

# BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email [editorial.bmjopen@bmj.com](mailto:editorial.bmjopen@bmj.com)

# BMJ Open

## Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study

|                               |   |
|-------------------------------|---|
| Journal:                      | <i>BMJ Open</i>   |
| Manuscript ID                 | bmjopen-2018-026421   |
| Article Type:                 | Research  |
| Date Submitted by the Author: | 03-Sep-2018   |
| Complete List of Authors:     | Bogosian, Angeliki; City University of London , School of health sciences<br>Morgan, Myfanwy; King's College London, Institute of Pharmaceutical Science<br>Moss-Morris, Rona; Kings College London |
| Keywords:                     | Multiple sclerosis < NEUROLOGY, secondary progressive, self-management, QUALITATIVE RESEARCH, HEALTH SERVICES ADMINISTRATION & MANAGEMENT   |
|                               |   |

SCHOLARONE™  
Manuscripts

1 Transition to secondary progressive MS

2  
3 **Multiple challenges for people after transitioning to secondary progressive multiple**  
4  
5 **sclerosis: a qualitative study**  
6  
7  
8  
9

10  
11 Bogosian A.<sup>\*1</sup>, Morgan, M.<sup>2</sup>, Moss-Morris R.<sup>3</sup>

12  
13  
14  
15 <sup>1</sup>School of Health Sciences, City, University of London, London UK,

16  
17 [Angeliki.bogosian.1@city.ac.uk](mailto:Angeliki.bogosian.1@city.ac.uk)

18  
19  
20 <sup>2</sup>Institute of Pharmaceutical Science, King's College London, London, UK,

21 [myfanwy.morgan@kcl.ac.uk](mailto:myfanwy.morgan@kcl.ac.uk)

22  
23  
24  
25 <sup>3</sup> Institute of Psychiatry, Psychology & Neuroscience, King's College Hospital, London, UK,

26 [rona.moss-morris@kcl.ac.uk](mailto:rona.moss-morris@kcl.ac.uk)

27  
28  
29  
30  
31 \*Address correspondence and reprint requests to Dr. Angeliki Bogosian, School of Health  
32 Sciences, City, University of London, EC1V 0HB, London, UK; email:

33  
34 [angeliki.bogosian.1@city.ac.uk](mailto:angeliki.bogosian.1@city.ac.uk); telephone number : +44(0)2070408532

35  
36  
37  
38  
39  
40  
41  
42 **Keywords:** secondary progressive, Multiple Sclerosis, transition, self-management,  
43  
44 qualitative research, health services

45  
46  
47  
48  
49  
50  
51 Word count: 3,850

1 Transition to secondary progressive MS  
2

3 Abstract  
4  
5

6 **Objectives:** Transitioning to secondary progressive multiple sclerosis (SPMS) is demanding for  
7  
8 both patients and healthcare professionals. The particular challenges and the ways patients  
9  
10 cope are poorly understood. The present study examines what challenges people face when  
11  
12 diagnosed with SPMS, by exploring experiences of people who have transitioned recently (up  
13  
14 to 5 years).  
15  
16

17  
18  
19 **Design:** Semi-structured qualitative interviews at two time points a year apart. Interviews  
20  
21 were analysed using inductive thematic analysis.  
22  
23

24  
25 **Setting:** United Kingdom  
26  
27

28 **Participants:** We interviewed twenty-one people at baseline and seventeen participated in  
29  
30 the follow-up interviews.  
31  
32

33 **Results:** The majority of participants reported expecting to transition to SPMS, and the  
34  
35 diagnosis did not make much difference to them. Participants described increasing emotional  
36  
37 and physical challenges after transitioning to SPMS and between the first and second  
38  
39 interview. Planning, using distractions and maintaining social roles helped participants cope  
40  
41 with the increased challenges. The same coping strategies were used between the two  
42  
43 interviews. Participants felt there was not much left to do regarding the management of their  
44  
45 symptoms. A key theme was the sense of abandonment from health care services after  
46  
47 transitioning to SPMS.  
48  
49  
50  
51

52  
53 **Conclusions:** After transitioning to SPMS people are faced with multiple challenges.  
54  
55 Participants described a lack of directions for symptoms management and lack of support  
56  
57 from the healthcare system. An integrated multidisciplinary health care approach is crucial at  
58  
59  
60

Transition to secondary progressive MS

the progressive stage of the disease to alleviate feelings of helplessness and promote symptom management.

For peer review only

1 Transition to secondary progressive MS  
2  
3  
4  
5

6 **Strength and limitations of this study**  
7  
8

- 9
- 10 • The present study is the first to use a longitudinal qualitative design to capture  
11 people's experience after transitioning to secondary progressive multiple sclerosis.  
12
  - 13 • The focus on people recently transitioned helped to narrow down people's  
14 experiences early on in diagnosis.  
15
  - 16 • We cannot determine whether the challenges described in this study are linked to  
17 having received an official diagnosis or to the challenges faced by increased disability,  
18 as we did not interview people just before being diagnosed and straight after.  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## Transition to secondary progressive MS

Multiple Sclerosis (MS) affects more than 2.5 million people worldwide, including 127,000 in the United Kingdom [1]. MS is a condition that presents unique challenges for the individuals, as it usually starts with minimal physical and cognitive dysfunction which progresses over time. There are three types of MS. The most common type is relapsing-remitting (RR, 85%-90% of MS cases) which is characterised by unpredictable attacks (relapses) of new or increasing neurological symptoms that are followed by periods of partial or complete recovery (remissions) [2]. The secondary progressive (SP) course develops in approximately 82% of those with RRMS by 20 years of onset [3]. Finally, a minority of people (10%) will be diagnosed with the primary progressive (PP) course that involves a steady disability increase without attacks [4].

The transition to secondary progressive multiple sclerosis (SPMS) is an expected part of the disease trajectory. Epidemiological studies indicate nearly 10% of people with RRMS reach the SPMS stage after five years, which increases to 25% at ten years and 75% at 30 years [5]. A mean of  $2.9 \pm 0.8$  years is a typical length of time when people are faced with the uncertainty of whether or not they have transitioned to SPMS [6]. The delay in the diagnosis is thought to be due to the subtle nature of early progression and absent of evidence-based treatment for SPMS [6]. People with SPMS are older, are less likely to be employed, and a lower proportion is female compare to people with RRMS [7]. When people transition to SPMS, they are likely to experience more severe neurological symptoms, more frequent hospitalisation [8], have more frequent and pronounced cognitive deficits [9, 10], and higher levels of fatigue [11]. The onset of SPMS has also been associated with fear, low mood [12], greater distress [13, 14], lower quality of life [15], and higher levels of depression and anxiety [16] than in both relapsing-remitting and primary progressive types of MS. Only three qualitative studies have been conducted to examine the experiences of people with SPMS. In

1 Transition to secondary progressive MS  
2

3 two of these studies, women with SPMS recognised the impact of the loss of meaningful  
4 activities on the sense of self [17, 18]. A recent qualitative study on patients' experiences  
5 while transitioning to SPMS showed that some people learned they had SPMS without any  
6 advanced knowledge or understanding of what SPMS meant for them, which sometimes  
7 caused confusion and upset [19].  
8  
9

10 We know little about people's experiences after transitioning to SPMS, and psychological and  
11 behavioural interventions aimed at people with SPMS are scarce. Further, a recent meta-  
12 analysis on the effectiveness of interventions for treating depression in MS identified 13  
13 papers, with 8 of these excluding people with progressive MS from participating [20]. When  
14 people with SPMS are included in psychological interventions, they also seem to gain fewer  
15 benefits compared to people with RRMS [21]. The psychological challenges that people with  
16 SPMS face may, therefore, differ to the ones that people with RRMS face  
17  
18

19 In this study, we aimed to explore the experiences of people who have recently transitioned  
20 from RRMS to SPMS. Knowing the challenges that patients face at this stage of their MS  
21 trajectory makes it easier to identify information needs and tailor support interventions.  
22 Further, it is not well understood how transitioning to SPMS contributes to psychological  
23 challenges and adjustment attempts. The present study is the first to use a longitudinal  
24 qualitative design to capture people's experience shortly (within five years) after  
25 transitioning. The follow-up interviews allowed respondents to reflect on the changes (or lack  
26 of them) since the first interview. The focus on people recently transitioned helped to narrow  
27 down people's experiences early on in diagnosis.  
28  
29  
30  
31  
32  
33

### 34 **Patients and public involvement**

35 This research was part of a larger research project, and two individuals with SPMS are part of  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



## Transition to secondary progressive MS

our user involvement committee, and they have helped with different aspects of the project from the initial conceptualisation of the study, feedback on the grant application and feedback of the topic guide. They were also asked to assess the burden of participation in the study. The two people with SPMS gave us feedback on an initial version of our themes. They inquired about whether the experiences differ based on the age of diagnosis or whether the people who described more psychological challenges had also reported cognitive difficulties. Following this, we checked the emerging themes to identify any patterns or differences in themes of people with different demographic characteristics. The two people with SPMS also suggested exploring further the experience of diagnosis and the importance of receiving the diagnosis of a SPMS from a healthcare professional. Finally, they commented on the clarity of description and presentation of the results, for example, they made some suggestions about how themes linked together and asked for a few additional quotes at places to better illustrate themes.

## Participants and methods

This research is part of an MS Society UK funded junior research fellowship with a view to increase understanding of psychological challenges and adjustment of people with progressive MS. The current study was approved by the West of Scotland Research Ethics Committee (14/WS/0077). We recruited participants through online adverts on the MS Society UK website, adverts after speaking engagements at MS Society events and through study's information sheets provided by research nurses at MS hospital clinics (Northamptonshire Healthcare NHS Foundation Trust and Cumbria Partnership NHS Foundation Trust). Participants with primary progressive and secondary progressive MS were recruited, but for the aims of this study we focused on the interviews of people with

1 Transition to secondary progressive MS

2  
3 secondary progressive MS. Eighty-seven people with primary and secondary progressive MS  
4  
5 expressed interest in participating in the study. Fifteen (17%) did not meet the inclusion  
6  
7 criterion of diagnosis within five years of progressive MS. The remaining 72 completed a short  
8  
9 screening questionnaire that included demographic questions, as well as questions about MS  
10  
11 duration, symptoms and walking ability. We chose to interview people using maximum  
12  
13 variation [22], i.e. sampling to represent different demographic characteristics. Interviewing  
14  
15 ceased once data saturation was reached, defined as the point at which no new information  
16  
17 or themes are observed in the data [23]. We interviewed 21 participants who were diagnosed  
18  
19 with secondary progressive MS and had given informed consent to take part in the study.  
20  
21  
22

23  
24 As shown in Table 1, participants were between 40 and 77 years of age (mean: 57.38 years).  
25  
26 More than half the sample was unemployed or retired due to MS (n=14, 66.66%) and lived  
27  
28 with their partners (n=15, 71.43%). Seventeen participants were interviewed for the second  
29  
30 time, four participants (19%) did not respond to the email invitations for a second interview.  
31  
32  
33

### 34 35 36 *Interviews*

37  
38 Participants were given the option of face-to-face or telephone interviews. In the first round,  
39  
40 all participants opted for telephone interviews, and the interviews lasted between 26 minutes  
41  
42 and 160 minutes (mean=79 minutes). The second set of interviews tended to be slightly  
43  
44 shorter as they focused on changes in between interviews and lasted between 36 minutes  
45  
46 and 103 minutes (mean=66.12). With one exception, participants in the second round also  
47  
48 opted for telephone interviews. Table 2 shows the topic guide used for the two interviews.  
49  
50 Examples people gave in the first interviews were also used as prompts to assess changes in  
51  
52 emotions, thoughts or symptom-management. All interviews were audiotaped with consent  
53  
54 and transcribed verbatim.  
55  
56  
57  
58  
59  
60

1 Transition to secondary progressive MS

2  
3 *Data analysis*

4  
5  
6 We used inductive thematic analysis [24]. An inductive approach means the themes identified  
7  
8 emerge from the data themselves [25]. Therefore, the inductive analysis is the process of  
9  
10 coding the data without trying to fit it into a pre-existing coding frame, or the researcher's  
11  
12 analytic preconceptions. This form of thematic analysis is, therefore, data-driven [24].  
13  
14

15  
16 Coding was undertaken by the first author (AB) under the supervision of the second author  
17  
18 (MM) and with discussion of emerging themes with the third author (RMM). A variety of  
19  
20 techniques were employed to increase familiarisation with the data. Audiotapes of each  
21  
22 interview were listened repeatedly, and transcripts were read and reread. We used NVivo 10  
23  
24 for coding. The analysis of the transcripts was conducted in parallel with data collection. First,  
25  
26 each coding unit in the first transcript was given a code name, using vocabulary as close as  
27  
28 possible to that used by participants themselves [26]. Initial codes were then applied  
29  
30 systematically to the entire dataset, and new codes developed and refined as appropriate.  
31  
32 We also grouped participants' interviews that shared similar demographic characteristics and  
33  
34 explored patterns or commonalities. We examined whether themes differed across sub-  
35  
36 groups (e.g. method of recruitment, gender, and family circumstances). Figure 1 shows the  
37  
38 steps followed during the analysis. The analysis was an iterative process and at times we had  
39  
40 to go back and forth between steps. In order to document the analysis process, a detailed  
41  
42 paper trail was kept with the notes taken after the interviews, the development of the codes  
43  
44 and relationship between the raw data and the refined categories and codes. The quotes  
45  
46 presented in the result section were chosen for typicality in illustrating the themes.  
47  
48 Pseudonyms are used for the quotes.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58

59 **Results**

1 Transition to secondary progressive MS  
2

3 Two overarching themes about (1) Transitioning to SPMS and challenges and (2) Adaptive  
4 strategies over time. The first theme illustrated challenges involved in the transition and the  
5  
6 second theme related to how participants responded to those challenges. Tables 3 provides  
7  
8 examples of SPMS transition and challenges over time and Table 4 provides examples of self-  
9  
10 management and changes over time.  
11  
12  
13  
14  
15

### 16 **Transitioning to SPMS and challenges**

#### 17 *Initial reaction to the transition*

18  
19 For the majority of the participants the transition to SPMS was expected rather than shocking.  
20  
21 For some, transitioning did not make much difference because at that point they had already  
22  
23 lost essential relationships and activities they valued. For others transitioning to SPMS did not  
24  
25 make much difference because the progressive worsening of their symptoms was slow and  
26  
27 subtle.  
28  
29  
30  
31  
32  
33

34  
35 We compared the interviews of people that found about the SPMS diagnosis in different ways,  
36  
37 for example, accidentally when visiting the hospital for other issues, or in one of the annual  
38  
39 consultations or they suspected they had transitioned and asked the neurologist for  
40  
41 confirmation. In contrast to the majority, the five participants, who found out about the  
42  
43 transition accidentally described being upset and shocked. These five people had MS between  
44  
45 3 to 21 years (median=12 years).  
46  
47  
48  
49

50 *[Neurologist's name] started other MRI's and tests and things and said that I'd*  
51  
52 *progressed to secondary progressive. So, I was shocked and- I was shocked that I got*  
53  
54 *signed off work, and it progressed. I thought he'd just say, "You're signed off for a*  
55  
56  
57  
58  
59  
60

1 Transition to secondary progressive MS

2  
3 *couple of weeks”, not that and, I just thought, you know, “If I sleep then I’ll be all right.”*

4  
5  
6 *(female, 45, T1)*

7  
8  
9 *Worsening of symptoms and emotional shifts*

10  
11  
12 Transitioning to SPMS also meant worsening of symptoms, and people described progressive  
13  
14 worsening of symptoms including mobility, fatigue, vision, and bladder dysfunction, urinary  
15  
16 tract infections and falls. There were further worsening of symptoms reported between the  
17  
18 first and second interview. This deterioration also brought more changes in participants’ lives.

19  
20  
21  
22 Transitioning to SPMS also meant worsening of emotional issues. A few participants had a  
23  
24 diagnosis of depression before or after the initial diagnosis of MS, which made managing MS  
25  
26 more difficult. However, the majority of participants described dealing with other difficult  
27  
28 emotions in both interviews, including feeling like a burden, being afraid of having accidents,  
29  
30 being trapped or feeling embarrassed. They also expressed low self-esteem and confidence,  
31  
32 and some participants described the uncertainty of whether they have the skills to cope with  
33  
34 MS, accept the condition and deal with stress.  
35  
36  
37  
38  
39

40 *I had a bad fall last week where I split all my head open, so I am feeling a bit lack of*  
41  
42 *confidence in just going out for a little walk up the road and back with my walker on*  
43  
44 *my own. (female, 54, T2)*

45  
46  
47  
48  
49  
50 Overall, in the second interview participants talked in more depth about their psychological  
51  
52 difficulties and challenges in coping over the years and presented a more severe picture than  
53  
54 in the first round of interviews. Further, people who described emotional challenges in the  
55  
56 first interview described the same challenges in the second interview, a year later.  
57  
58  
59  
60

1 Transition to secondary progressive MS  
2

3 *Arriving at the point of no help*  
4

5  
6 After transitioning to SPMS, participants reported that they did not feel health services had  
7  
8 anything more to offer since they could no longer have access to disease-modifying drugs.  
9

10 They saw their transition as a point beyond help.  
11

12  
13  
14 *I have an MS nurse but quite frankly you know I have come to an end what you can do,*  
15  
16 *I don't feel I am getting any support at all at the moment. I feel I am being left to my*  
17  
18 *own devices. Yes I see him every six months, every twelve months but there is nothing*  
19  
20 *he can offer so you know it is a bit of a waste of time really. (female, 54, T2)*  
21  
22

23  
24  
25 When asked whether there is any support that they would like to receive in the future, one  
26  
27 participant said: *'I think there is quite a lot of support when you're first diagnosed but I think*  
28  
29 *it tails off I think people find it more difficult to support you the longer you have the MS I think*  
30  
31 *people become quite cynical about the help that can be got and cynical about what the NHS*  
32  
33 *has to offer and cynical about the help that can be obtained as to whether it's any use or not.'*  
34  
35  
36 (female, 65, T2). Most participants shared a similar opinion.  
37  
38

39  
40 **Adaptive tasks and changes over time**  
41

42  
43 *Planning activities or scaling down activities*  
44

45  
46 Participants reported adjusting their holiday destinations and plans, to take into account their  
47  
48 limitations, without changing their previous lifestyle too much. Sometimes, across the two  
49  
50 interviews participants appeared to overestimate their limitations and underestimate their  
51  
52 ability to cope in the future. This discrepancy is illustrated below by the quotes of the same  
53  
54 participant in the first and second interview.  
55  
56  
57  
58  
59  
60

## Transition to secondary progressive MS

1  
2  
3 *I don't go too far now, I can only cope with about three and half hours on the plane at*  
4 *the most. I can't go long distance or anything like that, you know long haul anymore,*  
5 *it's usually the Canary Islands or somewhere like that, somewhere nice and close*  
6  
7  
8  
9  
10 *(female, 54, T1)*

11  
12  
13 *I am still determined that I am going to travel and see as many places as I want. We*  
14 *went away for six weeks over January/February, we went to New Zealand and*  
15 *Australia (female, 55, T2)*

