The experience of transitioning from relapsing remitting to secondary progressive Multiple Sclerosis: Views of patients and health professionals

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Abstract

Purpose: The majority of people with MS (pwMS) initially present with discreet periods of relapses followed by complete or partial remission of symptoms. Over time, most pwMS transition to secondary progressive MS (SPMS), characterised by a gradual accumulation of disability. This study aimed to explore the experiences, coping and needs associated with transitioning from RRMS to SPMS.

Method: Data was collected via semi-structured interviews with nine pwMS and 7 specialist MS health professionals (HPs). Thematic analysis was used to analyse the data.

Results: Four major themes were identified: 'Is this really happening?'; 'Becoming a reality'; 'A life of struggle'; and 'Brushing oneself off and moving on.' Findings suggested a process of moving from uncertainty towards confirmation of one's diagnostic label. Being reclassified with SPMS served as a turning point for many, and was accompanied by a range of cognitive, emotional and behavioural responses. The value of adequate information and support surrounding the transition, and the potential benefit of education and support for health professionals in relation to the transition were indicated.

Conclusions: Understanding pwMS' experiences of the transition is essential if clinicians are to provide pwMS with appropriate support during the transition.

Introduction

Multiple Sclerosis (MS) is an inflammatory disease of the **c**entral **n**ervous **s**ystem, and a common cause of disability in young adults *[1]*. Symptoms vary across individuals, and may include fatigue, sensory loss, as well as difficulties with balance, walking, vision, bladder and bowel control, memory and concentration *[2]*. Whilst there are now a number of disease modifying drugs for early phase MS, there is no ultimate cure. As MS has a limited effect on life expectancy *[3]*, most people with MS (pwMS) will live with the condition for many years and accumulate irreversible disability *[4]*.

Eighty-five percent of pwMS are initially diagnosed with Relapsing Remitting MS (RRMS), which is characterised by periods where symptoms appear for at least 24 hours (i.e. a relapse), following which many recover, with a lack of disease progression between relapses *[5]*. Within approximately three decades of the onset of RRMS, 65-90% of pwMS will be reclassified with Secondary Progressive MS (SPMS) *[2]*. SPMS is typically defined as deterioration independent of relapses for 6 months or more *[5]*. This transition tends to be subtle, and is generally not a distinct phase in itself, often being confirmed in retrospect *[6]*. Due to a lack of effective treatments for SPMS, this transition often involves withdrawal of previous treatments, and a significant reduction in potential treatment options. SPMS is associated with poorer quality of life *[7]*, and heightened rates of depression and anxiety *[8]* compared with other forms of MS.

Although research has examined the experiences of pwMS diagnosed with RRMS and of those living with established SPMS, to the best of our knowledge no published research to date has explored the experience of transitioning from RRMS to SPMS. Qualitative research has suggested that the period between the onset of symptoms and the receipt of the initial MS diagnosis may be characterised by anxiety about the meaning of symptoms, and some individuals may struggle to have their symptoms considered seriously by health professionals *[9, 10, 11]*. Such findings raise questions about the experiences of pwMS in the period leading up to a reclassification of SPMS, such as whether pwMS are aware of changes in their disease pattern, and what sense they make of such changes. Such

questions are salient given the common, yet not inevitable nature of the transition, as well as the fact that pwMS would have already been living with MS for some time before being reclassified, albeit in a different form. The impact of such factors on pwMS' ability to detect changes in their disease pattern and the meaning that they attribute to such changes merits exploration.

The receipt of a diagnosis of MS may be associated with a range of emotions, including relief, shock, fear, uncertainty, and isolation *[9, 10, 11, 12, 13, 14]*. Some research has suggested that over time, some pwMS may learn to cope and maintain an acceptable quality of life in MS *[15, 16, 17]*, but this may be dependent on the absence of severe symptoms *[17]*. Given the trajectory of irreversible disability associated with SPMS, how pwMS cope with the transition from RRMS to SPMS warrants exploration.

