explicit and personalized recommendations from consultants to guide their own DMT research. Nearly all participants also suggested that the opportunity to speak to other patients who had made their decisions would have been helpful.

4. Theme three: Considering the future with a DMT

Having made the decision to start a DMT, participants considered the impacts this might have on their future. This took on most significance around employment and having a family.

4.1 Employment

All participants discussed their consideration of changes to their future employment situation. For some their choice to commence a DMT was based partly on the goals of maintaining current work roles and alleviating the impediment of physical symptoms on work skills and abilities. Sophie discussed having to compromise financially by working fewer hours in order to focus on her health. As well as concerns around the functional and practical elements to performing work duties, Max expressed a fear that broader stigma around the disease could hamper his future professional prospects in his field of work, and consequently wanted to hide the diagnosis from his employers and colleagues.

4.2 Pregnancy and family

Only one participant discussed family planning, however the case reflects an important aspect of the DMT decision process. For Sophie the DMT decision and the impact of treatment on reproduction elicited broader considerations of family planning, leading to conversations with her partner about these major life decisions alongside considering her choice of DMT. Sophie also described her future strategic plans to potentially switch DMT in order to accommodate having children.

Table 2

Themes and illustrative quotes

1. RRMS Diagnosis: Emotional reactions of shock and hopelessness
Tom: *“it just hit me like a…a train shall we say. Because I wasn’t expecting it… and whatever he said to me that day, just didn’t register”*
Sophie: *“it felt like the beginning of the end…I could just see it all going downhill from now on”*
Max: *“that’s been one of my biggest difficulties with the whole MS thing it’s coming to term with that I’ve got something that I can’t win against. There might be hope in the future but at the moment there’s no win.”*
Yvonne: *“I think I was a bit shocked, and then I went into angry mode.”*
James: *“My parents brought me up on home cooked food, playing outside, strict regime of do everything apart from hang on street corners… I had one of the healthiest upbringings that any kid could have had… It’s an example of how you end up looking back at your life thinking where did we go wrong.”*
2. The DMT decision

2.1. Fear and uncertainty around DMT

Max: *“I’m being ruled a little bit by fear of the end product... How’s it going to affect me? I’ve no idea. I’m walking into the unknown”*

James: “*It may not even work or there may be another episode before then. That’s worse. But we don’t know.”*

Yvonne: *“I don’t want to be stuck in a wheelchair at the age of 60. There’s no guarantee that that won’t happen, because it’s only 50 to 70 per cent of slowing down the relapses... As far as it working, well, nobody knows, do they? Time will tell.”*

Sophie: *“I keep saying, oh I don’t want to do it and it’s scary.”*

Lily: “*I’ll make the decision to go with this one and then there’s always the option to change, you can change things if you want to.”*

Lily: *“Just the mechanical side of things, but apart from that, my daily routine… I’d like to know how I get on a plane with all the stuff… with my needles and my things (laughs), so no, I don’t see it making any difference to be honest.”*

2.2. Role of initial DMT decision in acceptance of RRMS

Sophie: *“…it sort of finalises that this is what you have and this is how you have to deal with it. Like this is your life now and this is what you have to do to carry on the way you are.”*

Lily: “*this was like the first kind of real step of admitting that I I’ve got MS and potentially it’s gonna get worse, but it didn’t scare me. It was just, as I say it was more an acceptance again… you know I’ve always anticipated it”*

2.3. DMT as a way of restoring hope and control

James: *“So, it’s a kind of, for now I’ve got a plan...I like having a plan. I like knowing what I’m doing.”*

Sophie: “*I know you can’t cure it but you think, at least I can try and stop it a little bit, whereas if you weren’t doing anything you’re just thinking ‘well it’s all down-hill from here isn’t it…?’… I’m doing it to make things better, so…you’ve just got to think of the positives... I’m trying to change my outlook a bit, and be a bit more positive.”*

Yvonne: “*you either wait for another relapse to come, or take the injections, or give it the best that they’re offering, and go with that. So, even though, yes, there are risks, and you could think, well, ‘what if?’, you’ve just got to get your mind set, look at the positive side of it, really*.”