16  
17  
18  
19  
20  
21 However, at times, participants found it difficult to plan or modify their activities and instead  
22 scaled back, especially when the condition progressed rapidly, and almost all participants who  
23 had mentioned difficulties finding alternative activities in the first interview had the same  
24 difficulties in the second interview.  
25  
26  
27  
28  
29  
30

31  
32 *I can't read the same that I used to; I can't go on the computer; I can't really watch TV;*  
33 *gardening, the high impact exercises, you know, the long walk so everything's just had*  
34 *to be tailored down and you know brought into a shorter time period. The human is*  
35 *pretty good at finding ways around things...so yeah you just adapt um it's a struggle*  
36 *you know there's no two ways about it but it is that life is definitely a struggle but*  
37 *again you get used to that really as well (female, 59, T2)*  
38  
39  
40  
41  
42  
43  
44  
45  
46

### Emotional regulation

47  
48  
49  
50 Strategies to manage emotional difficulties included distraction such as playing video games,  
51 reading books, going out for a meal, or avoiding thinking and talking about the future,  
52 avoiding MS group meetings and spending the day sleeping. Some people tried to be positive  
53 by repeating 'things could have been worse'. People reported using the same strategies  
54  
55  
56  
57  
58  
59  
60

1 Transition to secondary progressive MS

2  
3 between the two interviews. A few participants talked about how they would have liked  
4  
5 access to psychological services.  
6  
7

8  
9 *It would be nice to talk about how you feel about it, would be it'd be nice if...do you*  
10  
11 *know it would be nice if just to have somebody there saying you're doing a grand job*  
12  
13 *[Laugh] with how you're doing. Because you are isolated (female, 53, T2)*  
14  
15

16  
17 However, two participants said that they were offered psychological support, but they  
18  
19 thought this was unnecessary.  
20  
21

22 *Being social, fitting in and being of use*  
23  
24

25 For most of the participants transitioning to SPMS also meant increased mobility problems  
26  
27 and use of a wheelchair. Use of a wheelchair also posed accessibility issues leading to more  
28  
29 carefully planned outings. Even though going out came with more difficulties, and at times  
30  
31 people felt it was easier to stay in, most talked about the importance of being with friends  
32  
33 and family and retaining relationships and also meeting new people. Participants described  
34  
35 getting involved in charity work and helping others. They reported that this gave them a new  
36  
37 purpose, they learned new things and met people. Participants who talked about the  
38  
39 importance of being social or helping others in the first interview also talked about it in their  
40  
41 second interview, as illustrated below by the same participant at the two time points.  
42  
43  
44  
45  
46  
47

48 ...going out with friends, going out for dinner, going and mixing with other people,  
49  
50 which I would of quite enjoyed before and not thought anything about it, but now I  
51  
52 think, "oh do I really want to go?" but then I force myself, you have got to go, because  
53  
54 then when I do go, I do enjoy it and I do feel better because your mood's lifted and  
55  
56 once you are moving around, things are easier. (female, 59, T1)  
57  
58  
59  
60



### Transition to secondary progressive MS

1  
2  
3 We've got the local MS branch, we meet twice a month, first and third Tuesdays of  
4 the month. I find that very helpful. I do find that helpful to talk to other people that  
5 have got the same sorts of problems that you've got, gone through the same things.  
6  
7  
8 And again there's somebody there that, it's not perhaps a close friend, but has become  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

branch. (female, 59, T2)

### Discussion

Reflecting on the SPMS diagnosis, people overall did not express trauma or distress, only on the occasions, the diagnosis came as a surprise. People who have recently transitioned to SPMS reported facing a worsening of the condition alongside increased emotional challenges. In the second interview, most people described the increased severity of their symptoms and more emotional difficulties. Participants reported detailed planning, distractions and remaining as active and as involved in the community as possible helped to cope with the condition. Some participants overestimated their limitations and underestimated their capacity to cope between the first and the second interview but overall most reported using similar coping strategies between the two time points. A common theme across all interviews was a sense of abandonment from the health care services and the sense that nothing can be done at this stage of their condition. Therefore, providing appropriate support after the transition diagnosis is vital.

A qualitative study of people recently diagnosed with MS showed that psychological well-being was described as precariously contingent on reasonable current and future health status [27], for example, people were not sure whether they would be able to cope if they lost their job or had to use a wheelchair. The current study examines what happens after

## Transition to secondary progressive MS

1  
2  
3 people have moved to SPMS. Participants in our study talked about increased disability since  
4  
5 they have transitioned to SPMS or between the first and second interview, but despite these  
6  
7 increased difficulties, people felt that health care professionals had nothing more to offer and  
8  
9 there was nothing more they could do to control their emotional or physical symptoms.  
10  
11 Focusing on well-being is often on diagnosable depression and anxiety. However, participants  
12  
13 in the present study described having to deal with challenging emotions which may not reflect  
14  
15 in these clinical diagnoses.  
16  
17

18  
19  
20 An essential finding of this study is that people who described some challenges with self-  
21  
22 management in the first interview described the same challenges in the second interview, a  
23  
24 year later. This can be linked to their perception of SPMS as the stage where nothing further  
25  
26 can be done to manage things. According to the Common Sense Model [28]. Being diagnosed  
27  
28 with an illness that is perceived as more controllable will lead to less distress and more control  
29  
30 efforts such as seeking advice on symptom management. Participants interviewed here  
31  
32 described SPMS as a condition they and their health care team did not have any control over.  
33  
34 As people move from RRMS to SPMS, the capacity of personal and treatment control declines,  
35  
36 and creates a significant challenge in adapting to the change by identifying areas that they  
37  
38 can still have control while letting go of unattainable goals [29].  
39  
40  
41  
42  
43  
44  
45

46  
47 Participants in the current study reported that there is nothing they or health care  
48  
49 professionals can do to manage their increasing limitations. Even though self-management  
50  
51 interventions in progressive MS are scarce, there is some preliminary evidence of  
52  
53 interventions that could help with symptom management. For example, endurance training  
54  
55 can improve walking [30]; progressive resistance training may improve lower limb strength  
56  
57 [31]; bodyweight-supported treadmill can reduce pain [32], and mindfulness training can  
58  
59  
60

## Transition to secondary progressive MS

1  
2  
3 reduce anxiety, depression and impact of MS [33]. Where available, health care professionals  
4  
5 should signpost patients to appropriate services that can help with MS symptoms but more  
6  
7 needs to be done to find ways of developing these services, so they are more readily available.  
8  
9

10  
11 The present study has certain significant strengths. First, to our knowledge, it is the first study  
12  
13 attempting to investigate challenges and adaptive tasks shortly after people have transitioned  
14  
15 to SPMS. The particular advantage of the present study was its longitudinal approach that  
16  
17 allowed the identification of patterns over time. This showed that whereas more severe  
18  
19 emotional and physical symptoms were reported in the second interview, these did not result  
20  
21 in different or more challenges. While this may suggest participants feeling more comfortable  
22  
23 in opening up at time two having built a rapport with the interviewer, it may also reflect the  
24  
25 lack of support people were receiving. Finally, a strength of this study also lies in the specificity  
26  
27 of the sample selected, who were all people who had transitioned to SPMS within the  
28  
29 previous five years.  
30  
31  
32  
33  
34  
35

36 The study has certain limitations. Firstly, the qualitative exploratory nature of the study does  
37  
38 not allow for causal relationships to be established. Second, getting a SPMS diagnosis may  
39  
40 take years, in part due to substantial diagnostic uncertainty as a result of the subtlety of signs  
41  
42 of early progressive disease [6]. Therefore, it is hard to determine whether the challenges  
43  
44 described are linked to having received an official diagnosis or to the challenges faced by  
45  
46 increased disability, as we did not interview people just before being diagnosed and straight  
47  
48 after.  
49  
50  
51  
52  
53

54 Regardless of the above limitations, the findings presented here underline the additional  
55  
56 physical and emotional challenges people face when transitioned to SPMS and that people  
57  
58 try to adapt by planning, finding distractions and remaining social but they reported there  
59  
60

1 Transition to secondary progressive MS

2  
3 was nothing further to do regarding symptom management. Identifying physical and  
4  
5 emotional challenges at the time of the diagnosis to SPMS will help referral to appropriate  
6  
7 services within a multidisciplinary clinical team. Offering people options for continuing  
8  
9 symptoms management at the time of SPMS diagnosis may help with feelings of helplessness  
10  
11 accompany the diagnosis.  
12  
13  
14  
15

### 16 **Acknowledgments**

17  
18  
19 The authors would like to thank the people with MS who took part in this study.  
20  
21

### 22 **Conflict of interest**

23  
24  
25 We have no conflict of interest to declare.  
26  
27

### 28 **Funding**

29  
30  
31 This work was supported by Multiple Sclerosis UK under grant reference 4.  
32  
33

### 34 **Author statement**

35  
36  
37 AB and RMM designed the study. AB conducted the interviews, led the data analysis and  
38  
39 drafted the manuscript. MM contributed to the development of the topic guide, oversaw data  
40  
41 collection and analysis and contributed to drafts of the paper. RMM advised on the conduct  
42  
43 of the research, contributed towards refining themes, interpretations of the findings, and  
44  
45 drafts of the paper.  
46  
47  
48  
49

### 50 **Data sharing statement**

51  
52  
53 Paper trail and NVivo coding files available from the corresponding author  
54  
55  
56  
57  
58  
59  
60

## Transition to secondary progressive MS

## References

1. Mackenzie, I.S., et al., *Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a descriptive study in the General Practice Research Database*. Journal of Neurology, Neurosurgery & Psychiatry, 2013.
2. Compston, A. and A. Coles, *Multiple sclerosis*. Lancet, 2008. **372**: p. 1502 - 1517.
3. Fisniku, L.K., et al., *Disability and T2 MRI lesions: a 20-year follow-up of patients with relapse onset of multiple sclerosis*. Vol. 131. 2008. 808-817.
4. Lublin, F.D. and S.C. Reingold, *Defining the clinical course of multiple sclerosis: results of an international survey*. National Multiple Sclerosis Society (USA) Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis. Neurology, 1996. **46**(4): p. 907-11.
5. Tremlett, H., *Secondary Progressive Multiple Sclerosis*. MS in Focus, 2009. **13**: p. 13-14.
6. Sand, I.K., et al., *Diagnostic uncertainty during the transition to secondary progressive multiple sclerosis*. Multiple Sclerosis Journal, 2014. **20**(12): p. 1654-1657.
7. Gross, H.J. and C. Watson, *Characteristics, burden of illness, and physical functioning of patients with relapsing-remitting and secondary progressive multiple sclerosis: a cross-sectional US survey*. Neuropsychiatr Dis Treat, 2017. **13**(13): p. 1349-1357.
8. Planche V, G.M., Cregut D, Pereira B, Clavelou P. , *Cognitive impairment in a population-based study of patients with multiple sclerosis: differences between late relapsing– remitting, secondary progressive and primary progressive multiple sclerosis*. European journal of neurology, 2016. **23**(2): p. 282-9.
9. Papathanasiou, A., et al., *Cognitive impairment in relapsing remitting and secondary progressive multiple sclerosis patients: efficacy of a computerized cognitive screening battery*. ISRN neurology, 2014. **2014**.
10. Denney, D.R., L.A. Sworowski, and S.G. Lynch, *Cognitive impairment in three subtypes of multiple sclerosis*. Archives of Clinical Neuropsychology, 2005. **20**(8): p. 967-981.
11. Bakshi, R., et al., *Fatigue in multiple sclerosis and its relationship to depression and neurologic disability*. Multiple Sclerosis (Houndmills, Basingstoke, England), 2000. **6**(3): p. 181-185.
12. Thorne, S., et al., *Health care communication issues in multiple sclerosis: an interpretive description*. Qualitative Health Research, 2004. **14**(1): p. 5-22.
13. Vleugels, L., et al., *Psychological functioning in primary progressive versus secondary progressive multiple sclerosis*. Br J Med Psychol, 1998. **71 ( Pt 1)**(1): p. 99-106.
14. Montel, S.R. and C. Bungener, *Coping and quality of life in one hundred and thirty five subjects with multiple sclerosis*. Mult Scler, 2007. **13**(3): p. 393-401.
15. McNulty, K., H. Livneh, and L.M. Wilson, *Perceived Uncertainty, Spiritual Well-Being, and Psychosocial Adaptation in Individuals With Multiple Sclerosis*. 2004, Educational Publishing Foundation: US. p. 91-99.
16. Mohr, D.C., et al., *The Psychosocial Impact of Multiple Sclerosis: Exploring the Patient's Perspective*. Health Psychology, 1999. **18**: p. 376-382.
17. Olsson, M., J. Lexell, and S. Soderberg, *The meaning of women's experiences of living with multiple sclerosis*. Health Care Women Int, 2008. **29**(4): p. 416-30.
18. Olsson, M., L. Skar, and S. Soderberg, *Meanings of feeling well for women with multiple sclerosis*. Qual Health Res, 2010. **20**(9): p. 1254-61.
19. Davies, F., et al., *'You are just left to get on with it': qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis*. BMJ open, 2015. **5**(7): p. e007674.
20. Fiest, K.M., et al., *Systematic review and meta-analysis of interventions for depression and anxiety in persons with multiple sclerosis*. Mult Scler Relat Disord, 2016. **5**: p. 12-26.
21. Jongen, P.J., et al., *An intensive social cognitive program (can do treatment) in people with relapsing remitting multiple sclerosis and low disability: a randomized controlled trial protocol*. BMC Neurol, 2016. **16**(1): p. 81.

## Transition to secondary progressive MS

22. Patton, M., *Qualitative evaluation and research methods*. 1990, Thousand Oaks, California: Sage Publications Ltd.
23. Guest, G., A. Bunce, and L. Johnson, *How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability*. *Field Methods*, 2006. **18**(1): p. 59-82.
24. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. *Qualitative Research in Psychology*, 2006. **3**(2): p. 77-101.
25. Payne, S., *Interview in qualitative research*, in *Handbook of psychology of interviewing*, A. Memon and R. Bull, Editors. 1999, Wiley and Sons: London. p. 89-102.
26. Glaser, B. and S.A. Strauss, *Discovery of grounded theory. Strategies for qualitative research*. 1967, New York: Aldine de Gruyter.
27. Dennison, L., et al., *Experiences of adjusting to early stage Multiple Sclerosis*. *J Health Psychol*, 2011. **16**(3): p. 478-88.
28. Leventhal, H., M. Diefenbach, and E.A. Leventhal, *Illness cognition: using common sense to understand treatment adherence and affect cognition interactions*. *Cognitive therapy and research*, 1992. **16**(2): p. 143-163.
29. Heckhausen, J., C. Wrosch, and R. Schulz, *A motivational theory of life-span development*. *Psychological review*, 2010. **117**(1): p. 32.
30. Briken, S., et al., *Effects of exercise on fitness and cognition in progressive MS: a randomized, controlled pilot trial*. *Multiple Sclerosis Journal*, 2013: p. 1352458513507358.
31. Latimer-Cheung, A., et al., *Effects of exercise training on fitness, mobility, fatigue, and health-related quality of life among adults with multiple sclerosis: a systematic review to inform guideline development*. *Arch Phys Med Rehabil*, 2013. **94**: p. 1800 - 1828.e3.
32. Wier, L.M., et al., *Effect of robot-assisted versus conventional body-weight-supported treadmill training on quality of life for people with multiple sclerosis*. *J Rehabil Res Dev*, 2011. **48**(4): p. 483-92.
33. Bogosian, A., et al., *Distress improves after mindfulness training for progressive MS: A pilot randomised trial*. *Mult Scler*, 2015. **21**(9): p. 1184-94.

## Transition to secondary progressive MS

Table 1. Participants' characteristics

| <i>Participants' characteristics (T1)</i> | <i>Number (%)</i>   |
|---|---------------------|
| <i>Age (Mean, SD)</i>                     | <i>57.33 (9.13)</i> |
| <i>Gender-female</i>                      | <i>16 (72.7%)</i>   |
| <i>Marital status (N, %):</i>             |                     |
| <i>Married/cohabiting</i>                 | <i>15 (71.4%)</i>   |
| <i>Single</i>                             | <i>3 (14.3%)</i>    |
| <i>Divorced/separated</i>                 | <i>3 (14.3%)</i>    |
| <i>Time since initial diagnosis:</i>      |                     |
| <i>0-5 years</i>                          | <i>5 (23.8 %)</i>   |
| <i>6-10 years</i>                         | <i>3 (14.3%)</i>    |
| <i>11-15 years</i>                        | <i>3(14.3%)</i>     |
| <i>16-20 years</i>                        | <i>2 (9.5%)</i>     |
| <i>21years +</i>                          | <i>8 (38.1%)</i>    |
| <i>Time since SPMS diagnosis:</i>         |                     |
| <i>1 year</i>                             | <i>4 (18.2%)</i>    |
| <i>2 years</i>                            | <i>3 (13.6%)</i>    |
| <i>3 years</i>                            | <i>3 (13.6%)</i>    |
| <i>4 years</i>                            | <i>4 (18.2%)</i>    |
| <i>5 years</i>                            | <i>7 (31.8%)</i>    |
| <i>Walking ability (with aid):</i>        |                     |
| <i>0-5 meters</i>                         | <i>9 (42.8%)</i>    |
| <i>20 meters</i>                          | <i>3 (14.3%)</i>    |
| <i>100 meters</i>                         | <i>3 (14.3%)</i>    |
| <i>200 meters</i>                         | <i>4 (18.2%)</i>    |
| <i>500 meters</i>                         | <i>1 (4.8%)</i>     |
| <i>unknown</i>                            | <i>1 (4.8%)</i>     |

## Transition to secondary progressive MS

Table 2. Topic guide

| Questions  | Prompts  |
|--|--|
| Can you start by telling me all about what you thought and felt when you were first diagnosed with MS? | Main issues, explore concerns, feelings, (physical, psychological, family issues) what did he/she do about each problem that was identified?                             |
| Can you tell me about the time you found out you have moved to secondary progressive type of MS?       | Explore how did they find out, period before receiving the diagnosis, thoughts and feelings after receiving the secondary diagnosis.                                     |
| Can you tell me about what you think and feel about having MS now?                                     | Examples of issues identified?   |
| Can you tell me about all the things you found (un)helpful when dealing with challenges of MS?         | Feelings and thoughts on support interventions they were offered or sought/ how did they apply the advice given (if given), support they would like to see in the future |
| Are there any other relevant issues we haven't covered that you would like to mention?                 |  |