Research has highlighted a need for improved provision of sufficient, tailored information, and adequate protected time for communication of the initial MS diagnosis *[11, 13, 18]*. Ongoing professional support delivered by knowledgeable and empathic professionals has been identified as crucial for people with MS in order to support relapse management and to avoid feelings of abandonment *[10, 11, 17]*. The extent to which such needs are met in relation to the transition to SPMS, and whether additional needs specific to this transition exist, warrant investigation.

A growing body of qualitative literature in healthcare has explored the perspectives of HPs in combination with those of patients in examining the issues faced by patients and healthcare services *[19, 20, 21, 22, 23]*. These studies revealed high levels of agreement between patients and HPs, as well as highlighting tensions between what patients want and what services are able to provide. Evidence suggests that inclusion of HPs in research exploring patients' perspectives may contribute towards identification of barriers to meeting patients' needs, illuminating ways forward *[22]*. The value of including specialist HPs' perspectives on the experiences of pwMS, given their substantial direct contact with pwMS has also been demonstrated *[22]*. It has been argued that including multiple stakeholder perspectives is essential for gaining a holistic view of patient experiences *[22]*.

Some evidence has suggested that HPs display insight into the experiences of pwMS, and may identify a broader range of relevant issues than pwMS themselves, such as in relation to patients' unmet needs *[22]*. Hence, it was hoped that inclusion of HPs in the current study would lead to generation of a wider range of themes related to pwMS' experiences than by including pwMS alone. It was also hoped that inclusion of HPs would contribute to identification of unmet needs of pwMS during this transition, and the barriers to meeting such needs.

In light of the above, the current study aimed to investigate the following questions.

1) How do pwMS experience transitioning from RRMS to SPMS?
2) How do pwMS cope with this transition?
3) What are the needs of pwMS during this transition and the barriers to these being met?

Method

Participants

People with MS

Nine pwMS were recruited. Inclusion criteria were that participants had been reclassified with SPMS a maximum of 24 months previously, and were aware of a confirmed reclassification of SPMS following a previous diagnosis of RRMS. The latter criterion was in order to eliminate risk of distress caused by the researcher inadvertently revealing a diagnosis that pwMS may not have been aware of. PwMS experiencing onset of a new comorbid condition were excluded in order to avoid interference of the impact of the additional condition on their recall of transitioning from RRMS to SPMS. All participants were recruited from a neurological hospital in London. Participants who met the inclusion criteria were invited to participate by their clinician during routine clinic appointments. They were provided with written information about the study and, if interested in participating, could either contact the researcher directly, or provide their contact details to the researcher via a prepaid envelope so the researcher could contact them.

Health Professionals

Seven specialist MS health professionals employed in a neurological hospital were recruited at a service-wide meeting, during which the researcher carried out a presentation about the study. This sample comprised three MS specialist consultants, one consultant neurologist, two MS specialist nurses, and one MS specialist physiotherapist. All HPs who volunteered to take part were included.

A summary of some of the key characteristics of the participants is provided in tables 1 and 2.

Insert table 1 about here

Insert table 2 about here

Procedure

The study received full ethical approval from the Nottingham 2 – East Midlands research ethics committee and the Psychology Department, Royal Holloway, University of London.

Data was gathered via individual face-to-face, semi-structured interviews, as is common in Thematic Analysis *[24]*. Participants were interviewed individually in order to facilitate open accounts of their experiences. Interviews with HPs occurred at their place of work, while interviews with pwMS took place at their homes. Given that many pwMS experience difficulty with mobility, this form of data collection enabled pwMS to participate in this study within the comfort of their own homes.