Lily: *“I’m quite a practical person, just assessing that’s what my needs are at the moment…I feel that because I’m more aware of symptoms now… I need to look at maybe some prevention if I can. And it’s the right thing to do.”*

2.4. Normality

Max: *“So I’ve always been quite an active fit person, erm and I, one of my big frustrations before I got diagnosed was ‘why can’t I do this’? …hence the reason I want to get on the drugs as quickly as possible to hopefully get some sort of semblance of my life back… What was important about the decision? Getting better, or getting back to the most normal life as possible. It’s a simple answer.”*

Tom: *“…as long as I do what I can do, as long as I can get out and do what I need to do then I’m happy… It’s bad enough with my arm, not being able to like stir a cup of tea…just losing them sort of things, I think that’s the biggest worry.”*

Yvonne: *“It’s just, to me, it’s life, it’s my life, and that’s how it is…, it is what I am now, and it is what I’ve got… this is normal now to me, and that’s what it is.”*

James: “*What was really important was how’s it going to impact on my life. As I’ve said before, my work and living normally, as normal as possible, is my aim. So taking a daily tablet, that’s a daily reminder that I’ve got MS. I’ve ended up with a choice that’s monthly infusions, so I’m here once a month, but to me that is a far better scenario than everyday”*

Tom: *“I’ve had diabetes for 24 years, so it’s everyday routine, so having one injection in the morning with my other, it just goes into that routine of what I do.”*

2.5. Aiding the decision

Tom: *"I still think the tricky bit is coming down to not being recommended. It was like you walk away and just do it yourself… It would have been nice for him to say, 'look I think whichever one would suit you'… at least you're going away with some sort of recommendation to work on and investigate more."*

Lily: *"I got a stack of leaflets and information. I didn't read them all… they were quite kind of like 'look, take these away cause it's good to know, but really they are, it's more for information than I would recommend them', was what in my head they were kind of saying… all I want to know is what's their recommendation"*

James: ***"****all these facts and figures and it's sort of really helpful. But actually I think hearing from patients is so valuable… actually hearing anecdotal stuff is so much more valuable."*

Sophie: *"I suppose if you could have perhaps asked someone what they had chosen and why…and how they find doing all the injections and stuff, I think that would be quite helpful."*

Max: ***"****I think it would…could potentially have been good if I'd been struggling, to actually say 'do you know what, you can come onto a ward' and if there were a couple of people who would talk about what they're doing and how it's affecting them, that would have been extremely useful."*

3. Considering the future with a DMT

3.1. Employment

James: *"More, by the looks of things, more frequent episodes and maybe having to switch work."*

Tom: "*I couldn't physically work because, well, I'm right armed, right handed, it's er…it was a killer for a good few…about a week, I think, till I spoke to them and tried to get erm…on some sort of drugs just to shift it*."

Max: *"I certainly don't want everybody in work to know, I don't want people in the industry to know…what's the reason for that? Fear. Erm, if for a reason I wasn't able to do my job here and left this company, if everybody in the industry knows I've got MS would I get another job…probably not. Is there going to be stigmas on that side of it…probably."*

Sophie: "*it is fewer hours and it is a bit less money but I think your health is more important than money.*"

3.2. Pregnancy and family

Sophie: "*I think the big thing for me as well was about fertility as well. I mean I've never really thought about having children and what-have-you before, but I think once you're presented with a 'this could stop it' I think you do think more about it then… So I thought, if I do this one for now and then once I've had a family…if that's the route we decide to go down, and then I can start on the Aubagio one"*

4. Discussion

This exploratory study aimed to investigate the emotions and lived experience of a sample of RRMS patients in the UK, in the context of their initial diagnosis and DMT decisions. Interviews revealed a number of themes that captured initial reactions to diagnosis, motivations and perspectives on the initial DMT decision, and considerations of the future with a DMT.