Transition to secondary progressive MS

Table 3. Examples of SPMS transition and challenges over time

Table 4. Examples of self-management and changes over time

Figure 1. Data analysis flow

For peer review only

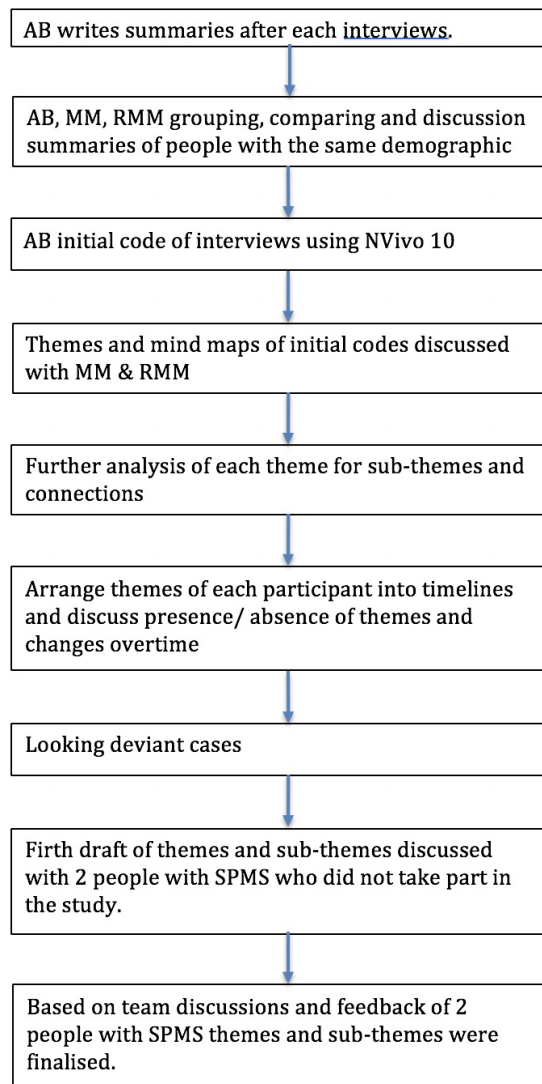


Figure 1. Data analysis flow

Figure 1. Data analysis flow

336x523mm (72 x 72 DPI)

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

| No. Item                                       | Guide questions/description                             | Reported on Page #  |
|--|---|---|
| <b>Domain 1: Research team and reflexivity</b> |   |   |
| <i>Personal Characteristics</i>                |   |   |
| 1. Interviewer/facilitator                     | Which author/s conducted the inter view or focus group? | Angeliki Bogosian   |
| 2. Credentials                                 | What were the researcher's credentials?<br>E.g. PhD, MD | Angeliki Bogosian<br>PhD, Senior lecturer<br><br>Myfanwy Morgan<br>PhD, Emeritus<br>Professor<br><br>Rona Moss-Morris<br>PhD, Professor   |
| 3. Occupation                                  | What was their occupation at the time of the study?     | Angeliki Bogosian<br>Research fellow<br><br>Myfanwy Morgan<br>Professor<br><br>Rona Moss-Morris<br>Professor  |
| 4. Gender                                      | Was the researcher male or female?                      | Female  |
| 5. Experience and training                     | What experience or training did the researcher have?    | The researcher has completed qualitative methodologies training as part of the MSc in Health Psychology course (Southampton University) and attended a two-day workshop on longitudinal |

|   |   |   |
|---|---|---|
|   |   | qualitative research organized by the Methodological Innovation Network and delivered at Southampton University (Nov 2012). At the time of this study the researcher had completed and published 3 qualitative studies as the lead researcher (conducting of interviews, analysis and write-up) and supervised 1 MSc student and 2 PhD students on their qualitative methodologies. |
| <i>Relationship with participants</i>       |   |   |
| 6. Relationship established                 | Was a relationship established prior to study commencement?   | No  |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research                                  | Participant information sheet and consent form  |
| 8. Interviewer characteristics              | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Participants and Methods  |

|  |  |                                |
|--|--|--------------------------------|
| <b>Domain 2: study design</b>            |  |                                |
| <i>Theoretical framework</i>             |  |                                |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Data analysis                  |
| <i>Participant selection</i>             |  |                                |
| 10. Sampling                             | How were participants selected? e.g. purposive, convenience, consecutive, snowball   | Participants and Methods       |
| 11. Method of approach                   | How were participants approached? e.g. face-to-face, telephone, mail, email  | Participants and Methods       |
| 12. Sample size                          | How many participants were in the study?   | Participants and Methods       |
| 13. Non-participation                    | How many people refused to participate or dropped out? Reasons?  | Participants and Methods       |
| <i>Setting</i>                           |  |                                |
| 14. Setting of data collection           | Where was the data collected? e.g. home, clinic, workplace   | Interviews                     |
| 15. Presence of non-participants         | Was anyone else present besides the participants and researchers?  | No                             |
| 16. Description of sample                | What are the important characteristics of the sample? e.g. demographic data, date  | Participants and Methods       |
| <i>Data collection</i>                   |  |                                |
| 17. Interview guide                      | Were questions, prompts, guides provided by the authors? Was it pilot tested?  | Table 2, Patient & involvement |
| 18. Repeat interviews                    | Were repeat interviews carried out? If yes, how many?  | Methods                        |

|  |   |                                |
|--|---|--------------------------------|
| 19. Audio/visual recording             | Did the research use audio or visual recording to collect the data?   | Interviews                     |
| 20. Field notes                        | Were field notes made during and/or after the inter view or focus group?  | Data analysis                  |
| 21. Duration                           | What was the duration of the inter views or focus group?  | Interviews                     |
| 22. Data saturation                    | Was data saturation discussed?  | Participants and Methods       |
| 23. Transcripts returned               | Were transcripts returned to participants for comment and/or correction?  | No                             |
| <b>Domain 3: analysis and findings</b> |   |                                |
| <i>Data analysis</i>                   |   |                                |
| 24. Number of data coders              | How many data coders coded the data?  | Data analysis                  |
| 25. Description of the coding tree     | Did authors provide a description of the coding tree?   | n/a                            |
| 26. Derivation of themes               | Were themes identified in advance or derived from the data?   | Data analysis                  |
| 27. Software                           | What software, if applicable, was used to manage the data?  | Data analysis                  |
| 28. Participant checking               | Did participants provide feedback on the findings?  | Patient and public involvement |
| <i>Reporting</i>                       |   |                                |
| 29. Quotations presented               | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Results                        |
| 30. Data and findings consistent       | Was there consistency between the data presented and the findings?  | Discussion                     |
| 31. Clarity of major themes            | Were major themes clearly presented in the findings?  | Results                        |
| 32. Clarity of minor themes            | Is there a description of diverse cases or discussion of minor themes?  | Results                        |

# BMJ Open

## Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study

|                                 |   |
|---------------------------------|---|
| Journal:                        | <i>BMJ Open</i>   |
| Manuscript ID                   | bmjopen-2018-026421.R1  |
| Article Type:                   | Research  |
| Date Submitted by the Author:   | 03-Dec-2018   |
| Complete List of Authors:       | Bogosian, Angeliki; City University of London , School of health sciences<br>Morgan, Myfanwy; King's College London, Institute of Pharmaceutical Science<br>Moss-Morris, Rona; Kings College London |
| <b>Primary Subject Heading</b>: | Neurology   |
| Secondary Subject Heading:      | Communication, Mental health, Neurology, Patient-centred medicine, Qualitative research   |
| Keywords:                       | Multiple sclerosis < NEUROLOGY, secondary progressive, self-management, QUALITATIVE RESEARCH, HEALTH SERVICES ADMINISTRATION & MANAGEMENT   |
|                                 |   |

SCHOLARONE™  
Manuscripts

Transition to secondary progressive MS

1  
2  
3 1 **Multiple challenges for people after transitioning to secondary progressive multiple**  
4  
5  
6 2 **sclerosis: a qualitative study**  
7

8  
9 3  
10  
11  
12 4 Bogosian A.<sup>\*1</sup>, Morgan, M.<sup>2</sup>, Moss-Morris R.<sup>3</sup>  
13

14  
15 5 <sup>1</sup>School of Health Sciences, City, University of London, London UK,  
16

17 6 [Angeliki.bogosian.1@city.ac.uk](mailto:Angeliki.bogosian.1@city.ac.uk)  
18

19  
20 7 <sup>2</sup>Institute of Pharmaceutical Science, King's College London, London, UK,  
21 8 [myfanwy.morgan@kcl.ac.uk](mailto:myfanwy.morgan@kcl.ac.uk)  
22  
23

24 9  
25  
26 10 <sup>3</sup> Institute of Psychiatry, Psychology & Neuroscience, King's College Hospital, London, UK,  
27 11 [rona.moss-morris@kcl.ac.uk](mailto:rona.moss-morris@kcl.ac.uk)  
28

29 12  
30  
31 13 \*Address correspondence and reprint requests to Dr. Angeliki Bogosian, School of Health  
32  
33 14 Sciences, City, University of London, EC1V 0HB, London, UK; email:  
34  
35 15 [angeliki.bogosian.1@city.ac.uk](mailto:angeliki.bogosian.1@city.ac.uk); telephone number : +44(0)2070408532  
36  
37  
38

39 16  
40  
41  
42 17 **Keywords:** secondary progressive, Multiple Sclerosis, transition, self-management,  
43  
44 18 qualitative research, health services  
45  
46

47 19  
48  
49  
50  
51 20 Word count: 3,850  
52  
53

54 21  
55  
56

57 22  
58  
59 23  
60



Transition to secondary progressive MS

24 Abstract

25 **Objectives:** Transitioning to secondary progressive multiple sclerosis (SPMS) is demanding for  
26 both patients and healthcare professionals. The particular challenges and the ways patients  
27 cope are poorly understood. The present study examines what challenges people face when  
28 diagnosed with SPMS, by exploring experiences of people who have transitioned recently (up  
29 to 5 years).

30 **Design:** Semi-structured qualitative interviews at two time points a year apart. Interviews  
31 were analysed using inductive thematic analysis.

32 **Setting:** United Kingdom

33 **Participants:** We interviewed twenty-one people at baseline and seventeen participated in  
34 the follow-up interviews.

35 **Results:** The majority of participants reported expecting to transition to SPMS, and the  
36 diagnosis did not make much difference to them. Participants described increasing emotional  
37 and physical challenges after transitioning to SPMS and between the first and second  
38 interview. Planning, using distractions and maintaining social roles helped participants cope  
39 with the increased challenges. The same coping strategies were used between the two  
40 interviews. Participants felt there was not much left to do regarding the management of their  
41 symptoms. A key theme was the sense of abandonment from health care services after  
42 transitioning to SPMS.

43 **Conclusions:** After transitioning to SPMS people are faced with multiple challenges.  
44 Participants described a lack of directions for symptoms management and lack of support  
45 from the healthcare system. An integrated multidisciplinary health care approach is crucial at

Transition to secondary progressive MS

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

46 the progressive stage of the disease to alleviate feelings of helplessness and promote  
47 symptom management.

For peer review only

Transition to secondary progressive MS

49

50 **Strength and limitations of this study**

- 51 • The present study is the first to use a longitudinal qualitative design to capture  
52 people's experience after transitioning to secondary progressive multiple sclerosis.
- 53 • The focus on people recently transitioned helped to narrow down people's  
54 experiences early on in diagnosis.
- 55 • We cannot determine whether the challenges described in this study are linked to  
56 having received an official diagnosis or to the challenges faced by increased disability,  
57 as we did not interview people just before being diagnosed and straight after.

58

## Transition to secondary progressive MS

## 59 Introduction

60 Multiple Sclerosis (MS) affects more than 2.5 million people worldwide, including 127,000 in  
61 the United Kingdom [1]. MS is a condition that presents unique challenges for the individuals,  
62 as it usually starts with minimal physical and cognitive dysfunction which progresses over  
63 time. There are three types of MS. The most common type is relapsing-remitting (RR, 85%-  
64 90% of people with MS are diagnosed with this type) which is characterised by unpredictable  
65 attacks (relapses) of new or increasing neurological symptoms that are followed by periods  
66 of partial or complete recovery (remissions) [2]. The secondary progressive (SP) course  
67 develops in approximately 82% of those with RRMS by 20 years of onset [3]. Finally, a minority  
68 of people (10%) will be diagnosed with the primary progressive (PP) course that involves a  
69 steady disability increase without attacks [4].

70 The transition to secondary progressive multiple sclerosis (SPMS) is an expected part of the  
71 disease trajectory. Epidemiological studies indicate nearly 10% of people with RRMS reach  
72 the SPMS stage after five years, which increases to 25% at ten years and 75% at 30 years [5].  
73 A mean of  $2.9 \pm 0.8$  years is a typical length of time when people are faced with the  
74 uncertainty of whether or not they have transitioned to SPMS [6]. The delay in the diagnosis  
75 is thought to be due to the subtle nature of early progression and absent of evidence-based  
76 treatment for SPMS that could increase patients' anxieties [6]. People with SPMS are older,  
77 are less likely to be employed, and a lower proportion is female compare to people with RRMS  
78 [7]. When people transition to SPMS, they are likely to experience more severe neurological  
79 symptoms, more frequent hospitalisation [8], have more frequent and pronounced cognitive  
80 deficits [9, 10], and higher levels of fatigue [11]. The onset of SPMS has also been associated  
81 with fear, low mood [12], greater distress [13, 14], lower quality of life [15], and higher levels

## Transition to secondary progressive MS

1  
2  
3 82 of depression and anxiety [16] than in both relapsing-remitting and primary progressive types  
4  
5  
6 83 of MS. Only four qualitative studies have been conducted to examine the experiences of  
7  
8 84 people with SPMS. In two of these studies, women with SPMS recognised the impact of the  
9  
10 85 loss of meaningful activities on the sense of self [17, 18]. A qualitative study on patients'  
11  
12 86 experiences while transitioning to SPMS showed that some people learned they had SPMS  
13  
14 87 without any advanced knowledge or understanding of what SPMS meant for them, which  
15  
16 88 sometimes caused confusion and upset [19]. In the fourth study, MS health professionals  
17  
18 89 highlighted the value of adequate information and support around the transition period,  
19  
20 90 while patients talked about the reclassification with SPMS as a turning point [20].  
21  
22  
23  
24  
25

26 91 We know little about people's experiences after transitioning to SPMS, and psychological and  
27  
28 92 behavioural interventions aimed at people with SPMS are scarce. Further, a recent meta-  
29  
30 93 analysis on the effectiveness of interventions for treating depression in MS identified 13  
31  
32 94 papers, with 8 of these excluding people with progressive MS from participating [21]. When  
33  
34 95 people with SPMS are included in psychological interventions, they also seem to gain fewer  
35  
36 96 benefits compared to people with RRMS [22]. The psychological challenges that people with  
37  
38 97 SPMS face may, therefore, differ to the ones that people with RRMS face  
39  
40  
41  
42

43 98 In this study, we explored psychological and physiological challenges people experience after  
44  
45 99 transitioning to SPMS and the strategies they use to manage those challenges over time.  
46  
47

48 100 Knowing the challenges that patients face at this stage of their MS trajectory makes it easier  
49  
50 101 to identify information needs and tailor support interventions. Further, it is not well  
51  
52 102 understood how transitioning to SPMS contributes to psychological challenges and  
53  
54 103 adjustment attempts. The present study is the first to use a longitudinal qualitative design to  
55  
56 104 capture people's experience shortly (within five years) after transitioning, so recollection of  
57  
58  
59  
60

Transition to secondary progressive MS

1  
2  
3 105 transition is recent but also there is time for people to have developed new coping strategies.  
4  
5  
6 106 The follow-up interviews allowed respondents to reflect on the changes (or lack of them)  
7  
8 107 since the first interview. The focus on people recently transitioned helped to narrow down  
9  
10 108 people's experiences early on in diagnosis.

### 109 **Patients and public involvement**

110 This research was part of a larger research project, and two individuals with SPMS were part  
111 of our user involvement committee, and they have helped with different aspects of the  
112 project from the initial conceptualisation of the study, feedback on the grant application and  
113 feedback of the topic guide. They were also asked to assess the burden of participation in the  
114 study. The two people with SPMS gave us feedback on an initial version of our themes. They  
115 inquired about whether the experiences differ based on the age of diagnosis or whether the  
116 people who described more psychological challenges had also reported cognitive difficulties.  
117 Following this, we checked the emerging themes to identify any patterns or differences in  
118 themes of people with different demographic characteristics. The two people with SPMS also  
119 suggested exploring further the experience of diagnosis and the importance of receiving the  
120 diagnosis of a SPMS from a healthcare professional. Finally, they commented on the clarity of  
121 description and presentation of the results, for example, they made some suggestions about  
122 how themes linked together and asked for a few additional quotes at places to better  
123 illustrate themes. Participants of the study were sent the final results of the study but were  
124 not asked to provide feedback.

### 125 **Participants and methods**

126 This research is part of an MS Society UK funded junior research fellowship awarded to the  
127 first author with a view to increase understanding of psychological challenges and adjustment

## Transition to secondary progressive MS

1  
2  
3 128 of people with progressive MS. The current study was approved by the West of Scotland  
4  
5 129 Research Ethics Committee (14/WS/0077). We recruited participants through online adverts  
6  
7  
8 130 on the MS Society UK website, adverts after speaking engagements at MS Society events and  
9  
10  
11 131 through study's information sheets provided by research nurses at MS hospital clinics  
12  
13 132 (Northamptonshire Healthcare NHS Foundation Trust and Cumbria Partnership NHS  
14  
15 133 Foundation Trust). At that stage through the participants' information sheet, potential  
16  
17  
18 134 participants learnt the aims of the research project and what the researchers were planning  
19  
20 135 to use the information for, i.e. develop a psychological intervention tailored to the needs of  
21  
22  
23 136 people with progressive MS. Participants who self-reported that they had received a diagnosis  
24  
25 137 of primary progressive and secondary progressive MS from their neurologist or MS nurse  
26  
27  
28 138 were recruited, but for the aims of this study we focused on the interviews of people with  
29  
30 139 secondary progressive MS. Eighty-seven people with primary and secondary progressive MS  
31  
32  
33 140 expressed interest in participating in the study. Fifteen (17%) did not meet the inclusion  
34  
35 141 criterion of diagnosis within five years of progressive MS. The remaining 72 completed a short  
36  
37  
38 142 screening questionnaire that included demographic questions, as well as questions about MS  
39  
40 143 duration, symptoms and walking ability. We chose to interview people using maximum  
41  
42 144 variation [23], i.e. sampling to represent different demographic characteristics. No one  
43  
44  
45 145 refused participation after they have been invited to the interview. Participants were  
46  
47 146 recruited from a wide range of locations in the UK, including more rural (small towns) and  
48  
49  
50 147 urban areas, therefore there was also a variability on the services they were able to access.  
51  
52 148 Interviewing ceased once data saturation was reached, defined as the point at which no new  
53  
54  
55 149 information or themes are observed in the data [24]. We interviewed 21 participants who  
56  
57 150 were diagnosed with secondary progressive MS and had given informed consent to take part  
58  
59 151 in the study.  
60

## Transition to secondary progressive MS

1  
2  
3 152 As shown in Table 1, participants were between 40 and 77 years of age (mean: 57.38 years)  
4  
5  
6 153 at the time of the interview. More than half the sample was unemployed or retired due to MS  
7  
8 154 (n=14, 66.66%) and lived with their partners (n=15, 71.43%). Half of the participants  
9  
10 155 interviewed (n=12, 57.1%) were able to walk for 20 meters or less, which is reflective of the  
11  
12  
13 156 demographics of people with SPMS. Most people with MS accumulate no more than  
14  
15 157 moderate disability (fully ambulatory) during relapsing remitting phase [25] and the onset of  
16  
17  
18 158 SP phase represents the key determinant of severe disability accumulation [25-27]. Seventeen  
19  
20 159 participants were interviewed for the second time, four participants (19%) did not respond to  
21  
22  
23 160 the email invitations for a second interview, and no reason was provided.