Participants

The interview schedules were developed using published guidance *[25]*, based on relevant literature, and further developed through discussions with service users. Each of the questions in the interview schedule for HPs mirrored those for pwMS, in that they asked HPs about the experiences of pwMS. For instance, whilst pwMS were asked 'How did you deal with the impact of this reclassification?', HPs were asked 'How do you think pwMS deal with the impact of this reclassification?'. The interview schedule was used in a flexible manner, enabling the researcher to ask follow-up questions

regarding interesting and unanticipated issues that were brought up. Many of the initial questions were open and exploratory (e.g. 'Can you tell me what it was like to be reclassified with SPMS?'), which allowed participants to provide detailed accounts of what was important to them. Interviews lasted between 22 and 81 minutes for pwMS, and 18 to 48 minutes for HPs. Interviews were audio recorded. A sample of the interview questions are displayed in table 3 below.

Insert table 3 about here

Analysis

The data was analysed using inductive Thematic Analysis (TA) as outlined by Braun and Clarke *[26, **27**]*. Given the lack of research specifically addressing the transition from RRMS to SPMS, it was decided that an approach which identified themes within participants' understanding would provide scope for further investigation in the future. TA is commonly used as a method for exploring people's experiences *[23, 28]* as it is capable of providing rich, detailed and complex accounts of data *[26]*. TA was also chosen due to its flexibility, regarding both its epistemological position, and its ability to integrate data from multiple stakeholders *[23, 29, 30]*.

As TA is not tied to any particular epistemological position, it has been argued that whatever epistemological position is adopted, researchers ought to make their epistemological assumptions explicit *[26]*. The current study adopted a critical realist approach *[25]*, which sits between the opposing poles of realism and relativism. This position assumes that although data are capable of revealing the nature of reality, it is not a direct, 'mirror-like' reflection of such reality. Instead, interpretation is required in order to further one's understanding of the underlying influences that impact on the phenomena of interest. Such influences include social, physiological, and psychological processes, which may be outside participants' awareness. This choice of epistemological position reflected a desire to incorporate the experiences and insights of participants, the meanings attached to the experiences of pwMS, as well as acknowledging the impact of their wider context on these meanings.

Qualitative software (NVivo 10) was used to assist the researcher in managing and organising the data. The stages of analysis, as outlined by Braun and Clarke *[26]*, were as follows:

Familiarising oneself with the data: All interviews were transcribed and read a number of times so that patterns of meaning could begin to emerge. The recordings were also listened to several times to ensure the accuracy of the transcription.

Generating initial codes: Units of meaning within the data were identified and relevant data extracts were collated for each code by the primary researcher. Initial coding revealed substantial overlap between data for pwMS and HPs. Following review and discussion with co-researchers, it was decided to code the data for pwMS and HPs together as a whole, as in other similar studies *[23]*. Data extracts were coded as many times as was necessary to ensure that each code contained all relevant extracts.

Searching for themes: Once the entire dataset had been coded, similar or related codes were then organised into potential themes. All initial codes relevant to the research questions were combined into themes.

Reviewing themes: Candidate themes were then reviewed and refined. This involved considering whether the collated extracts formed a coherent pattern within each theme. If not, the theme was revised. This was done either by renaming the theme, combining overlapping themes, creating a new theme in the case of diverse themes, relocating extracts that did not fit into another existing theme, or discarding them from the analysis. This process was repeated until all the candidate themes formed a coherent pattern. Following this, the validity of each theme was assessed in relation to the entire dataset. This process also allowed for coding of any additional data within themes that had been missed in previous coding stages. Sections of the transcripts were also analysed by co-researchers to facilitate discussion and agreement of themes and cross-validation.

Defining and naming themes: Collated data extracts within each theme were then reviewed in order to identify what particular aspect of the data they captured. Themes were defined and named accordingly.

Producing the report: The final stage of report production involved selecting examples of transcript to illustrate elements of the themes. These extracts clearly identified issues within each theme, and presented a clear example of each point that was made.

Results

Four main themes were generated from participants' accounts. The themes and their definitions are summarised in table 4 below.

Insert table 4 about here

Theme 1: Is this really happening?