This study evidenced initial emotional reactions to diagnosis of shock and despair which appeared overwhelming and disempowering for participants, supporting previous findings (Dennison et al., 2011; Possa et al., 2017; Eskyte et al., 2019). Whilst other work has demonstrated a tendency for some patients to delay treatment in order to distance confrontation with the disease (Van Capelle et al., 2016; Van Reenan et al., 2019; Manzano et al., 2020), most participants spoke proactively about wanting to tackle the disease through early treatment, despite their fears.

Previous work has attested to the potential for a shift from initial despair to a more positive outlook and reassessment of values in those with an MS diagnosis (Mohr et al., 1999; Pakenham and Cox, 2009). This was most evident in Lily, who had been diagnosed 12 years prior. Lily often expressed positivity and appeared to have come to terms more with her MS, gaining experience in recognizing and managing her symptoms, and the impacts they had on her life. Lily's case reflects other accounts that suggest that developing a more positive outlook takes time (Irvine et al., 2009).

It should be noted however, that our findings suggest that more recently diagnosed patients can also adopt more positive outlooks and begin the process of acceptance. Moreover, this appeared to be tied to the DMT decision, which was pivotal in restoring hope for the future, and for some was an important step in the process of acceptance of the diagnosis, which is a critical element of a broader psychological and emotional adjustment to it (Eskyte et al., 2019) and to redefining the self (Lowden et al., 2014). Such indications of acceptance in newly diagnosed patients could reflect less severe early symptoms in early phase MS (Dennison et al., 2011) rather than genuine stable adjustment. Nevertheless, our findings support existing calls for research to incorporate the potential for positive change (Mohr et al., 1999; Irvine et al., 2009), and we argue this should accommodate recently diagnosed patients as well as those living with MS for longer.

The DMT decision evoked a juxtaposition of fear and uncertainty with hope for controlling the disease. This tension reflects work highlighting that recently diagnosed patients faced uncertainty over disease trajectory, risk of side effects, and the efficacy of treatments (Irvine et al., 2009; Manzano et al., 2020), and that patients may therefore view DMTs as both threatening and an opportunity to control one's life (Eskyte et al., 2019; Visser et al., 2020). Uncertainty and fear was certainly present amongst participants, however there was also positivity and optimism in proactively pursuing the initiation of a DMT soon after diagnosis. DMT initiation was seen as a way of taking control that helped to ameliorate initial despair and to restore a sense of hope, appearing to be empowering for participants. Despite this positivity, for some the DMT decision also appeared to be a forced choice akin to an obligation, mirroring findings elsewhere (Van Reenan et al., 2019). Whilst most accounts of the DMT decision process were couched in emotive language reflecting the tension between despair and hope, Lily often described a process driven by more pragmatic considerations. Clearly, this could well be due to having lived with her diagnosis for much longer, and hence the interaction between emotions relating to diagnosis and the DMT decision were less pronounced.

A key motivation for initiating a DMT in the current study was to preserve a sense of normality in patients and to maintain their pre-diagnosis identity. There were physical dimensions to normality (e.g., continuing to play sports) and psychological (e.g., perceiving oneself as healthy; see Table 2). Normality was also a key factor in choosing which specific DMT to initiate, through its method of administration. Previous research by Van Capelle et al. (2017) found that invasive treatments such as injections could antagonize a constant confrontation with the disease and elicit feelings of being different, whilst oral medication was considered more normal. Conversely, our findings revealed that for some, oral medication represented an antagonistic daily confrontation with the disease, whilst less frequent (but more invasive) infusions enabled a greater sense of normality. Treatment administration routes can thus elicit sensitivity to disease stigma and identity threat in a similar manner to other symbolic reminders (Dennison et al., 2011), shaping DMT decisions through resistance to perceiving oneself as unwell.