161 *Interviews*

26  
27  
28  
29 162 Researchers had not established a relationship with the participants prior to study  
30  
31 163 commencement. Participants were given the option of face-to-face or telephone interviews.  
32  
33  
34 164 In the first round, all participants opted for telephone interviews, and the interviews lasted  
35  
36 165 between 26 minutes and 160 minutes (mean=79 minutes). Interviews were conducted by the  
37  
38  
39 166 first author (AB, female). AB has conducted her MSc, PhD and post-doctoral studies in the  
40  
41 167 area of MS and through her contact with people with MS and her knowledge from the  
42  
43  
44 168 literature has come to the conclusion that people with progressive MS are underrepresented  
45  
46 169 in research literature and they feel left out when it comes to treatments and health care  
47  
48  
49 170 services. This sparked the interest in the research topic. The initial interviews were conducted  
50  
51 171 between April 2014 and April 2015. The second set of interviews tended to be slightly shorter  
52  
53 172 as they focused on changes in between interviews and lasted between 36 minutes and 103  
54  
55  
56 173 minutes (mean=66.12). With one exception, participants in the second round also opted for  
57  
58  
59 174 telephone interviews. There was no one else present during the interview besides the  
60



Transition to secondary progressive MS

1  
2  
3 175 participant and the researcher (AB). The second round of interviews were conducted between  
4  
5  
6 176 July 2015 and April 2016. There was some variation in the intervals between the first and  
7  
8 177 second interview, due to staff changing institute and participants' availability. One interview  
9  
10 178 was conducted 13 months after the first interview, seven interviews were conducted 14  
11  
12  
13 179 months after the first interview, 8 interviews were conducted 15 months after the first  
14  
15 180 interview and one interview was conducted 18 months after the first interview. Table 2 shows  
16  
17 181 the topic guide used for the two interviews. Examples people gave in their first interviews  
18  
19 182 were also used as prompts to assess changes in emotions, thoughts or symptom-  
20  
21 183 management. All interviews were audiotaped with consent and transcribed verbatim.  
22  
23 184 Transcripts were not sent back to participants to comment.  
24  
25  
26  
27

#### 28 185 *Data analysis*

29  
30  
31 186 We used inductive thematic analysis [28]. An inductive approach means the themes identified  
32  
33 187 emerge from the data themselves [29]. Therefore, the inductive analysis is the process of  
34  
35 188 coding the data without trying to fit it into a pre-existing coding frame, or the researcher's  
36  
37 189 analytic preconceptions. This form of thematic analysis is, therefore, data-driven [28].  
38  
39  
40

41  
42 190 Coding was undertaken by the first author (AB) under the supervision of the second author  
43  
44 191 (MM) and with discussion of emerging themes with the third author (RMM). AB has extensive  
45  
46 192 experience analysing qualitative methodologies. She completed qualitative methodologies  
47  
48 193 training as part of the MSc in Health Psychology course (Southampton University) and  
49  
50 194 attended a two-day workshop on longitudinal qualitative research organized by the  
51  
52 195 Methodological Innovation Network and delivered at Southampton University (Nov 2012). At  
53  
54 196 the time of this study the researcher had completed and published 3 qualitative studies as  
55  
56 197 the lead researcher (conducting of interviews, analysis and write-up), supervised 2 MSc  
57  
58  
59  
60

## Transition to secondary progressive MS

1  
2  
3 198 student and 2 PhD students on their qualitative methodologies, and was teaching a series of  
4  
5  
6 199 qualitative methodologies lectures for MSc and Doctorate students. A variety of techniques  
7  
8 200 were employed to increase familiarisation with the data. Audiotapes of each interview were  
9  
10  
11 201 listened repeatedly, and transcripts were read and reread. We used NVivo 10 for coding. The  
12  
13 202 analysis of the transcripts was conducted in parallel with data collection and refinement of  
14  
15 203 the themes continued after the end of the data collection, during writing up. First, each coding  
16  
17 204 unit in the first transcript was given a code name, using vocabulary as close as possible to that  
18  
19  
20 205 used by participants themselves [30]. Initial codes were then applied systematically to the  
21  
22  
23 206 entire dataset, and new codes developed and refined as appropriate. We also grouped  
24  
25 207 participants' interviews that shared similar demographic characteristics and explored  
26  
27  
28 208 patterns or commonalities. We examined whether themes differed across sub-groups (e.g.  
29  
30 209 method of recruitment, gender, and family circumstances). Figure 1 shows the steps followed  
31  
32  
33 210 during the analysis. The analysis was an iterative process and at times we had to go back and  
34  
35 211 forth between steps. The coding tree in table 3, shows how we moved from codes to refined  
36  
37  
38 212 categories. In order to document the analysis process, a detailed paper trail was kept with the  
39  
40 213 notes taken after the interviews, the development of the codes and relationship between the  
41  
42 214 raw data and the refined categories and codes. The quotes presented in the result section  
43  
44  
45 215 were chosen for typicality in illustrating the themes. Pseudonyms are used for the quotes.

216 **Results**

51 217 Two overarching themes about (1) Transitioning to SPMS and challenges and (2) Adaptive  
52  
53 218 strategies over time. The first theme illustrated challenges involved in the transition and the  
54  
55  
56 219 second theme related to how participants responded to those challenges. Tables 4 provides  
57  
58 220 examples of SPMS transition and challenges over time and Table 5 provides examples of self-

1 Transition to secondary progressive MS

2  
3 221 management and changes over time.

4  
5  
6 222 **Transitioning to SPMS and challenges**

7  
8  
9 223 *Initial reaction to the transition*

10  
11  
12 224 For the majority of the participants the transition to SPMS was expected rather than shocking.

13  
14  
15 225 For some, transitioning did not make much difference because at that point they had already

16  
17 226 lost essential relationships and activities they valued. For others transitioning to SPMS did not

18  
19  
20 227 make much difference because the progressive worsening of their symptoms was slow and

21  
22 228 subtle.

23  
24  
25 229 We compared the interviews of people that found about the SPMS diagnosis in different ways,

26  
27  
28 230 for example, accidentally when visiting the hospital for other issues, or in one of the annual

29  
30  
31 231 consultations or they suspected they had transitioned and asked the neurologist for

32  
33 232 confirmation. In contrast to the majority, the five participants, who found out about the

34  
35 233 transition accidentally described being upset and shocked. These five people had MS between

36  
37  
38 234 3 to 21 years (median=12 years).

39  
40 235 *[Neurologist's name] started other MRI's and tests and things and said that I'd*

41  
42 236 *progressed to secondary progressive. So, I was shocked and- I was shocked that I got*

43  
44 237 *signed off work, and it progressed. I thought he'd just say, "You're signed off for a*

45  
46 238 *couple of weeks", not that and, I just thought, you know, "If I sleep then I'll be all right."*

47  
48  
49  
50 239 *(female, 45, T1)*

51  
52  
53 240 *Worsening of symptoms and emotional shifts*

54  
55  
56 241 Transitioning to SPMS also meant worsening of symptoms, and people described progressive

57  
58  
59 242 worsening of symptoms including mobility, fatigue, vision, and bladder dysfunction, urinary

60

## Transition to secondary progressive MS

1  
2  
3 243 tract infections and falls. There were further worsening of symptoms reported between the  
4  
5  
6 244 first and second interview. This deterioration also brought more changes in participants' lives.  
7  
8  
9 245 Transitioning to SPMS also meant worsening of emotional issues. A few participants had a  
10  
11 246 diagnosis of depression before or after the initial diagnosis of MS, which made managing MS  
12  
13 247 more difficult. However, the majority of participants described dealing with other difficult  
14  
15  
16 248 emotions in both interviews, including feeling like a burden, being afraid of having accidents,  
17  
18 249 being trapped or feeling embarrassed. They also expressed low self-esteem and confidence,  
19  
20  
21 250 and some participants described the uncertainty of whether they have the skills to cope with  
22  
23 251 MS, accept the condition and deal with stress.

24  
25  
26 252 *I had a bad fall last week where I split all my head open, so I am feeling a bit lack of*  
27  
28  
29 253 *confidence in just going out for a little walk up the road and back with my walker on*  
30  
31 254 *my own. (female, 54, T2)*  
32  
33

34 255  
35  
36 256 Overall, in the second interview participants talked in more depth about their psychological  
37  
38 257 difficulties and challenges in coping over the years and presented a more severe picture than  
39  
40  
41 258 in the first round of interviews. Further, people who described emotional challenges in the  
42  
43 259 first interview described the same challenges in the second interview, a year later.

260 *Arriving at the point of no help*

44  
45  
46  
47  
48  
49  
50 261 After transitioning to SPMS, most participants reported that they did not feel health services  
51  
52 262 had anything more to offer since they could no longer have access to disease-modifying drugs.  
53  
54 263 A few participants talked about the benefits of physiotherapy but either the sessions offered  
55  
56  
57 264 in the NHS were too few or physiotherapy was expensive to access privately. They saw their  
58  
59 265 transition as a point beyond help.  
60

## Transition to secondary progressive MS

1  
2  
3 266 *I have an MS nurse but quite frankly you know I have come to an end what you can do,*  
4  
5  
6 267 *I don't feel I am getting any support at all at the moment. I feel I am being left to my*  
7  
8 268 *own devices. Yes I see him every six months, every twelve months but there is nothing*  
9  
10 269 *he can offer so you know it is a bit of a waste of time really. (female, 54, T2)*

11  
12  
13  
14 270 However, a few participants reported doing their own research and identifying treatments  
15  
16 271 that could potentially help them (e.g. oxygen therapy, incontinence nurse) and then asked  
17  
18 272 their healthcare team to refer them accordingly. Also, a few participants attended self-  
19  
20 273 management courses run by local MS charities or access psychological treatments as part of  
21  
22 274 research projects.

23  
24  
25  
26 275 When asked whether there is any support that they would like to receive in the future, one  
27  
28 276 participant said: *'I think there is quite a lot of support when you're first diagnosed but I think*  
29  
30 277 *it tails off I think people find it more difficult to support you the longer you have the MS I think*  
31  
32 278 *people become quite cynical about the help that can be got and cynical about what the NHS*  
33  
34 279 *has to offer and cynical about the help that can be obtained as to whether it's any use or not.'*  
35  
36 280 (female, 65, T2). Most participants shared a similar opinion.

### 281 **Adaptive tasks and changes over time**

#### 282 *Planning activities or scaling down activities*

283 Participants reported adjusting their holiday destinations and plans, to take into account their  
284 limitations, without changing their previous lifestyle too much. Planning ahead for future  
285 deterioration (e.g. financially, house modifications) and planning activities and days out  
286 meticulously and well in advanced, helped people feel in control. Sometimes, across the two  
287 interviews participants appeared to overestimate their limitations and underestimate their

## Transition to secondary progressive MS

288 ability to cope in the future at the first interview compared with what people reported at the  
289 second interview. This discrepancy is illustrated below by the quotes of the same participant  
290 in the first and second interview.

291 *I don't go too far now, I can only cope with about three and half hours on the plane at*  
292 *the most. I can't go long distance or anything like that, you know long haul anymore,*  
293 *it's usually the Canary Islands or somewhere like that, somewhere nice and close*  
294 *(female, 54, T1)*

295 *I am still determined that I am going to travel and see as many places as I want. We*  
296 *went away for six weeks over January/February, we went to New Zealand and*  
297 *Australia (female, 55, T2)*

298 However, at times, participants found it difficult to plan or modify their activities and instead  
299 scaled back, especially when the condition progressed rapidly, and almost all participants who  
300 had mentioned difficulties finding alternative activities in the first interview had the same  
301 difficulties in the second interview.

302 *I can't read the same that I used to; I can't go on the computer; I can't really watch TV;*  
303 *gardening, the high impact exercises, you know, the long walk so everything's just had*  
304 *to be tailored down and you know brought into a shorter time period. The human is*  
305 *pretty good at finding ways around things...so yeah you just adapt um it's a struggle*  
306 *you know there's no two ways about it but it is that life is definitely a struggle but*  
307 *again you get used to that really as well (female, 59, T2)*

308 *Emotional regulation*

309 Strategies to manage emotional difficulties included distraction such as playing video games,

## Transition to secondary progressive MS

1  
2  
3 310 reading books, going out for a meal, or avoiding thinking and talking about the future,  
4  
5  
6 311 avoiding MS group meetings and spending the day sleeping. Some people tried to be positive  
7  
8 312 by repeating 'things could have been worse'. Further, partners played an important role in  
9  
10 313 emotionally supporting the participants, by helping them adjust to new MS challenges or by  
11  
12 314 being available to discuss participants' worries. People reported using the same strategies  
13  
14 315 between the two interviews. A few participants talked about how they would have liked  
15  
16 316 access to psychological services.

17  
18  
19  
20  
21 317 *It would be nice to talk about how you feel about it, would be it'd be nice if...do you*  
22  
23 318 *know it would be nice if just to have somebody there saying you're doing a grand job*  
24  
25 319 *[Laugh] with how you're doing. Because you are isolated (female, 53, T2)*

26  
27  
28  
29 320 However, two participants said that they were offered psychological support, but they  
30  
31 321 thought this was unnecessary.

322 *Being social, fitting in and being of use*

32  
33  
34  
35  
36  
37 323 For most of the participants transitioning to SPMS also meant increased mobility problems  
38  
39 324 and use of a wheelchair. Use of a wheelchair also posed accessibility issues leading to more  
40  
41 325 carefully planned outings. Even though going out came with more difficulties, and at times  
42  
43 326 people felt it was easier to stay in, most talked about the importance of being with friends  
44  
45 327 and family and retaining relationships and also meeting new people. Participants described  
46  
47 328 getting involved in charity work, MS research and helping others. They reported that this gave  
48  
49 329 them a new purpose, they learned new things and met people. Participants who talked about  
50  
51 330 the importance of being social or helping others in the first interview also talked about it in  
52  
53 331 their second interview, as illustrated below by the same participant at the two time points.  
54  
55  
56  
57  
58  
59  
60

## Transition to secondary progressive MS

1  
2  
3 332 ...going out with friends, going out for dinner, going and mixing with other people,  
4  
5  
6 333 which I would of quite enjoyed before and not thought anything about it, but now I  
7  
8 334 think, "oh do I really want to go?" but then I force myself, you have got to go, because  
9  
10 335 then when I do go, I do enjoy it and I do feel better because your mood's lifted and  
11  
12  
13 336 once you are moving around, things are easier. (female, 59, T1)

14  
15  
16 337 We've got the local MS branch, we meet twice a month, first and third Tuesdays of  
17  
18 338 the month. I find that very helpful. I do find that helpful to talk to other people that  
19  
20 339 have got the same sorts of problems that you've got, gone through the same things.  
21  
22  
23 340 And again there's somebody there that, it's not perhaps a close friend, but has become  
24  
25 341 or is becoming more of a close friend that we will see one another outside of the MS  
26  
27  
28 342 branch. (female, 59, T2)

31 **Discussion**

32  
33  
34 344 Reflecting on the SPMS diagnosis, people overall did not express trauma or distress, only on  
35  
36  
37 345 the occasions, the diagnosis came as a surprise. People who have recently transitioned to  
38  
39 346 SPMS reported facing a worsening of the condition alongside increased emotional challenges.  
40  
41  
42 347 In the second interview, most people described the increased severity of their symptoms and  
43  
44 348 more emotional difficulties. Participants reported detailed planning, distractions and  
45  
46  
47 349 remaining as active and as involved in the community as possible helped to cope with the  
48  
49 350 condition. Some participants overestimated their limitations and underestimated their  
50  
51  
52 351 capacity to cope between the first and the second interview but overall most reported using  
53  
54 352 similar coping strategies between the two time points. A common theme across all interviews  
55  
56  
57 353 was a sense of abandonment from the health care services and the sense that nothing can be  
58  
59 354 done at this stage of their condition. Therefore, providing appropriate support after the  
60



## Transition to secondary progressive MS

1  
2  
3 355 transition diagnosis is vital.  
4  
5

6 356 A qualitative study of people recently diagnosed with MS showed that psychological well-  
7  
8  
9 357 being was described as precariously contingent on reasonable current and future health  
10  
11 358 status [31], for example, people were not sure whether they would be able to cope if they  
12  
13  
14 359 lost their job or had to use a wheelchair. The current study examines what happens after  
15  
16 360 people have moved to SPMS. Participants in our study talked about increased disability since  
17  
18 361 they have transitioned to SPMS or between the first and second interview, but despite these  
19  
20  
21 362 increased difficulties, people felt that health care professionals had nothing more to offer and  
22  
23 363 there was nothing more they could do to control their emotional or physical symptoms.  
24  
25  
26 364 Focusing on well-being is often on diagnosable depression and anxiety. However, participants  
27  
28 365 in the present study described having to deal with challenging emotions which may not reflect  
29  
30  
31 366 in these clinical diagnoses.  
32

33  
34 367 An essential finding of this study is that people who described some challenges with self-  
35  
36 368 management in the first interview described the same challenges in the second interview, a  
37  
38  
39 369 year later. This can be linked to their perception of SPMS as the stage where nothing further  
40  
41 370 can be done to manage things. According to the Common Sense Model [32]. Being diagnosed  
42  
43  
44 371 with an illness that is perceived as more controllable will lead to less distress and more control  
45  
46 372 efforts such as seeking advice on symptom management. Participants interviewed here  
47  
48  
49 373 described SPMS as a condition they and their health care team did not have any control over.  
50  
51 374 As people move from RRMS to SPMS, the capacity of personal and treatment control declines,  
52  
53 375 and creates a significant challenge in adapting to the change by identifying areas that they  
54  
55  
56 376 can still have control while letting go of unattainable goals [33].  
57

58  
59 377 Participants in the current study reported that there is nothing they or health care  
60

## Transition to secondary progressive MS

1  
2  
3 378 professionals can do to manage their increasing limitations. Even though self-management  
4  
5  
6 379 interventions in progressive MS are scarce, there is some preliminary evidence of  
7  
8 380 interventions that could help with symptom management. For example, endurance training  
9  
10 381 can improve walking [34]; progressive resistance training may improve lower limb strength  
11  
12 382 [35]; bodyweight-supported treadmill can reduce pain [36], and mindfulness training can  
13  
14 383 reduce anxiety, depression and impact of MS [37]. Where available, health care professionals  
15  
16 384 should signpost patients to appropriate services that can help with MS symptoms but more  
17  
18 385 needs to be done to find ways of developing these services, so they are more readily available.  
19  
20  
21  
22

23 386 The present study has certain significant strengths. First, to our knowledge, it is the first study  
24  
25 387 attempting to investigate challenges and adaptive tasks shortly after people have transitioned  
26  
27 388 to SPMS. The particular advantage of the present study was its longitudinal approach that  
28  
29 389 allowed the identification of patterns over time. This showed that whereas more severe  
30  
31 390 emotional and physical symptoms were reported in the second interview, these did not result  
32  
33 391 in different or more challenges. While this may suggest participants feeling more comfortable  
34  
35 392 in opening up at time two having built a rapport with the interviewer, it may also reflect the  
36  
37 393 lack of support people were receiving. Finally, a strength of this study also lies in the specificity  
38  
39 394 of the sample selected, who were all people who had transitioned to SPMS within the  
40  
41 395 previous five years.  
42  
43  
44  
45  
46  
47

48 396 The study has certain limitations. Firstly, the qualitative exploratory nature of the study does  
49  
50 397 not allow for causal relationships to be established. Second, getting a SPMS diagnosis may  
51  
52 398 take years, in part due to substantial diagnostic uncertainty as a result of the subtlety of signs  
53  
54 399 of early progressive disease [6]. Therefore, it is hard to determine whether the challenges  
55  
56 400 described are linked to having received an official diagnosis or to the challenges faced by  
57  
58  
59  
60

## Transition to secondary progressive MS

1  
2  
3 401 increased disability, as we did not interview people just before being diagnosed and straight  
4  
5  
6 402 after. Furthermore, participants self-reported transitioning to SPMS, although they were  
7  
8 403 asked to confirmed that they have received the transitioning diagnosis officially from an MS  
9  
10 404 health professional, we did not verify this information by cross-checking their medical  
11  
12  
13 405 records. Also, their recollections of the time of the diagnosis might not be accurately  
14  
15 406 represented during the interviews that took place up to five years later. Finally, telephone  
16  
17  
18 407 interviews might be considered inferior to face-to-face, since rapport can be harder to  
19  
20 408 establish. However, research indicates both telephone and in-person interviews can be used  
21  
22  
23 409 productively in qualitative research[38], with the former potentially allowing participants to  
24  
25 410 feel more relaxed and willing to disclose sensitive information[39], enhancing the data's  
26  
27  
28 411 trustworthiness.