Participant accounts indicated that before being reclassified with SPMS the majority of pwMS noticed subtle changes in their disease pattern, which were often noticed retrospectively as pwMS struggled to carry out their usual activities:

> *… with hindsight I've noticed that each year there are things that I could have done fairly easily the previous year that I would now be struggling with this year.* ***PwMS 6***

Participants' accounts captured how the period before the official reclassification was often characterised by uncertainty about the underlying cause or meaning of the changes described above. Such uncertainty stemmed from the subtle, transitory nature of the transition, making it difficult to determine if progression was actually taking place, as well as a lack of knowledge about SPMS.

> *… we do get patients who'll say that their symptoms have been getting worse for a few months, and it's obviously not a relapse, but they might not realise that actually it's just their condition deteriorating.* ***HP 2***

Some pwMS responded to such uncertainty by attempting to ignore or deny the possibility that they were transitioning to SPMS, by attributing the changes in their disease pattern to causes other than SPMS:

> *I thought that it was a relapse, and that it would get better … I couldn't face the fact that it would just - that that's it. That's too, kind of, a final thing.* ***PwMS 9***

In contrast, participants' accounts highlighted how some pwMS psychologically braced themselves for a reclassification of SPMS, through acknowledging the possibility that they were transitioning to SPMS and seeking information about it:

> *… I was preparing myself thinking my MS is getting worse … At that stage then you start looking at what to expect if you're entering that phase. And that's when I starting reading things about fatigue and heaviness in the legs ... I read up bits and I thought yes … I think I am.* ***PwMS 2***

Many participants described a sense of delay in being reclassified, stemming, in part, from the complex and unpredictable nature of MS, which may have posed challenges for MS consultants in determining whether pwMS met diagnostic criteria for SPMS. Additionally, HPs described a reluctance to reclassify patients due to the psychological impact that this could have on patients. This sense of delay was viewed by many participants as hindering the process of adjustment to SPMS:

> *… you're waiting all that time knowing in your head that I'm not getting better, but not being able to have that label ... it makes the acceptance process a lot longer, because you're sitting there and not knowing for ages.* ***HP 2***

One HP described the difficult impact that reclassifying patients could have on HPs themselves, which may have further contributed to their reluctance to reclassify pwMS until a sufficient degree of certainty had been reached:

> *… the person delivering the news will be demonised. And, um, however much they don't want to be in that role ... everyone wants to be liked ... wants to do something positive. And actually being in the role of a doctor often means you're bringing quite negative things to a discussion … and it is not nice. Um, and it takes a while for people to recognise that, at some level, it's not personal.* ***HP 5***

Several participants described forewarning and education about SPMS as important, but often lacking. However, the fact that the transition does not occur with all pwMS posed challenges for knowing how best to prepare patients, so as to avoid worrying them unnecessarily:

> *… when they're Relapsing Remitting, you don't want to really go on too much about Secondary Progression, because it's a bit of a negative way of looking at things. You want to be optimistic, and you don't want to emphasise that too much, because the patient will go away feeling very depressed.* ***HP 7***

Theme 2: Becoming a Reality

Whilst some pwMS described feelings of shock and devastation in response to being reclassified with SPMS, others reported that the reclassification provided clarification about the changes they had noticed in their disease pattern. For some, their new diagnostic label felt more in line with their experience than their previous label of RRMS had, enabling them to make sense of their condition:

Um, it was kind of just … well, that makes sense more than up and down. It's not up and down. It just made sense to me, in what was happening to me … it just described the condition more. ***PwMS 9***

Whilst some participants described the reclassification as somewhat expected, it still served as a psychological blow:

I don't think it's so unexpected for most people. But the other side of that is that it's the last thing they want to hear. ***HP 3***

Participant accounts highlighted how regardless of the extent to which the reclassification was expected, the reclassification frequently served as a point of confirmation of one's disease status, and a turning point towards greater acknowledgement of **their** condition. Some participants described a sense of relief at feeling able to adjust their lifestyle in accordance with their degree of disability:

… it was a relief because I was able to then rethink, and think well actually I can't do all those things now, I know I can't do all those things, and I'm not going to be able to do them. So I've had to redesign my social life. ***PwMS 2***

Several participants highlighted the value of providing pwMS with information and support to enable them to negotiate life with SPMS. This was sometimes described as lacking, with some pwMS being left feeling abandoned by their health professionals:

I had one patient who, um, she got told by the registrar "oh you're Secondary Progressive now," and that was it ... Didn't get told anything about it, didn't get told what it was, what it meant for her - nothing. ***HP 2***

Many participants emphasised the importance of appropriate follow-up support, both immediately following the reclassification (e.g. a debriefing session with a MS nurse), and in the months and years beyond. This was also often described as lacking, compared to the initial MS diagnosis:

> *I think one of the big differences as well is that at diagnosis there is a lot of support there… there's follow-up, um, nursing support … there's lots going on. But then, I think a lot of them are just left to it when they get the Secondary Progressive diagnosis.* ***HP 2***

Participants also emphasised the importance of delivering the news of the reclassification in a hopeful, yet sensitive and empathic manner, and allowing patients enough time to process the news and ask any questions that they might have. The manner in which the reclassification was delivered to pwMS was sometimes described as insensitive, highlighting a potential need for communication training in relation to the reclassification of SPMS:

> *I think the medics need better training around communication and empathy. I think they don't realise - they don't think what that would mean to them if they were told that.* ***HP 2***

Theme 3: A life of struggle

Participant accounts highlighted a sense of anxiety and dread about the future following the reclassification, as well as a gloomy resignation towards an inevitable decline in one's condition. Some described giving up hope, and assuming a passive stance in relation to their MS:

> *… some give up hope … they don't see that there's much that they can do, so they say "oh physiotherapy's not going to help me…" … there's nothing for me now.* ***HP 2***

The accounts of several participants highlighted how some pwMS struggled to accept the irreversibility of their SPMS and attempted to soldier on in spite of their deteriorating condition:

... you've got some people who will battle on, and battle on, and they'll do things by, you know, like that chap … literally crawling out across a gravel front drive to get into a taxi to then go to work. ***HP 4***

Some participants described efforts of pwMS to identify means of alleviating SPMS. These sometimes included invasive and potentially painful measures, which was likely to reflect the extent to which pwMS were struggling to accept the irreversibility of their condition:

… they're getting more desperate about the fact that they are getting more disabled, so they will try all the faddy things that are out there on the internet, be it the extreme diets, or, eh, I had somebody who went to Dubai and had their atlas bone - a bit of bone chipped out of their neck because somebody on the internet said that would stop their MS in its tracks. ***HP 4***

Several participants described increasing restriction among pwMS arising from worsening disability associated with the transition to SPMS. Many had to withdraw from previous activities, and experienced a loss of spontaneity and increasing isolation. Several participants described grief regarding loss of their previous way of life:

… you have to just say goodbye to the previous life, I think. To me, anyway, my spontaneous, quickly … I go for a trip here or there … that isn't possible anymore. ***PwMS 5***

Many participants described frustration in response to the transition, arising from the decline in one's physical functioning, and the irreversibility of SPMS:

*And now I can't even say what's frustrating me the most … the balance, or no muscles, because I have no more muscles left ... It isn't going anywhere. It's just going to stick around, the *******.* ***PwMS 5***

Theme 4: Brushing oneself off and moving on

The title of this theme aims to encapsulate the flexibility and resilience captured by many participants' account of the responses of some pwMS to the reclassification of SPMS. Some pwMS described how prior adjustment to living with MS, and expectations of being reclassified with SPMS served to buffer them somewhat against the impact of the reclassification:

> *… as these things get worse, you know, you're kind of slowly having to accommodate it, and having to accept it, because you have no damn choice. But it's not easy. So when you're then told it's Secondary Progressive you think well - yeah well, I've finally got to terms with all of this anyway. So there's a bit of a 'so what' about it ... I don't welcome this news ... life is really going to be horrible, but I'm not surprised.* ***PwMS 4***

Several participants described coping through achieving a balance between accepting their condition, and a focus on what they could control. Acceptance of their condition did not mean that pwMS adopted a passive stance in relation to the transition, however. On the contrary, a number of participants described focusing on doing as much as they could do to optimise their condition, whilst accepting the limits of what their efforts could achieve in controlling the inevitable deterioration associated with SPMS:

> *… once you've done everything you can do, and you really are sort of doing as much exercise as you can do, you've looked up where you should be with drugs, the medications, this, that and the other, there isn't anything else to do but to accept it, and to be calm.* ***PwMS 6***

Several participants described adapting their lives in accordance with their current and projected levels of disability, such as by obtaining necessary equipment and identifying alternative activities and hobbies. Although often described in positive terms, there was also a sense of necessity and lack of choice in some participants' accounts of this response:

… you have to think of other things. And that's been hard. That's been really hard, actually, finding other things to do - that you can do, particularly when you've got numb hands and fingers, and stuff. I mean I'm doing patchwork now … ***PwMS 6***

Some participants described turning to others for both practical and emotional support as helpful in coping with the transition:

I think the people who go through that transition well generally have got a good support network, um, where there is genuinely a supportive family there, saying "you know, come on, it's really not that bad, you know, we're in this together." ***HP 4***

The accounts of several participants also captured how some pwMS coped through making the most of their present circumstances and not looking too far into the future:

… some people do just take the disease as it comes and just get on with their day to day life, and will take the change in diagnosis in the same way, and they'll just … whatever happens happens, and they'll deal with it as it comes. ***HP 2***

Several participants described viewing SPMS as a mere label in the context of an overall progressive illness as helpful. Viewing the reclassification in this way enabled pwMS not to worry too much about the meaning and implications of their new diagnostic category, but as a mere continuation of what they had already been experiencing:

MS is progressive, no matter which way you do it. No matter if it's Primary, Relapsing Remitting, Secondary … it's all progressively deteriorating. And really the classification of it all doesn't really mean a lot. ***PwMS 6***

A few participants described cultivating an attitude of positivity as helpful in coping with the transition, which included making the most of **their** current level of functioning:

I've still got to make the most of the time I've got while I can walk around and do things ... So I suppose I'm still using the same strategy as I used when I was first diagnosed. Do as much as you can while you can. ***PwMS 2***

Discussion

The results highlighted how, prior to the reclassification of SPMS, many pwMS noticed subtle changes in their disease pattern, and experienced uncertainty regarding the meaning of such changes. This is somewhat reflective of existing literature reporting uncertainty about one's diagnosis prior to the initial diagnosis of MS *[9, 10, 11]*. Compared to becoming aware of novel symptoms during the pre-diagnostic phase of MS, leading pwMS to seek professional support, the subtle and transient nature of the changes during the transition made it difficult for many pwMS to be certain if their disease had in fact changed. This resonates with Mishel's (1988) theory of uncertainty in illness, which proposes that uncertainty arises from situations where one is unable to assign a definite value to items or events and/or is unable to make accurate predictions regarding outcomes *[31]*.

For some pwMS, the reclassification was completely unexpected and served as a shock, with some participants reporting a lack of pre-existing awareness of the potential for transitioning to SPMS. Additionally, many pwMS experienced a sense of delay on the part of HPs in providing clarification regarding the changes in their disease pattern via reclassification. Existing research has also reported delays in receiving the initial diagnosis of MS, as pwMS seek clarification and legitimization of their symptoms *[11, 32]*.