Participants desired greater steer from health care professionals in making their DMT decision, and whilst the information received from them was considered helpful, they wanted more direction and recommendation in managing their own research into treatment options outside the consultation room. However, the most apparent gap in aiding the decision process was in the absence of opportunity to speak to other patients who had made their decision. Amidst the uncertainty around DMT efficacy and risk of side effects, great value was seen in consulting others with lived experience of the same decision, and with insights that professionals cannot provide (Eskyte et al., 2019).

Considerations of the future, especially regarding societal and familial roles, impacted treatment decisions amongst participants. For some, employment concerns were more practical (e.g., performing tasks at work). For others, initiating a DMT was a way to conceal the disease and symptoms from employers and colleagues, for fear that associated stigma could limit future employment opportunities. Indeed, such fears were realized by participants in a study by Van Capelle et al. (2015). Disease concealment (Irvine et al., 2009) and distancing (Dennison et al., 2011) are common experiences for people with MS, and our findings illustrate that similar concerns impact working life and can motivate DMT initiation.

Finally, although the potential impact on having children was only expressed by one participant, it was clear that decisions around which DMT to initiate had led to an unexpected and somewhat premature reflection on her life goals and future family roles, which interacted with her treatment decision. This finding underlines recent calls to increase awareness amongst healthcare professionals of the perspectives of women with MS regarding pregnancy (Colaceci et al., 2021), and the need for greater consistency amongst clinicians when prescribing DMTs and giving related advice about pregnancy (Yam et al., 2021). Indeed, the DMT treatment decision can for some lead to an analogous decision around reproductive choices (Eskyte et al., 2019; Webb et al., 2020).

The present study is limited by the small sample size which may have yielded somewhat idiosyncratic findings. This is entirely consonant with IPA however, which requires relatively small sample numbers to enable robust analysis, and there is no correct or ideal sample size for research using this method, with a size of 6 commonly reported for theoretical sufficiency (Smith & Osborne, 2003). The makeup of our sample was such that one participant was not recently diagnosed. We felt it important to include this participant in recognition of the fact that not every patient making a decision about DMT will have been recently diagnosed. A second limitation is that we did not speak to patients who had decided not to start a DMT, or were undecided. Future work should thus incorporate more diverse viewpoints of the post-diagnosis journey and DMT decision. This could enable an exploration of how the introduction of DMTs might change the process of adjusting to and coming to terms with an MS diagnosis, including changes in self-perception, values, and roles. Finally, our analysis did not explore differences between DMT type. Future research with larger samples would be useful in uncovering differences or similarities between patients pursuing DMTs with different risk-benefit profiles.

The introduction of a wide range of DMTs within the NHS in the past 20 years has provided a rich choice, however it has led to complex decision making for the patient and MS team, particularly as decisions can occur during the process of emotional adjustment immediately following diagnosis. This study highlights the importance of considering the lived experience, the emotional and psychological worlds, and the life roles of patients with RRMS in shaping initial DMT decisions, and in understanding the impact of making these decisions on patients' lives, values, and goals. As these are likely to change and develop within the subsequent months and years following diagnosis, the initial DMT decision should not be considered a 'one off' fixed event, but rather one under regular ongoing review with the MS team, in order to accommodate the changing lived experience of patients.

CRediT authorship contribution statement

Gina Carey: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original

David Rog: Conceptualization, Writing – review and editing, Funding acquisition

Hazel Roddam: Conceptualization, Methodology, Writing – Review and Editing, Project administration, Funding acquisition

Jessie Janssen: Conceptualization, Methodology, Validation, Writing – Review and editing, Project administration

Ambreen Chohan: Writing – review and editing, Project administration

Neil Wilson: Formal analysis, Writing – original draft, Writing - review and editing

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