29  
30 412 Regardless of the above limitations, the findings presenting here underline the additional  
31  
32  
33 413 physical and emotional challenges people face when transitioned to SPMS and that people  
34  
35 414 try to adapt by planning, finding distractions and remaining social but they reported there  
36  
37  
38 415 was nothing further to do regarding symptom management. Identifying physical and  
39  
40 416 emotional challenges at the time of the diagnosis to SPMS will help referral to appropriate  
41  
42  
43 417 services within a multidisciplinary clinical team. Offering people options for continuing  
44  
45 418 symptoms management at the time of SPMS diagnosis may help with feelings of helplessness  
46  
47  
48 419 accompany the diagnosis.

## 420 **Acknowledgments**

421 The authors would like to thank the people with MS who took part in this study.

## 422 **Conflict of interest**

1 Transition to secondary progressive MS

2  
3 423 We have no conflict of interest to declare.

4  
5  
6 424 **Funding**

7  
8  
9 425 This work was supported by Multiple Sclerosis UK under grant reference 4.

10  
11  
12 426 **Author statement**

13  
14  
15 427 AB and RMM designed the study. AB conducted the interviews, led the data analysis and  
16  
17 428 drafted the manuscript. MM contributed to the development of the topic guide, oversaw data  
18  
19 429 collection and analysis and contributed to drafts of the paper. RMM advised on the conduct  
20  
21 430 of the research, contributed towards refining themes, interpretations of the findings, and  
22  
23 431 drafts of the paper.

24  
25  
26 432 **Data sharing statement**

27  
28  
29 433 Paper trail and NVivo coding files available from the corresponding author

30  
31  
32 434

33  
34  
35 435

## Transition to secondary progressive MS

## 436 References

- 437 1. Mackenzie, I.S., et al., *Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a*  
438 *descriptive study in the General Practice Research Database*. Journal of Neurology,  
439 Neurosurgery & Psychiatry, 2013.
- 440 2. Compston, A. and A. Coles, *Multiple sclerosis*. Lancet, 2008. **372**: p. 1502 - 1517.
- 441 3. Fisniku, L.K., et al., *Disability and T2 MRI lesions: a 20-year follow-up of patients with relapse*  
442 *onset of multiple sclerosis*. Vol. 131. 2008. 808-817.
- 443 4. Lublin, F.D. and S.C. Reingold, *Defining the clinical course of multiple sclerosis: results of an*  
444 *international survey*. National Multiple Sclerosis Society (USA) Advisory Committee on Clinical  
445 *Trials of New Agents in Multiple Sclerosis*. Neurology, 1996. **46**(4): p. 907-11.
- 446 5. Tremlett, H., *Secondary Progressive Multiple Sclerosis*. MS in Focus, 2009. **13**: p. 13-14.
- 447 6. Sand, I.K., et al., *Diagnostic uncertainty during the transition to secondary progressive multiple*  
448 *sclerosis*. Multiple Sclerosis Journal, 2014. **20**(12): p. 1654-1657.
- 449 7. Gross, H.J. and C. Watson, *Characteristics, burden of illness, and physical functioning of*  
450 *patients with relapsing-remitting and secondary progressive multiple sclerosis: a cross-*  
451 *sectional US survey*. Neuropsychiatr Dis Treat, 2017. **13**(13): p. 1349-1357.
- 452 8. Planche V, G.M., Cregut D, Pereira B, Clavelou P. , *Cognitive impairment in a population-based*  
453 *study of patients with multiple sclerosis: differences between late relapsing– remitting,*  
454 *secondary progressive and primary progressive multiple sclerosis*. European journal of  
455 neurology, 2016. **23**(2): p. 282-9.
- 456 9. Papathanasiou, A., et al., *Cognitive impairment in relapsing remitting and secondary*  
457 *progressive multiple sclerosis patients: efficacy of a computerized cognitive screening battery*.  
458 ISRN neurology, 2014. **2014**.
- 459 10. Denney, D.R., L.A. Sworowski, and S.G. Lynch, *Cognitive impairment in three subtypes of*  
460 *multiple sclerosis*. Archives of Clinical Neuropsychology, 2005. **20**(8): p. 967-981.
- 461 11. Bakshi, R., et al., *Fatigue in multiple sclerosis and its relationship to depression and neurologic*  
462 *disability*. Multiple Sclerosis (Houndmills, Basingstoke, England), 2000. **6**(3): p. 181-185.
- 463 12. Thorne, S., et al., *Health care communication issues in multiple sclerosis: an interpretive*  
464 *description*. Qualitative Health Research, 2004. **14**(1): p. 5-22.
- 465 13. Vleugels, L., et al., *Psychological functioning in primary progressive versus secondary*  
466 *progressive multiple sclerosis*. Br J Med Psychol, 1998. **71 ( Pt 1)**(1): p. 99-106.
- 467 14. Montel, S.R. and C. Bungener, *Coping and quality of life in one hundred and thirty five subjects*  
468 *with multiple sclerosis*. Mult Scler, 2007. **13**(3): p. 393-401.
- 469 15. McNulty, K., H. Livneh, and L.M. Wilson, *Perceived Uncertainty, Spiritual Well-Being, and*  
470 *Psychosocial Adaptation in Individuals With Multiple Sclerosis*. 2004, Educational Publishing  
471 Foundation: US. p. 91-99.
- 472 16. Mohr, D.C., et al., *The Psychosocial Impact of Multiple Sclerosis: Exploring the Patient's*  
473 *Perspective*. Health Psychology, 1999. **18**: p. 376-382.
- 474 17. Olsson, M., J. Lexell, and S. Soderberg, *The meaning of women's experiences of living with*  
475 *multiple sclerosis*. Health Care Women Int, 2008. **29**(4): p. 416-30.
- 476 18. Olsson, M., L. Skar, and S. Soderberg, *Meanings of feeling well for women with multiple*  
477 *sclerosis*. Qual Health Res, 2010. **20**(9): p. 1254-61.
- 478 19. Davies, F., et al., *'You are just left to get on with it': qualitative study of patient and carer*  
479 *experiences of the transition to secondary progressive multiple sclerosis*. BMJ open, 2015. **5**(7):  
480 p. e007674.
- 481 20. O'Loughlin, E., et al., *The experience of transitioning from relapsing remitting to secondary*  
482 *progressive multiple sclerosis: views of patients and health professionals*. Disabil Rehabil,  
483 2017. **39**(18): p. 1821-1828.
- 484 21. Fiest, K.M., et al., *Systematic review and meta-analysis of interventions for depression and*  
485 *anxiety in persons with multiple sclerosis*. Mult Scler Relat Disord, 2016. **5**: p. 12-26.

## Transition to secondary progressive MS

- 1  
2  
3 486 22. Jongen, P.J., et al., *An intensive social cognitive program (can do treatment) in people with*  
4 487 *relapsing remitting multiple sclerosis and low disability: a randomized controlled trial protocol.*  
5 488 *BMC Neurol*, 2016. **16**(1): p. 81.  
6 489 23. Patton, M., *Qualitative evaluation and research methods*. 1990, Thousand Oaks, California:  
7 490 Sage Publications Ltd.  
8 491 24. Guest, G., A. Bunce, and L. Johnson, *How Many Interviews Are Enough?: An Experiment with*  
9 492 *Data Saturation and Variability*. *Field Methods*, 2006. **18**(1): p. 59-82.  
10 493 25. Scalfari, A., et al., *The natural history of multiple sclerosis, a geographically based study 10:*  
11 494 *relapses and long-term disability*. *Brain*, 2010. **133**(7): p. 1914 - 1929.  
12 495 26. Eriksson, M., O. Andersen, and B. Runmarker, *Long-term follow up of patients with clinically*  
13 496 *isolated syndromes, relapsing-remitting and secondary progressive multiple sclerosis*. *Mult*  
14 497 *Scler*, 2003. **9**(3): p. 260-74.  
15 498 27. Tremlett, H., et al., *Impact of multiple sclerosis relapses on progression diminishes with time.*  
16 499 *Neurology*, 2009. **73**(20): p. 1616-23.  
17 500 28. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. *Qualitative Research in*  
18 501 *Psychology*, 2006. **3**(2): p. 77-101.  
19 502 29. Payne, S., *Interview in qualitative research*, in *Handbook of psychology of interviewing*, A.  
20 503 Memon and R. Bull, Editors. 1999, Wiley and Sons: London. p. 89-102.  
21 504 30. Glaser, B. and S.A. Strauss, *Discovery of grounded theory. Strategies for qualitative research.*  
22 505 1967, New York: Aldine de Gruyter.  
23 506 31. Dennison, L., et al., *Experiences of adjusting to early stage Multiple Sclerosis*. *J Health Psychol*,  
24 507 2011. **16**(3): p. 478-88.  
25 508 32. Leventhal, H., M. Diefenbach, and E.A. Leventhal, *Illness cognition: using common sense to*  
26 509 *understand treatment adherence and affect cognition interactions*. *Cognitive therapy and*  
27 510 *research*, 1992. **16**(2): p. 143-163.  
28 511 33. Heckhausen, J., C. Wrosch, and R. Schulz, *A motivational theory of life-span development.*  
29 512 *Psychological review*, 2010. **117**(1): p. 32.  
30 513 34. Briken, S., et al., *Effects of exercise on fitness and cognition in progressive MS: a randomized,*  
31 514 *controlled pilot trial*. *Multiple Sclerosis Journal*, 2013: p. 1352458513507358.  
32 515 35. Latimer-Cheung, A., et al., *Effects of exercise training on fitness, mobility, fatigue, and health-*  
33 516 *related quality of life among adults with multiple sclerosis: a systematic review to inform*  
34 517 *guideline development*. *Arch Phys Med Rehabil*, 2013. **94**: p. 1800 - 1828.e3.  
35 518 36. Wier, L.M., et al., *Effect of robot-assisted versus conventional body-weight-supported*  
36 519 *treadmill training on quality of life for people with multiple sclerosis*. *J Rehabil Res Dev*, 2011.  
37 520 **48**(4): p. 483-92.  
38 521 37. Bogosian, A., et al., *Distress improves after mindfulness training for progressive MS: A pilot*  
39 522 *randomised trial*. *Mult Scler*, 2015. **21**(9): p. 1184-94.  
40 523 38. Sturges, J.E. and K.J. Hanrahan, *Comparing telephone and face-to-face qualitative*  
41 524 *interviewing: a research note*. *Qualitative Research*, 2004. **4**(1): p. 107-118.  
42 525 39. Novick, G., *Is there a bias against telephone interviews in qualitative research?* *Research in*  
43 526 *Nursing & Health*, 2008. **31**(4): p. 391-398.

527

528

## Transition to secondary progressive MS

529

530 Table 1. Participants' characteristics

| <i>Participants' characteristics (T1)</i> | <i>Number (%)</i>   |
|---|---------------------|
| <i>Age (Mean, SD)</i>                     | <i>57.33 (9.13)</i> |
| <i>Gender-female</i>                      | <i>16 (72.7%)</i>   |
| <i>Marital status (N, %):</i>             |                     |
| <i>Married/cohabiting</i>                 | <i>15 (71.4%)</i>   |
| <i>Single</i>                             | <i>3 (14.3%)</i>    |
| <i>Divorced/separated</i>                 | <i>3 (14.3%)</i>    |
| <i>Time since initial diagnosis:</i>      |                     |
| <i>0-5 years</i>                          | <i>5 (23.8 %)</i>   |
| <i>6-10 years</i>                         | <i>3 (14.3%)</i>    |
| <i>11-15 years</i>                        | <i>3(14.3%)</i>     |
| <i>16-20 years</i>                        | <i>2 (9.5%)</i>     |
| <i>21years +</i>                          | <i>8 (38.1%)</i>    |
| <i>Time since SPMS diagnosis:</i>         |                     |
| <i>1 year</i>                             | <i>4 (18.2%)</i>    |
| <i>2 years</i>                            | <i>3 (13.6%)</i>    |
| <i>3 years</i>                            | <i>3 (13.6%)</i>    |
| <i>4 years</i>                            | <i>4 (18.2%)</i>    |
| <i>5 years</i>                            | <i>7 (31.8%)</i>    |
| <i>Walking ability (with aid):</i>        |                     |
| <i>0-5 meters (EDSS 7-8)</i>              | <i>9 (42.8%)</i>    |
| <i>20 meters (EDSS 6.5)</i>               | <i>3 (14.3%)</i>    |
| <i>100 meters (EDSS 6)</i>                | <i>3 (14.3%)</i>    |
| <i>200 meters (EDSS 5)</i>                | <i>4 (18.2%)</i>    |
| <i>500 meters (EDSS ≤4)</i>               | <i>1 (4.8%)</i>     |
| <i>unknown</i>                            | <i>1 (4.8%)</i>     |

531

532



## Transition to secondary progressive MS

533 Table 2. Topic guide

| Questions  | Prompts  |
|--|--|
| Can you start by telling me all about what you thought and felt when you were first diagnosed with MS? | Main issues, explore concerns, feelings, (physical, psychological, family issues) what did he/she do about each problem that was identified?                             |
| Can you tell me about the time you found out you have moved to secondary progressive type of MS?       | Explore how did they find out, period before receiving the diagnosis, thoughts and feelings after receiving the secondary diagnosis.                                     |
| Can you tell me about what you think and feel about having MS now?                                     | Examples of issues identified?   |
| Can you tell me about all the things you found (un)helpful when dealing with challenges of MS?         | Feelings and thoughts on support interventions they were offered or sought/ how did they apply the advice given (if given), support they would like to see in the future |
| Are there any other relevant issues we haven't covered that you would like to mention?                 |  |

534

535



## Transition to secondary progressive MS

536

537 Table 3. Coding tree of time 1 and time 2 interviews

| Themes                               | Sub-themes   | Parent codes                               | Associated child codes   |                        |   |
|--------------------------------------|--|--|--|------------------------|---|
| Transitioning to SPMS and challenges | Initial reaction to the transition   | SPMS diagnosis                             | Time of diagnosis<br>It's easy to say SPMS<br>Before diagnosis<br>Before knowing<br>Now I know<br>Finding out (tests, hospitals, MRI, lumbar puncture)<br>Being informed |                        |   |
|                                      |  | I knew I had SPMS                          | You know you're on secondary MS is part of me  |                        |   |
|                                      |  | It was a shock                             | Shock of diagnosis   |                        |   |
|                                      |  | I can't do things I enjoy                  | It's not a good disease<br>Cannot do things<br>Cannot do things I used to enjoy<br>Can't walk<br>Can't wear normal clothes   |                        |   |
|                                      |  | Progression is slow                        | Progression: creeps up on you<br>Progression is slow   |                        |   |
|                                      |  | Worsening of symptoms and emotional shifts | Symptoms getting worse   | Symptoms getting worse | Various symptoms<br>Symptoms<br>Progression is scary<br>MS is serious |
|                                      |  |  |  |                        | Depression before diagnosis   |
| Depression after diagnosis           | Tormented<br>Depression diagnosis<br>Thinking of nothing else<br>Depressed<br>It's hard                                      |  |  |                        |   |
| I'm afraid/embarrassed               | Embarrassing<br>Scared<br>Disfigurement<br>Weight gain is depressing<br>Fear of the unknown<br>I'm not as frightened anymore |  |  |                        |   |

## Transition to secondary progressive MS

|                                     |  |  |  |
|-------------------------------------|--|--|--|
|                                     |  | I feel I'm a burden  | Annoyed<br>Cry   |
|                                     | Arriving at the point of no help               | Contact with MS healthcare professions<br>Neurologists' appointments | General hospitals don't understand MS<br>Dealing with medics<br><br>MS nurses<br>Neurologists<br>Physiotherapy   |
|                                     |  | Nothing to offer   | Getting medical help<br>Medication   |
|                                     |  | Support services: currently offered and future                       | There is nothing for SPMS<br>Psychological support would have been good at diagnosis<br>I'd like to just talk to someone who understands MS  |
| Adaptive tasks and changes overtime | Planning activities or scaling down activities | Holidays   | Planning holidays  |
|                                     |  | Planning in advance  | Cannot plan in advance<br>Need to plan meticulously<br>Use of diaries/ reminders   |
|                                     |  | If you can't do it, do it differently                                | Partner showed me wheelchair is good<br>Small things but meaningful<br>It's silly to rebel   |
|                                     |  | Can't do much  | Bad days: do nothing Resting<br>Can't exercise<br>Life is dull<br>Knowing my limits  |
|                                     | Emotional regulation                           | Distractions   | Sleeping<br>Day-time TV<br>Video-games   |
|                                     |  | Help from partner/ family  | Partner helps emotionally<br>Being outdoors<br>Couldn't cope without my partner<br>Harder if you're on your own<br>Partner looks after me<br>Partner control<br>Partner gets angry |

Transition to secondary progressive MS

|  |   |                                       |  |
|--|---|---------------------------------------|--|
|  |   | Not thinking/talking about the future | Reading about MS<br>I don't like to talk about it  |
|  |   | "things could have been worse"        | A frame of mind<br>Men cope better<br>Young people cope better   |
|  | Being social, fitting in and being of use | Accessibility problems                | Disrespectful people<br>Accessibility issues   |
|  |   | MS group meetings                     | Exchanging info<br>Comparing with other people<br>Comparing with other patients<br>Partner organised support group |
|  |   | Family visits                         | Grandchildren don't understand<br>We're trying to be normal<br>We do things for the family<br>Family life          |
|  |   | Friendships                           | Revealing MS<br>I don't look ill<br>I have very good friends   |
|  |   | Voluntary work                        | Helping other with MS<br>I wish I could help   |