Both of these findings may have been underpinned by several factors. Inclusion of HPs in this study enabled insight into such underlying factors. Whilst the unpredictable and variable nature of MS may have contributed to delays in reclassifying patients, HPs' desire to protect pwMS against the potential impact of bad news may have also played a role. This is reflected by research regarding the

initial MS diagnosis which highlighted the role of uncertainty in diagnostic test results, and HPs' desire to protect pwMS from the full truth about their diagnosis, in contributing to delays in communication of the diagnosis *[33, 34]*. HPs' desire to protect pwMS from worry and distress may have also influenced the extent of provision of preparatory education about the transition. Careful consideration of the timing of such education is paramount, given the potential distress associated with receipt of such news and the fact that not all individuals with RRMS transition to SPMS.

Regardless of the extent of pwMS' expectations of SPMS, the reclassification served as a point of confirmation of one's disease status, often associated with heightened acknowledgement of one's current and projected levels of disability. According to Charmaz, for those who have been struggling with chronic illness, provision of a diagnostic label may serve to legitimize one's illness experience, and enable redefining of one's illness and adaptation to one's degree of disability *[35]*. This may have underpinned feelings of relief reported by some participants in response to the reclassification. Relief has also been reported in relation to the initial MS diagnosis *[11]*.

The manner in which the reclassification was communicated to pwMS was sometimes described as suboptimal, highlighting the importance of training around sensitive and appropriate communication of the reclassification. Furthermore, following the reclassification, many pwMS described feeling abandoned by their MS team. Participant accounts highlighted the importance of sufficient information provision and follow-up support, and suggested that this was often lacking compared with the initial diagnosis. It is possible that a sense of impotence among HPs in the face of SPMS may have possibly contributed to this. Immediate access to information following diagnosis has been reported as crucial for allaying pwMS' fear about their prognosis *[36]*, and enabling patients to make sense of their illness experience and participate in active management of their condition *[37]*. Similarly, identifying ways to maintain engagement in meaningful activities is important in helping people cope with SPMS *[38]*. Given the potential impact that delivering the news of the reclassification can have on HPs themselves, and how this may possibly impact their

subsequent interactions with patients, they may also benefit from emotional support, such as education about coping skills *[39]*, or supportive counselling *[40]*.

In light of the buffering effect that previous adjustment to MS had against the impact of the transition, it could be helpful for health professionals to explore pwMS' existing resources and coping strategies. This could enable supporting pwMS to draw upon such resources in coping with the transition. The value of recognising and building upon patients' existing experiences and coping mechanisms for managing chronic illness has been highlighted *[41]*. Such input may potentially enable pwMS to reappraise the transition as merely another label in the context of an overall progressive illness, and lead to a sense of empowerment through recognising the experiences and resources that they have already developed in coping with MS.

This study had a number of limitations. Given the limited sample size, the generalisability of the results in relation to the wider MS population cannot be determined. Additionally, the fact that participant accounts were generated retrospectively may have affected participants' recall of events. However, as seven out of nine of the pwMS recruited were interviewed within 12 months of being reclassified, this may have reduced such bias. Finally, although it was hoped that inclusion of HPs would enhance the range of themes generated, the degree to which HPs' accounts accurately reflected the experiences of pwMS may be contested.

In light of the needs of pwMS highlighted by this study, examining the benefit of specific forms of interventions aimed at enhancing supportive mechanisms and addressing unmet needs throughout the transition would be useful. For instance, examining the impact of preparatory education about the transition (e.g. a booklet) on the well-being of pwMS who later undergo the transition could be useful. Although the current results suggested that it may be appropriate to provide such education following the initial MS diagnosis, the optimal timing of such education requires further investigation, given the potential for distress arising from this news. Additionally, the helpfulness of specific forms of follow-up support following the reclassification, such as providing pwMS with the

option of an immediate debriefing session with a MS specialist HP, and provision of peer support interventions, could be useful.

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Declaration of Interest

The authors report no conflicts of interest.

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