538

539

For peer review only

Transition to secondary progressive MS

Table 4. Examples of SPMS transition and challenges over time

Table 5. Examples of self-management and changes over time

Figure 1. Data analysis flow

For peer review only

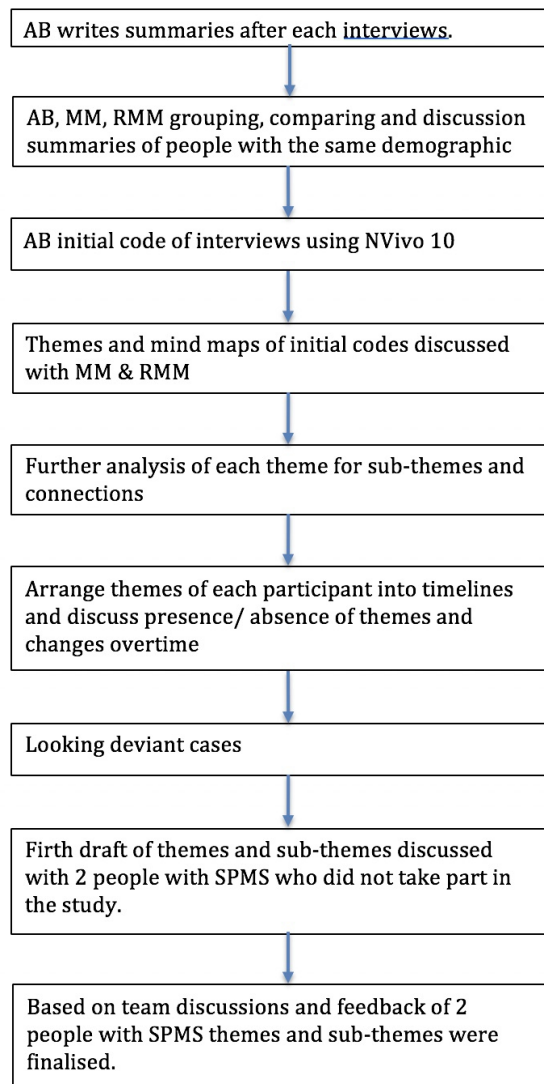


Figure 1. Data analysis flow

Figure 1. Data analysis flow

336x523mm (72 x 72 DPI)

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

| No. Item                                       | Guide questions/description                             | Reported on Page #   |
|--|---|--|
| <b>Domain 1: Research team and reflexivity</b> |   |  |
| <i>Personal Characteristics</i>                |   |  |
| 1. Interviewer/facilitator                     | Which author/s conducted the inter view or focus group? | Angeliki Bogosian<br><br>Page 9, line 165  |
| 2. Credentials                                 | What were the researcher's credentials?<br>E.g. PhD, MD | Angeliki Bogosian<br>PhD, Senior lecturer<br><br>Myfanwy Morgan<br>PhD, Emeritus<br>Professor<br><br>Rona Moss-Morris<br>PhD, Professor<br><br>Page 1 (title page) |
| 3. Occupation                                  | What was their occupation at the time of the study?     | Angeliki Bogosian<br>Research fellow<br><br>Myfanwy Morgan<br>Professor<br><br>Rona Moss-Morris<br>Professor<br><br>Page 1 (title page) &<br>7 (line 126-127)      |
| 4. Gender                                      | Was the researcher male or female?                      | Female<br><br>Page 9, line 165   |
| 5. Experience and training                     | What experience or training did the researcher have?    | Data analysis<br><br>Page 10, line 190-<br>198   |
| <i>Relationship with participants</i>          |   |  |

|   |   |   |
|---|---|---|
| 6. Relationship established                 | Was a relationship established prior to study commencement?   | Interviews<br>Page 9, line 161                    |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research                                  | Participants and methods<br>Page 8, lines 133-136 |
| 8. Interviewer characteristics              | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Interviews<br>Page 9, lines 164-169               |

|  |  |   |
|--|--|---|
| <b>Domain 2: study design</b>            |  |   |
| <i>Theoretical framework</i>             |  |   |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Data analysis<br><br>Page 10, line185   |
| <i>Participant selection</i>             |  |   |
| 10. Sampling                             | How were participants selected? e.g. purposive, convenience, consecutive, snowball   | Participants and Methods<br><br>Page 8, lines 143-144                             |
| 11. Method of approach                   | How were participants approached? e.g. face-to-face, telephone, mail, email  | Participants and Methods<br><br>Page 8, lines 129-133                             |
| 12. Sample size                          | How many participants were in the study?   | Participants and Methods<br><br>Page 8, line 149                                  |
| 13. Non-participation                    | How many people refused to participate or dropped out? Reasons?  | Participants and Methods<br><br>Pages 8 (lines 144-145) & 9 (line 159)            |
| <i>Setting</i>                           |  |   |
| 14. Setting of data collection           | Where was the data collected? e.g. home, clinic, workplace   | Interviews<br><br>Pages 9, line 163 & lines 172-173                               |
| 15. Presence of non-participants         | Was anyone else present besides the participants and researchers?  | Interviews<br><br>Page 9, line 173-174  |
| 16. Description of sample                | What are the important characteristics of the sample? e.g. demographic data, date  | Participants and Methods<br>Table 1<br><br>Pages 8 (line 151) & 9 (lines 152-155) |
| <i>Data collection</i>                   |  |   |



|  |   |   |
|--|---|---|
| 17. Interview guide                    | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Table 2, Patient & involvement, Interviews<br><br>Pages 7 (line 113) & 10 (lines 179-182) |
| 18. Repeat interviews                  | Were repeat interviews carried out? If yes, how many?                         | Participants and methods<br><br>Pages 9 (lines 157-159)                                   |
| 19. Audio/visual recording             | Did the research use audio or visual recording to collect the data?           | Interviews<br><br>Page 10, line 182   |
| 20. Field notes                        | Were field notes made during and/or after the inter view or focus group?      | Data analysis<br><br>Page 11, lines 211-214   |
| 21. Duration                           | What was the duration of the inter views or focus group?                      | Interviews<br><br>Page 9, line 164 & line 171   |
| 22. Data saturation                    | Was data saturation discussed?  | Participants and Methods<br><br>Page 8, lines 147-149                                     |
| 23. Transcripts returned               | Were transcripts returned to participants for comment and/or correction?      | Interviews<br><br>Page 10, line 183   |
| <b>Domain 3: analysis and findings</b> |   |   |
| <i>Data analysis</i>                   |   |   |
| 24. Number of data coders              | How many data coders coded the data?  | Data analysis<br><br>Page 10, lines 189-190   |
| 25. Description of the coding tree     | Did authors provide a description of the coding tree?                         | Table 3   |
| 26. Derivation of themes               | Were themes identified in advance or derived from the data?                   | Data analysis<br><br>Page 10, lines 185-186   |
| 27. Software                           | What software, if applicable, was used to manage the data?                    | Data analysis<br><br>Page 11, line 200  |
| 28. Participant checking               | Did participants provide feedback on the findings?                            | Patient and public involvement  |

|                                  |   |   |
|----------------------------------|---|---|
|                                  |   | Page 7, lines 123-124   |
| <i>Reporting</i>                 |   |   |
| 29. Quotations presented         | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Results<br>Pages 12-17, lines 221-341   |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings?  | Results<br>Pages 12-17, lines 221-341   |
| 31. Clarity of major themes      | Were major themes clearly presented in the findings?  | Results<br>Pages 12-17, lines: 216-220, 223-231, 240-244, 246-250, 255-258, 260-261, 264, 274-279, 282-289, 297-300, 308-314, 322-330 |
| 32. Clarity of minor themes      | Is there a description of diverse cases or discussion of minor themes?  | Results<br>Pages 12-17, lines: 231-233, 244-246, 262-263, 269-273, 314-315, 319-320   |

# BMJ Open

## Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study

|                                 |   |
|---------------------------------|---|
| Journal:                        | <i>BMJ Open</i>   |
| Manuscript ID                   | bmjopen-2018-026421.R2  |
| Article Type:                   | Research  |
| Date Submitted by the Author:   | 04-Jan-2019   |
| Complete List of Authors:       | Bogosian, Angeliki; City University of London , School of health sciences<br>Morgan, Myfanwy; King's College London, Institute of Pharmaceutical Science<br>Moss-Morris, Rona; Kings College London |
| <b>Primary Subject Heading</b>: | Neurology   |
| Secondary Subject Heading:      | Communication, Mental health, Neurology, Patient-centred medicine, Qualitative research   |
| Keywords:                       | Multiple sclerosis < NEUROLOGY, secondary progressive, self-management, QUALITATIVE RESEARCH, HEALTH SERVICES ADMINISTRATION & MANAGEMENT   |
|                                 |   |

SCHOLARONE™  
Manuscripts

Transition to secondary progressive MS

1  
2  
3 1 **Multiple challenges for people after transitioning to secondary progressive multiple**  
4  
5  
6 2 **sclerosis: a qualitative study**  
7

8  
9 3  
10  
11  
12 4 Bogosian A.<sup>\*1</sup>, Morgan, M.<sup>2</sup>, Moss-Morris R.<sup>3</sup>  
13

14  
15 5 <sup>1</sup>School of Health Sciences, City, University of London, London UK,  
16

17 6 [Angeliki.bogosian.1@city.ac.uk](mailto:Angeliki.bogosian.1@city.ac.uk)  
18

19  
20 7 <sup>2</sup>Institute of Pharmaceutical Science, King's College London, London, UK,  
21 8 [myfanwy.morgan@kcl.ac.uk](mailto:myfanwy.morgan@kcl.ac.uk)  
22  
23

24 9  
25  
26 10 <sup>3</sup> Institute of Psychiatry, Psychology & Neuroscience, King's College Hospital, London, UK,  
27 11 [rona.moss-morris@kcl.ac.uk](mailto:rona.moss-morris@kcl.ac.uk)  
28

29 12  
30  
31 13 \*Address correspondence and reprint requests to Dr Angeliki Bogosian, School of Health  
32  
33 14 Sciences, City, University of London, EC1V 0HB, London, UK; email:  
34  
35 15 [angeliki.bogosian.1@city.ac.uk](mailto:angeliki.bogosian.1@city.ac.uk); telephone number: +44(0)2070408532  
36  
37  
38  
39 16

40  
41  
42 17 **Keywords:** secondary progressive, Multiple Sclerosis, transition, self-management,  
43  
44 18 qualitative research, health services  
45  
46  
47  
48 19

49  
50  
51 20 Word count: 3,850  
52  
53  
54 21

55  
56  
57  
58 22  
59  
60 23

Transition to secondary progressive MS

24 Abstract

25 **Objectives:** Transitioning to secondary progressive multiple sclerosis (SPMS) is demanding for  
26 both patients and healthcare professionals. The particular challenges and the ways patients  
27 cope are poorly understood. The present study examines what challenges people face when  
28 diagnosed with SPMS, by exploring experiences of people who have transitioned recently (up  
29 to 5 years).

30 **Design:** Semi-structured qualitative interviews at two time points a year apart. Interviews  
31 were analysed using inductive thematic analysis.

32 **Setting:** United Kingdom

33 **Participants:** We interviewed twenty-one people at baseline and seventeen participated in  
34 the follow-up interviews.

35 **Results:** The majority of participants reported expecting to transition to SPMS, and the  
36 diagnosis did not make much difference to them. Participants described increasing emotional  
37 and physical challenges after transitioning to SPMS and between the first and second  
38 interview. Planning, using distractions and maintaining social roles helped participants cope  
39 with the increased challenges. The same coping strategies were used between the two  
40 interviews. Participants felt there was not much left to do regarding the management of their  
41 symptoms. A key theme was the sense of abandonment from health care services after  
42 transitioning to SPMS.

43 **Conclusions:** After transitioning to SPMS people are faced with multiple challenges.  
44 Participants described a lack of directions for symptoms management and lack of support  
45 from the healthcare system. An integrated multidisciplinary health care approach is crucial at

Transition to secondary progressive MS

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

46 the progressive stage of the disease to alleviate feelings of helplessness and promote  
47 symptom management.

For peer review only

Transition to secondary progressive MS

49

50 **Strength and limitations of this study**

- 51 • The present study is the first to use a longitudinal qualitative design to capture  
52 peoples' experience after transitioning to secondary progressive multiple sclerosis.
- 53 • The focus on people recently transitioned helped to narrow down peoples'  
54 experiences early on in diagnosis.
- 55 • We cannot determine whether the challenges described in this study are linked to  
56 having received an official diagnosis or to the challenges faced by increased disability,  
57 as we did not interview people just before being diagnosed and straight after.

58

Transition to secondary progressive MS

## 59 Introduction

60 Multiple Sclerosis (MS) affects more than 2.5 million people worldwide, including 127,000 in  
61 the United Kingdom [1]. MS is a condition that presents unique challenges for the individuals,  
62 as it usually starts with minimal physical and cognitive dysfunction which progresses over  
63 time. There are three types of MS. The most common type is relapsing-remitting (RR, 85%-  
64 90% of people with MS are diagnosed with this type) which is characterised by unpredictable  
65 attacks (relapses) of new or increasing neurological symptoms that are followed by periods  
66 of partial or complete recovery (remissions) [2]. The secondary progressive (SP) course  
67 develops in approximately 82% of those with RRMS by 20 years of onset [3]. Finally, a minority  
68 of people (10%) will be diagnosed with the primary progressive (PP) course that involves a  
69 steady disability increase without attacks [4].

70 The transition to secondary progressive multiple sclerosis (SPMS) is an expected part of the  
71 disease trajectory. Epidemiological studies indicate nearly 10% of people with RRMS reach  
72 the SPMS stage after five years, which increases to 25% at ten years and 75% at 30 years [5].  
73 A mean of  $2.9 \pm 0.8$  years is a typical length of time when people are faced with the  
74 uncertainty of whether or not they have transitioned to SPMS [6]. The delay in the diagnosis  
75 is thought to be due to the subtle nature of early progression and clinicians' reluctance to  
76 label a patient as having SPMS, given the absence of evidence-based treatment for SPMS and  
77 patients' anxieties regarding its prognosis [6]. People with SPMS are older, are less likely to  
78 be employed, and a lower proportion is female when compared to people with RRMS [7].  
79 When people transition to SPMS, they are likely to experience more severe neurological  
80 symptoms, more frequent hospitalisation [8], have more frequent and pronounced cognitive  
81 deficits [9, 10], and higher levels of fatigue [11] compared to people with RRMS. The onset of



## Transition to secondary progressive MS

1  
2  
3 82 SPMS has also been associated with fear, low mood [12], greater distress [13, 14], lower  
4  
5  
6 83 quality of life [15], and higher levels of depression and anxiety [16] than in both relapsing-  
7  
8 84 remitting and primary progressive types of MS. Only four qualitative studies have been  
9  
10  
11 85 conducted to examine the experiences of people with SPMS. In two of these studies, women  
12  
13 86 with SPMS recognised the impact of the loss of meaningful activities on the sense of self [17,  
14  
15 87 18]. A qualitative study on patients' experiences while transitioning to SPMS showed that  
16  
17  
18 88 some people learned they had SPMS without any advanced knowledge or understanding of  
19  
20  
21 89 what SPMS meant for them, which sometimes caused confusion and upset [19]. In the fourth  
22  
23 90 study, MS health professionals highlighted the value of adequate information and support  
24  
25 91 around the transition period, while patients talked about the reclassification with SPMS as a  
26  
27 92 turning point [20].

28  
29  
30  
31 93 We know little about peoples' experiences after transitioning to SPMS, and psychological and  
32  
33 94 behavioural interventions aimed at people with SPMS are scarce. Further, a recent meta-  
34  
35 95 analysis on the effectiveness of interventions for treating depression in MS identified 13  
36  
37 96 papers, with 8 of these excluding people with progressive MS from participating [21]. When  
38  
39 97 people with SPMS are included in psychological interventions, they also seem to gain fewer  
40  
41 98 benefits compared to people with RRMS [22]. The psychological challenges that people with  
42  
43 99 SPMS face may, therefore, differ to the ones that people with RRMS face.

44  
45  
46  
47  
48 100 In this study, we explored psychological and physiological challenges people experience after  
49  
50 101 transitioning to SPMS and the strategies they use to manage those challenges over time.  
51  
52 102 Knowing the challenges that patients face at this stage of their MS trajectory makes it easier  
53  
54 103 to identify information needs and tailor support interventions.

55  
56  
57  
58 104 Further, it is not well understood how transitioning to SPMS contributes to psychological  
59  
60

Transition to secondary progressive MS

1  
2  
3 105 challenges and adjustment attempts. The present study is the first to use a longitudinal  
4  
5 106 qualitative design to capture peoples' experience shortly (within five years) after  
6  
7  
8 107 transitioning, so recollection of transition is recent but also there is time for people to have  
9  
10 108 developed new coping strategies. The follow-up interviews allowed respondents to reflect on  
11  
12 109 the changes (or lack of them) since the first interview. The focus on people recently  
13  
14 110 transitioned helped to narrow down peoples' experiences early on in diagnosis.

## 111 **Methods**

### 112 *Patients and public involvement*

113 This research was part of a larger research project, and two individuals with SPMS were part  
114 of our user involvement committee, and they have helped with different aspects of the  
115 project from the initial conceptualisation of the study, feedback on the grant application and  
116 feedback of the topic guide. They were also asked to assess the burden of participation in the  
117 study. The two people with SPMS gave us feedback on an initial version of our themes. They  
118 inquired about whether the experiences differ based on the age of diagnosis or whether the  
119 people who described more psychological challenges had also reported cognitive difficulties.  
120 Following this, we checked the emerging themes to identify any patterns or differences in  
121 themes of people with different demographic characteristics. The two people with SPMS also  
122 suggested exploring further the experience of diagnosis and the importance of receiving the  
123 diagnosis of SPMS from a healthcare professional. Finally, they commented on the clarity of  
124 description and presentation of the results, for example, they made some suggestions about  
125 how themes linked together and asked for a few additional quotes at places to better  
126 illustrate themes. Participants of the study were sent the final results of the study but were  
127 not asked to provide feedback.

Transition to secondary progressive MS

128 *Participants*

129 This research is part of an MS Society UK funded junior research fellowship awarded to the  
130 first author with a view to increasing understanding of psychological challenges and  
131 adjustment of people with progressive MS. The current study was approved by the West of  
132 Scotland Research Ethics Committee (14/WS/0077). We recruited participants through online  
133 adverts on the MS Society UK website, adverts after speaking engagements at MS Society  
134 events and through study's information sheets provided by research nurses at MS hospital  
135 clinics (Northamptonshire Healthcare NHS Foundation Trust and Cumbria Partnership NHS  
136 Foundation Trust). At that stage through the participants' information sheet, potential  
137 participants learnt the aims of the research project and what the researchers were planning  
138 to use the information for, i.e. develop a psychological intervention tailored to the needs of  
139 people with progressive MS. Participants who self-reported that they had received a diagnosis  
140 of PPMS and SPMS from their neurologist or MS nurse were recruited, but here we focused  
141 on the interviews of people with SPMS. Eighty-seven people with PPMS and SPMS expressed  
142 interest in participating in the study. Fifteen (17%) did not meet the inclusion criterion of  
143 diagnosis within five years of progressive MS. The remaining 72 completed a short screening  
144 questionnaire that included demographic questions, as well as questions about MS duration,  
145 symptoms and walking ability. We chose to interview people using maximum variation [23],  
146 i.e. sampling to represent different demographic characteristics. No one refused participation  
147 after they have been invited to the interview. Participants were recruited from a wide range  
148 of locations in the UK, including more rural (small towns) and urban areas. Therefore, there  
149 was also a variability on the services they were able to access. Interviewing ceased once data  
150 saturation was reached, defined as the point at which no new information or themes are

Transition to secondary progressive MS

151 observed in the data [24]. We interviewed 21 participants who were diagnosed with SPMS  
152 and had given informed consent to take part in the study.

153 As shown in Table 1, participants were between 40 and 77 years of age (mean: 57.38 years)  
154 at the time of the interview. More than half the sample was unemployed or retired due to MS  
155 (n=14, 66.66%) and lived with their partners (n=15, 71.43%). Half of the participants  
156 interviewed (n=12, 57.1%) were able to walk for 20 meters or less, which is reflective of the  
157 demographics of people with SPMS. Most people with MS accumulate no more than  
158 moderate disability (fully ambulatory) during relapsing-remitting phase [25], and the onset  
159 of the SP phase represents the key determinant of severe disability accumulation [25-27].  
160 Seventeen participants were interviewed for the second time, four participants (19%) did not  
161 respond to the email invitations for a second interview, and no reason was provided.

### 162 *Interviews*

163 Researchers had not established a relationship with the participants prior to study  
164 commencement, with the exception of one participant, who had taken part in a previous  
165 study. Participants were given the option of face-to-face or telephone interviews. In the first  
166 round, all participants opted for telephone interviews, and the interviews lasted between 26  
167 minutes and 160 minutes (mean=79 minutes). Interviews were conducted by the first author  
168 (AB, female). AB has conducted her MSc, PhD and post-doctoral studies in the area of MS and  
169 through her contact with people with MS and her knowledge from the literature has  
170 concluded that people with progressive MS are underrepresented in the research literature  
171 and they feel left out when it comes to treatments and health care services. This sparked the  
172 interest in the research topic. The initial interviews were conducted between April 2014 and  
173 April 2015. The second set of interviews tended to be slightly shorter as they focused on

Transition to secondary progressive MS

1  
2  
3 174 changes between interviews and lasted between 36 minutes and 103 minutes (mean=66.12).  
4  
5  
6 175 With one exception, participants in the second round also opted for telephone interviews.  
7  
8 176 There was no one else present during the interview besides the participant and the researcher  
9  
10 177 (AB). The second round of interviews was conducted between July 2015 and April 2016. There  
11  
12  
13 178 was some variation in the intervals between the first and second interview, due to staff  
14  
15 179 changing institute and participants' availability. One interview was conducted 13 months  
16  
17  
18 180 after the first interview, seven interviews were conducted 14 months after the first interview,  
19  
20 181 eight interviews were conducted 15 months after the first interview and one interview was  
21  
22  
23 182 conducted 18 months after the first interview. Table 2 shows the topic guide used for the two  
24  
25 183 interviews. Examples people gave in their first interviews were also used as prompts to assess  
26  
27 184 changes in emotions, thoughts or symptom-management. All interviews were audiotaped  
28  
29  
30 185 with consent and transcribed verbatim. Transcripts were not sent back to participants to  
31  
32  
33 186 comment.

### 187 *Data analysis*

38  
39 188 We used inductive thematic analysis [28]. An inductive approach means the themes identified  
40  
41 189 emerge from the data themselves [29]. Therefore, the inductive analysis is the process of  
42  
43  
44 190 coding the data without trying to fit it into a pre-existing coding frame, or the researcher's  
45  
46 191 analytic preconceptions. This form of thematic analysis is, therefore, data-driven [28].

48  
49 192 Coding was undertaken by the first author (AB) under the supervision of the second author  
50  
51 193 (MM) with discussions of emerging themes with the third author (RMM). AB has extensive  
52  
53  
54 194 experience analysing qualitative methodologies. She completed qualitative methodologies  
55  
56 195 training as part of the MSc in Health Psychology course (Southampton University) and  
57  
58  
59 196 attended a two-day workshop on longitudinal qualitative research organised by the  
60

## Transition to secondary progressive MS

1  
2  
3 197 Methodological Innovation Network and delivered at Southampton University (Nov 2012). At  
4  
5  
6 198 the time of this study the researcher had completed and published three qualitative studies  
7  
8 199 as the lead researcher (conducting of interviews, analysis and write-up), supervised 2 MSc  
9  
10 200 student and 2 PhD students on their qualitative methodologies, and was teaching a series of  
11  
12 201 qualitative methodologies lectures for MSc and Doctoral students. A variety of techniques  
13  
14  
15 202 were employed to increase familiarisation with the data. Audiotapes of each interview were  
16  
17  
18 203 listened repeatedly, and transcripts were read and reread. We used NVivo 10 for coding.  
19  
20  
21 204 The analysis of the transcripts was conducted in parallel with data collection and refinement  
22  
23 205 of the themes continued after the end of the data collection, during writing up. First, each  
24  
25 206 coding unit in the first transcript was given a code name, using vocabulary as close as possible  
26  
27  
28 207 to that used by participants themselves [30]. Initial codes were then applied systematically to  
29  
30 208 the entire dataset, and new codes developed and refined as appropriate. We also grouped  
31  
32 209 participants' interviews that shared similar demographic characteristics and explored  
33  
34  
35 210 patterns or commonalities. We examined whether themes differed across sub-groups (e.g.  
36  
37  
38 211 method of recruitment, gender, and family circumstances). Figure 1 shows the steps followed  
39  
40 212 during the analysis. The analysis was an iterative process, and at times we had to go back and  
41  
42  
43 213 forth between steps. The coding tree in table 3, shows how we moved from codes to refined  
44  
45 214 categories. In order to document the analysis process, a detailed paper trail was kept with the  
46  
47  
48 215 notes taken after the interviews, the development of the codes and relationship between the  
49  
50 216 raw data and the refined categories and codes. The quotes presented in the result section  
51  
52  
53 217 were chosen for typicality in illustrating the themes. Pseudonyms are used for the quotes.  
54  
55

**218 Results**

56  
57  
58  
59 219 Two overarching themes about (1) Transitioning to SPMS and challenges and (2) Adaptive  
60

Transition to secondary progressive MS

220 strategies over time. The first theme illustrated challenges involved in the transition and the  
221 second theme related to how participants responded to those challenges. Tables 4 provides  
222 examples of SPMS transition and challenges over time and Table 5 provides examples of self-  
223 management and changes over time.

#### 224 **Transitioning to SPMS and challenges**

##### 225 *Initial reaction to the transition*

226 For the majority of the participants, the transition to SPMS was expected rather than  
227 shocking. For some, transitioning did not make much difference because at that point they  
228 had already lost essential relationships and activities they valued. For others transitioning to  
229 SPMS did not make much difference because the progressive worsening of their symptoms  
230 was slow and subtle.

231 We compared the interviews of people that found about the SPMS diagnosis in different ways,  
232 for example, accidentally when visiting the hospital for other issues, or in one of the annual  
233 consultations or they suspected they had transitioned and asked the neurologist for  
234 confirmation. In contrast to the majority, the five participants, who found out about the  
235 transition accidentally described being upset and shocked. These five people had MS between  
236 3 to 21 years (median=12 years).

237 *[Neurologist's name] started other MRI's and tests and things and said that I'd*  
238 *progressed to secondary progressive. So, I was shocked and- I was shocked that I got*  
239 *signed off work, and it progressed. I thought he'd just say, "You're signed off for a*  
240 *couple of weeks", not that and, I just thought, you know, "If I sleep then I'll be all right."*  
241 *(female, 45, T1)*

Transition to secondary progressive MS

242 *Worsening of symptoms and emotional shifts*

243 Transitioning to SPMS also meant worsening of symptoms, and people described progressive  
244 worsening of symptoms including mobility, fatigue, vision, and bladder dysfunction, urinary  
245 tract infections and falls. There were further worsening of symptoms reported between the  
246 first and second interview. This deterioration also brought more changes in participants' lives.  
247 Transitioning to SPMS also meant worsening of emotional issues. A few participants had a  
248 diagnosis of depression before or after the initial diagnosis of MS, which made managing MS  
249 more difficult. However, the majority of participants described dealing with other difficult  
250 emotions in both interviews, including feeling like a burden, being afraid of having accidents,  
251 being trapped or feeling embarrassed. They also expressed low self-esteem and confidence,  
252 and some participants described the uncertainty of whether they have the skills to cope with  
253 MS, accept the condition and deal with stress.

254 *I had a bad fall last week where I split all my head open, so I am feeling a bit lack of*  
255 *confidence in just going out for a little walk up the road and back with my walker on*  
256 *my own. (female, 54, T2)*

258 Overall, in the second interview participants talked in more depth about their psychological  
259 difficulties and challenges in coping over the years and presented a more severe picture than  
260 in the first round of interviews. Further, people who described emotional challenges in the  
261 first interview described the same challenges in the second interview, a year later.

262 *Arriving at the point of no help*

263 After transitioning to SPMS, most participants reported that they did not feel health services



Transition to secondary progressive MS

264 had anything more to offer since they could no longer have access to disease-modifying drugs.

265 A few participants talked about the benefits of physiotherapy but either the sessions offered

266 in the NHS were too few, or physiotherapy was expensive to access privately. They saw their

267 transition as a point beyond help.

268 *I have an MS nurse but quite frankly you know I have come to an end what you can do,*

269 *I don't feel I am getting any support at all at the moment. I feel I am being left to my*

270 *own devices. Yes I see him every six months, every twelve months but there is nothing*

271 *he can offer so you know it is a bit of a waste of time really. (female, 54, T2)*

272 However, a few participants reported doing their own research and identifying treatments

273 that could potentially help them (e.g. oxygen therapy, incontinence nurse) and then asked

274 their healthcare team to refer them accordingly. Also, a few participants attended self-

275 management courses run by local MS charities or access psychological treatments as part of

276 research projects.

277 When asked whether there is any support that they would like to receive in the future, one

278 participant said: *'I think there is quite a lot of support when you're first diagnosed but I think*

279 *it tails off I think people find it more difficult to support you the longer you have the MS I think*

280 *people become quite cynical about the help that can be got and cynical about what the NHS*

281 *has to offer and cynical about the help that can be obtained as to whether it's any use or not.'*

282 (female, 65, T2). Most participants shared a similar opinion.

### 283 **Adaptive tasks and changes over time**

#### 284 *Planning activities or scaling down activities*

285 Participants reported adjusting their holiday destinations and plans, to take into account their

## Transition to secondary progressive MS

1  
2  
3 286 limitations, without changing their previous lifestyle too much. Planning for future  
4  
5  
6 287 deterioration (e.g. financially, house modifications) and planning activities and days out  
7  
8 288 meticulously and well in advanced, helped people feel in control. Sometimes, across the two  
9  
10  
11 289 interviews participants appeared to overestimate their limitations and underestimate their  
12  
13 290 ability to cope in the future at the first interview compared with what people reported at the  
14  
15 291 second interview. This discrepancy is illustrated below by the quotes of the same participant  
16  
17  
18 292 in the first and second interview.

21 293 *I don't go too far now, I can only cope with about three and a half hours on the plane*  
22  
23 294 *at the most. I can't go long distance or anything like that, you know long haul anymore,*  
24  
25 295 *it's usually the Canary Islands or somewhere like that, somewhere nice and close*  
26  
27  
28 296 *(female, 54, T1)*

31 297 *I am still determined that I am going to travel and see as many places as I want. We*  
32  
33 298 *went away for six weeks over January/February, we went to New Zealand and*  
34  
35  
36 299 *Australia (female, 55, T2)*

39 300 However, at times, participants found it difficult to plan or modify their activities and instead  
40  
41 301 scaled back, especially when the condition progressed rapidly, and almost all participants who  
42  
43 302 had mentioned difficulties finding alternative activities in the first interview had the same  
44  
45  
46 303 difficulties in the second interview.

50 304 *I can't read the same that I used to; I can't go on the computer; I can't really watch TV;*  
51  
52 305 *gardening, the high impact exercises, you know, the long walk so everything's just had*  
53  
54 306 *to be tailored down and you know brought into a shorter time period. The human is*  
55  
56  
57 307 *pretty good at finding ways around things...so yeah you just adapt um it's a struggle*  
58  
59 308 *you know there's no two ways about it, but it is that life is definitely a struggle but*

Transition to secondary progressive MS

309 *again you get used to that really as well (female, 59, T2)*

310 *Emotional regulation*

311 Strategies to manage emotional difficulties included distraction such as playing video games,  
312 reading books, going out for a meal, or avoiding thinking and talking about the future,  
313 avoiding MS group meetings and spending the day sleeping. Some people tried to be positive  
314 by repeating 'things could have been worse'.

315 Further, partners played an important role in emotionally supporting the participants, by  
316 helping them adjust to new MS challenges or by being available to discuss participants'  
317 worries. People reported using the same strategies between the two interviews. A few  
318 participants talked about how they would have liked access to psychological services.

319 *It would be nice to talk about how you feel about it, would be it'd be nice if...do you*  
320 *know it would be nice if just to have somebody there saying you're doing a grand job*  
321 *[Laugh] with how you're doing. Because you are isolated (female, 53, T2)*

322 However, two participants said that they were offered psychological support, but they  
323 thought this was unnecessary.

324 *Being social, fitting in and being of use*

325 For most of the participants transitioning to SPMS also meant increased mobility problems  
326 and use of a wheelchair. Use of a wheelchair also posed accessibility issues leading to more  
327 carefully planned outings. Even though going out came with more difficulties, and at times  
328 people felt it was easier to stay in, most talked about the importance of being with friends  
329 and family and retaining relationships and also meeting new people. Participants described  
330 getting involved in charity work, MS research and helping others. They reported that this gave

## Transition to secondary progressive MS

331 them a new purpose, they learned new things and met people. Participants who talked about  
332 the importance of being social or helping others in the first interview also talked about it in  
333 their second interview, as illustrated below by the same participant at the two time points.

334 ...going out with friends, going out for dinner, going and mixing with other people,  
335 which I would have quite enjoyed before and not thought anything about it, but now  
336 I think, "oh do I really want to go?" but then I force myself, you have got to go, because  
337 then when I do go, I do enjoy it and I do feel better because your mood's lifted and  
338 once you are moving around, things are easier. (female, 59, T1)

339 We've got the local MS branch, we meet twice a month, first and third Tuesdays of  
340 the month. I find that very helpful. I do find that helpful to talk to other people that  
341 have got the same sorts of problems that you've got, gone through the same things.  
342 And again, there's somebody there that, it's not perhaps a close friend, but has  
343 become or is becoming more of a close friend that we will see one another outside of  
344 the MS branch. (female, 59, T2)

**345 Discussion**

346 Reflecting on the SPMS diagnosis, people overall did not express trauma or distress, only on  
347 the occasions, the diagnosis came as a surprise. People who have recently transitioned to  
348 SPMS reported facing a worsening of the condition alongside increased emotional challenges.  
349 In the second interview, most people described the increased severity of their symptoms and  
350 more emotional difficulties. Participants reported detailed planning, distractions and  
351 remaining as active and as involved in the community as possible helped to cope with the  
352 condition. Some participants overestimated their limitations and underestimated their  
353 capacity to cope between the first and the second interview but overall most reported using

## Transition to secondary progressive MS

1  
2  
3 354 similar coping strategies between the two time points. A common theme across all interviews  
4  
5  
6 355 was a sense of abandonment from the health care services and the sense that nothing can be  
7  
8 356 done at this stage of their condition. Therefore, providing appropriate support after the  
9  
10 357 transition diagnosis is vital.

11  
12  
13 358 A qualitative study of people recently diagnosed with MS showed that psychological well-  
14  
15  
16 359 being was described as precariously contingent on reasonable current and future health  
17  
18 360 status [31], for example, people were not sure whether they would be able to cope if they  
19  
20  
21 361 lost their job or had to use a wheelchair. The current study examines what happens after  
22  
23 362 people have moved to SPMS. Participants in our study talked about increased disability since  
24  
25  
26 363 they have transitioned to SPMS or between the first and second interview, but despite these  
27  
28 364 increased difficulties, people felt that health care professionals had nothing more to offer and  
29  
30  
31 365 there was nothing more they could do to control their emotional or physical symptoms.  
32  
33 366 Focusing on well-being is often on diagnosable depression and anxiety. However, participants  
34  
35  
36 367 in the present study described having to deal with challenging emotions which may not reflect  
37  
38 368 in these clinical diagnoses.

39  
40  
41 369 An essential finding of this study is that people who described some challenges with self-  
42  
43  
44 370 management in the first interview described the same challenges in the second interview, a  
45  
46 371 year later. This can be linked to their perception of SPMS as the stage where nothing further  
47  
48 372 can be done to manage things. According to the Common Sense Model [32]. Being diagnosed  
49  
50  
51 373 with an illness that is perceived as more controllable will lead to less distress and more control  
52  
53 374 efforts such as seeking advice on symptom management. Participants interviewed here  
54  
55  
56 375 described SPMS as a condition they and their health care team did not have any control over.  
57  
58 376 As people move from RRMS to SPMS, the capacity of personal and treatment control declines,  
59  
60

## Transition to secondary progressive MS

377 and creates a significant challenge in adapting to the change by identifying areas that they  
378 can still have control while letting go of unattainable goals [33].

379 Participants in the current study reported that there is nothing they or health care  
380 professionals can do to manage their increasing limitations. Even though self-management  
381 interventions in progressive MS are scarce, there is some preliminary evidence of  
382 interventions that could help with symptom management. For example, endurance training  
383 can improve walking [34]; progressive resistance training may improve lower limb strength  
384 [35]; bodyweight-supported treadmill can reduce pain [36], and mindfulness training can  
385 reduce anxiety, depression and impact of MS [37]. Where available, health care professionals  
386 should signpost patients to appropriate services that can help with MS symptoms but more  
387 needs to be done to find ways of developing these services, so they are more readily available.

388 The present study has certain significant strengths. First, to our knowledge, it is the first study  
389 attempting to investigate challenges and adaptive tasks shortly after people have transitioned  
390 to SPMS. The particular advantage of the present study was its longitudinal approach that  
391 allowed the identification of patterns over time. This showed that whereas more severe  
392 emotional and physical symptoms were reported in the second interview, these did not result  
393 in different or more challenges. While this may suggest participants feeling more comfortable  
394 in opening up at time two, having built a rapport with the interviewer, it may also reflect the  
395 lack of support people were receiving. Finally, a strength of this study also lies in the specificity  
396 of the sample selected, who were all people who had transitioned to SPMS within the  
397 previous five years.

398 The study has certain limitations. Firstly, the qualitative exploratory nature of the study does  
399 not allow for causal relationships to be established. Second, getting an SPMS diagnosis may

## Transition to secondary progressive MS

1  
2  
3 400 take years, in part due to substantial diagnostic uncertainty as a result of the subtlety of signs  
4  
5  
6 401 of early progressive disease [6]. Therefore, it is hard to determine whether the challenges  
7  
8 402 described are linked to having received an official diagnosis or to the challenges faced by  
9  
10 403 increased disability, as we did not interview people just before being diagnosed and straight  
11  
12 404 after. Furthermore, participants self-reported transitioning to SPMS, although they were  
13  
14 405 asked to confirm that they have received the transitioning diagnosis officially from an MS  
15  
16 406 health professional, we did not verify this information by cross-checking their medical  
17  
18 407 records. Also, their recollections of the time of the diagnosis might not be accurately  
19  
20 408 represented during the interviews that took place up to five years later. Finally, telephone  
21  
22 409 interviews might be considered inferior to face-to-face, since rapport can be harder to  
23  
24 410 establish. However, research indicates both telephone and in-person interviews can be used  
25  
26 411 productively in qualitative research[38], with the former potentially allowing participants to  
27  
28 412 feel more relaxed and willing to disclose sensitive information[39], enhancing the data's  
29  
30 413 trustworthiness.

31  
32  
33  
34  
35  
36  
37  
38 414 Regardless of the above limitations, the findings presenting here underline the additional  
39  
40 415 physical and emotional challenges people face when transitioned to SPMS and that people  
41  
42 416 try to adapt by planning, finding distractions and remaining social but they reported there  
43  
44 417 was nothing further to do regarding symptom management. Identifying physical and  
45  
46 418 emotional challenges at the time of the diagnosis to SPMS will help referral to appropriate  
47  
48 419 services within a multidisciplinary clinical team. Offering people options for continuing  
49  
50 420 symptoms management at the time of SPMS diagnosis may help with feelings of helplessness  
51  
52 421 that accompany the diagnosis.

## 422 **Acknowledgements**

Transition to secondary progressive MS

423 The authors would like to thank the people with MS who took part in this study.

424 **Conflict of interest**

425 We have no conflict of interest to declare.

426 **Funding**

427 Multiple Sclerosis UK supported this work under grant reference 4.

428 **Author statement**

429 AB and RMM designed the study. AB conducted the interviews, led the data analysis and  
430 drafted the manuscript. MM contributed to the development of the topic guide, oversaw data  
431 collection and analysis and contributed to drafts of the paper. RMM advised on the conduct  
432 of the research, contributed towards refining themes, interpretations of the findings, and  
433 drafts of the paper.

434 **Data sharing statement**

435 Paper trail and NVivo coding files available from the corresponding author

436

437



## Transition to secondary progressive MS

## 438 References

- 439 1. Mackenzie, I.S., et al., *Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a*  
440 *descriptive study in the General Practice Research Database*. Journal of Neurology,  
441 Neurosurgery & Psychiatry, 2013.
- 442 2. Compston, A. and A. Coles, *Multiple sclerosis*. Lancet, 2008. **372**: p. 1502 - 1517.
- 443 3. Fisniku, L.K., et al., *Disability and T2 MRI lesions: a 20-year follow-up of patients with relapse*  
444 *onset of multiple sclerosis*. Vol. 131. 2008. 808-817.
- 445 4. Lublin, F.D. and S.C. Reingold, *Defining the clinical course of multiple sclerosis: results of an*  
446 *international survey*. National Multiple Sclerosis Society (USA) Advisory Committee on Clinical  
447 *Trials of New Agents in Multiple Sclerosis*. Neurology, 1996. **46**(4): p. 907-11.
- 448 5. Tremlett, H., *Secondary Progressive Multiple Sclerosis*. MS in Focus, 2009. **13**: p. 13-14.
- 449 6. Sand, I.K., et al., *Diagnostic uncertainty during the transition to secondary progressive multiple*  
450 *sclerosis*. Multiple Sclerosis Journal, 2014. **20**(12): p. 1654-1657.
- 451 7. Gross, H.J. and C. Watson, *Characteristics, burden of illness, and physical functioning of*  
452 *patients with relapsing-remitting and secondary progressive multiple sclerosis: a cross-*  
453 *sectional US survey*. Neuropsychiatr Dis Treat, 2017. **13**(13): p. 1349-1357.
- 454 8. Planche V, G.M., Cregut D, Pereira B, Clavelou P. , *Cognitive impairment in a population-based*  
455 *study of patients with multiple sclerosis: differences between late relapsing– remitting,*  
456 *secondary progressive and primary progressive multiple sclerosis*. European journal of  
457 neurology, 2016. **23**(2): p. 282-9.
- 458 9. Papathanasiou, A., et al., *Cognitive impairment in relapsing remitting and secondary*  
459 *progressive multiple sclerosis patients: efficacy of a computerized cognitive screening battery*.  
460 ISRN neurology, 2014. **2014**.
- 461 10. Denney, D.R., L.A. Sworowski, and S.G. Lynch, *Cognitive impairment in three subtypes of*  
462 *multiple sclerosis*. Archives of Clinical Neuropsychology, 2005. **20**(8): p. 967-981.
- 463 11. Bakshi, R., et al., *Fatigue in multiple sclerosis and its relationship to depression and neurologic*  
464 *disability*. Multiple Sclerosis (Houndmills, Basingstoke, England), 2000. **6**(3): p. 181-185.
- 465 12. Thorne, S., et al., *Health care communication issues in multiple sclerosis: an interpretive*  
466 *description*. Qualitative Health Research, 2004. **14**(1): p. 5-22.
- 467 13. Vleugels, L., et al., *Psychological functioning in primary progressive versus secondary*  
468 *progressive multiple sclerosis*. Br J Med Psychol, 1998. **71 ( Pt 1)**(1): p. 99-106.
- 469 14. Montel, S.R. and C. Bungener, *Coping and quality of life in one hundred and thirty five subjects*  
470 *with multiple sclerosis*. Mult Scler, 2007. **13**(3): p. 393-401.
- 471 15. McNulty, K., H. Livneh, and L.M. Wilson, *Perceived Uncertainty, Spiritual Well-Being, and*  
472 *Psychosocial Adaptation in Individuals With Multiple Sclerosis*. 2004, Educational Publishing  
473 Foundation: US. p. 91-99.
- 474 16. Mohr, D.C., et al., *The Psychosocial Impact of Multiple Sclerosis: Exploring the Patient's*  
475 *Perspective*. Health Psychology, 1999. **18**: p. 376-382.
- 476 17. Olsson, M., J. Lexell, and S. Soderberg, *The meaning of women's experiences of living with*  
477 *multiple sclerosis*. Health Care Women Int, 2008. **29**(4): p. 416-30.
- 478 18. Olsson, M., L. Skar, and S. Soderberg, *Meanings of feeling well for women with multiple*  
479 *sclerosis*. Qual Health Res, 2010. **20**(9): p. 1254-61.
- 480 19. Davies, F., et al., *'You are just left to get on with it': qualitative study of patient and carer*  
481 *experiences of the transition to secondary progressive multiple sclerosis*. BMJ open, 2015. **5**(7):  
482 p. e007674.
- 483 20. O'Loughlin, E., et al., *The experience of transitioning from relapsing remitting to secondary*  
484 *progressive multiple sclerosis: views of patients and health professionals*. Disabil Rehabil,  
485 2017. **39**(18): p. 1821-1828.
- 486 21. Fiest, K.M., et al., *Systematic review and meta-analysis of interventions for depression and*  
487 *anxiety in persons with multiple sclerosis*. Mult Scler Relat Disord, 2016. **5**: p. 12-26.

## Transition to secondary progressive MS

- 1  
2  
3 488 22. Jongen, P.J., et al., *An intensive social cognitive program (can do treatment) in people with*  
4 489 *relapsing remitting multiple sclerosis and low disability: a randomized controlled trial protocol.*  
5 490 *BMC Neurol*, 2016. **16**(1): p. 81.  
6 491 23. Patton, M., *Qualitative evaluation and research methods*. 1990, Thousand Oaks, California:  
7 492 Sage Publications Ltd.  
8 493 24. Guest, G., A. Bunce, and L. Johnson, *How Many Interviews Are Enough?: An Experiment with*  
9 494 *Data Saturation and Variability*. *Field Methods*, 2006. **18**(1): p. 59-82.  
10 495 25. Scalfari, A., et al., *The natural history of multiple sclerosis, a geographically based study 10:*  
11 496 *relapses and long-term disability*. *Brain*, 2010. **133**(7): p. 1914 - 1929.  
12 497 26. Eriksson, M., O. Andersen, and B. Runmarker, *Long-term follow up of patients with clinically*  
13 498 *isolated syndromes, relapsing-remitting and secondary progressive multiple sclerosis*. *Mult*  
14 499 *Scler*, 2003. **9**(3): p. 260-74.  
15 500 27. Tremlett, H., et al., *Impact of multiple sclerosis relapses on progression diminishes with time.*  
16 501 *Neurology*, 2009. **73**(20): p. 1616-23.  
17 502 28. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. *Qualitative Research in*  
18 503 *Psychology*, 2006. **3**(2): p. 77-101.  
19 504 29. Payne, S., *Interview in qualitative research*, in *Handbook of psychology of interviewing*, A.  
20 505 Memon and R. Bull, Editors. 1999, Wiley and Sons: London. p. 89-102.  
21 506 30. Glaser, B. and S.A. Strauss, *Discovery of grounded theory. Strategies for qualitative research.*  
22 507 1967, New York: Aldine de Gruyter.  
23 508 31. Dennison, L., et al., *Experiences of adjusting to early stage Multiple Sclerosis*. *J Health Psychol*,  
24 509 2011. **16**(3): p. 478-88.  
25 510 32. Leventhal, H., M. Diefenbach, and E.A. Leventhal, *Illness cognition: using common sense to*  
26 511 *understand treatment adherence and affect cognition interactions*. *Cognitive therapy and*  
27 512 *research*, 1992. **16**(2): p. 143-163.  
28 513 33. Heckhausen, J., C. Wrosch, and R. Schulz, *A motivational theory of life-span development*.  
29 514 *Psychological review*, 2010. **117**(1): p. 32.  
30 515 34. Briken, S., et al., *Effects of exercise on fitness and cognition in progressive MS: a randomized,*  
31 516 *controlled pilot trial*. *Multiple Sclerosis Journal*, 2013: p. 1352458513507358.  
32 517 35. Latimer-Cheung, A., et al., *Effects of exercise training on fitness, mobility, fatigue, and health-*  
33 518 *related quality of life among adults with multiple sclerosis: a systematic review to inform*  
34 519 *guideline development*. *Arch Phys Med Rehabil*, 2013. **94**: p. 1800 - 1828.e3.  
35 520 36. Wier, L.M., et al., *Effect of robot-assisted versus conventional body-weight-supported*  
36 521 *treadmill training on quality of life for people with multiple sclerosis*. *J Rehabil Res Dev*, 2011.  
37 522 **48**(4): p. 483-92.  
38 523 37. Bogosian, A., et al., *Distress improves after mindfulness training for progressive MS: A pilot*  
39 524 *randomised trial*. *Mult Scler*, 2015. **21**(9): p. 1184-94.  
40 525 38. Sturges, J.E. and K.J. Hanrahan, *Comparing telephone and face-to-face qualitative*  
41 526 *interviewing: a research note*. *Qualitative Research*, 2004. **4**(1): p. 107-118.  
42 527 39. Novick, G., *Is there a bias against telephone interviews in qualitative research?* *Research in*  
43 528 *Nursing & Health*, 2008. **31**(4): p. 391-398.

529

530

## Transition to secondary progressive MS

531

532 Table 1. Participants' characteristics

| <i>Participants' characteristics (T1)</i> | <i>Number (%)</i>   |
|---|---------------------|
| <i>Age (Mean, SD)</i>                     | <i>57.33 (9.13)</i> |
| <i>Gender-female</i>                      | <i>16 (72.7%)</i>   |
| <i>Marital status (N, %):</i>             |                     |
| <i>Married/cohabiting</i>                 | <i>15 (71.4%)</i>   |
| <i>Single</i>                             | <i>3 (14.3%)</i>    |
| <i>Divorced/separated</i>                 | <i>3 (14.3%)</i>    |
| <i>Time since initial diagnosis:</i>      |                     |
| <i>0-5 years</i>                          | <i>5 (23.8 %)</i>   |
| <i>6-10 years</i>                         | <i>3 (14.3%)</i>    |
| <i>11-15 years</i>                        | <i>3(14.3%)</i>     |
| <i>16-20 years</i>                        | <i>2 (9.5%)</i>     |
| <i>21years +</i>                          | <i>8 (38.1%)</i>    |
| <i>Time since SPMS diagnosis:</i>         |                     |
| <i>1 year</i>                             | <i>4 (18.2%)</i>    |
| <i>2 years</i>                            | <i>3 (13.6%)</i>    |
| <i>3 years</i>                            | <i>3 (13.6%)</i>    |
| <i>4 years</i>                            | <i>4 (18.2%)</i>    |
| <i>5 years</i>                            | <i>7 (31.8%)</i>    |
| <i>Walking ability (with aid):</i>        |                     |
| <i>0-5 meters (EDSS 7-8)</i>              | <i>9 (42.8%)</i>    |
| <i>20 meters (EDSS 6.5)</i>               | <i>3 (14.3%)</i>    |
| <i>100 meters (EDSS 6)</i>                | <i>3 (14.3%)</i>    |
| <i>200 meters (EDSS 5)</i>                | <i>4 (18.2%)</i>    |
| <i>500 meters (EDSS ≤4)</i>               | <i>1 (4.8%)</i>     |
| <i>unknown</i>                            | <i>1 (4.8%)</i>     |

533

534

## Transition to secondary progressive MS

535 Table 2. Topic guide

| Questions  | Prompts  |
|--|--|
| Can you start by telling me all about what you thought and felt when you were first diagnosed with MS? | Main issues, explore concerns, feelings, (physical, psychological, family issues) what did he/she do about each problem that was identified?                             |
| Can you tell me about the time you found out you have moved to secondary progressive type of MS?       | Explore how did they find out, period before receiving the diagnosis, thoughts and feelings after receiving the secondary diagnosis.                                     |
| Can you tell me about what you think and feel about having MS now?                                     | Examples of issues identified?   |
| Can you tell me about all the things you found (un)helpful when dealing with challenges of MS?         | Feelings and thoughts on support interventions they were offered or sought/ how did they apply the advice given (if given), support they would like to see in the future |
| Are there any other relevant issues we haven't covered that you would like to mention?                 |  |

536

537

## Transition to secondary progressive MS

538

539 Table 3. Coding tree of time 1 and time 2 interviews

| Themes  | Sub-themes   | Parent codes                               | Associated child codes   |                             |   |
|---|--|--|--|-----------------------------|---|
| Transitioning to SPMS and challenges  | Initial reaction to the transition   | SPMS diagnosis                             | Time of diagnosis<br>It's easy to say SPMS<br>Before diagnosis<br>Before knowing<br>Now I know<br>Finding out (tests, hospitals, MRI, lumbar puncture)<br>Being informed |                             |   |
|   |  | I knew I had SPMS                          | You know you're on secondary MS is part of me  |                             |   |
|   |  | It was a shock                             | Shock of diagnosis   |                             |   |
|   |  | I can't do things I enjoy                  | It's not a good disease<br>Cannot do things<br>Cannot do things I used to enjoy<br>Can't walk<br>Can't wear normal clothes   |                             |   |
|   |  | Progression is slow                        | Progression: creeps up on you<br>Progression is slow   |                             |   |
|   |  | Worsening of symptoms and emotional shifts | Symptoms getting worse   | Depression before diagnosis | Various symptoms<br>Progression is scary<br>MS is serious |
|   |  |  |  |                             | Depression after diagnosis                                |
| Tormented<br>Depression diagnosis<br>Thinking of nothing else<br>Depressed<br>It's hard |  |  |  |                             |   |
| I'm afraid/embarrassed  | Embarrassing<br>Scared<br>Disfigurement<br>Weight gain is depressing<br>Fear of the unknown<br>I'm not as frightened anymore |  |  |                             |   |

## Transition to secondary progressive MS

|                                     |  |  |  |
|-------------------------------------|--|--|--|
|                                     |  | I feel I'm a burden  | Annoyed<br>Cry   |
|                                     | Arriving at the point of no help               | Contact with MS healthcare professions<br>Neurologists' appointments | General hospitals don't understand MS<br>Dealing with medics<br><br>MS nurses<br>Neurologists<br>Physiotherapy   |
|                                     |  | Nothing to offer   | Getting medical help<br>Medication   |
|                                     |  | Support services: currently offered and future                       | There is nothing for SPMS<br>Psychological support would have been good at diagnosis<br>I'd like to just talk to someone who understands MS  |
| Adaptive tasks and changes overtime | Planning activities or scaling down activities | Holidays   | Planning holidays  |
|                                     |  | Planning in advance  | Cannot plan in advance<br>Need to plan meticulously<br>Use of diaries/ reminders   |
|                                     |  | If you can't do it, do it differently                                | Partner showed me a wheelchair is good<br>Small things but meaningful<br>It's silly to rebel   |
|                                     |  | Can't do much  | Bad days: do nothing Resting<br>Can't exercise<br>Life is dull<br>Knowing my limits  |
|                                     | Emotional regulation                           | Distractions   | Sleeping<br>Day-time TV<br>Video-games   |
|                                     |  | Help from partner/ family  | Partner helps emotionally<br>Being outdoors<br>Couldn't cope without my partner<br>Harder if you're on your own<br>Partner looks after me<br>Partner control<br>Partner gets angry |

Transition to secondary progressive MS

|  |   |                                       |  |
|--|---|---------------------------------------|--|
|  |   | Not thinking/talking about the future | Reading about MS<br>I don't like to talk about it  |
|  |   | "things could have been worse"        | A frame of mind<br>Men cope better<br>Young people cope better   |
|  | Being social, fitting in and being of use | Accessibility problems                | Disrespectful people<br>Accessibility issues   |
|  |   | MS group meetings                     | Exchanging info<br>Comparing with other people<br>Comparing with other patients<br>Partner organised support group |
|  |   | Family visits                         | Grandchildren don't understand<br>We're trying to be normal<br>We do things for the family<br>Family life          |
|  |   | Friendships                           | Revealing MS<br>I don't look ill<br>I have very good friends   |
|  |   | Voluntary work                        | Helping others with MS<br>I wish I could help  |

540

541

For peer review only



## Transition to secondary progressive MS

Table 4. Examples of SPMS transition and challenges over time

| Interview                        | P15  | P19   | P12  |
|----------------------------------|--|---|--|
| <i>Pre-transitioning Context</i> | Participant transitioned to SPMS 14 years after initial diagnosis. Before the MS diagnosis, she was diagnosed with depression. She needed support after the diagnosis, but none was offered.   | Participant transitioned to SPMS 7 years after initial diagnosis. Unable to work due to MS and he faced financial difficulties after the diagnosis of MS.   | Participant transitioned to SPMS 21 years after initial diagnosis. Before the MS diagnosis, she had a lot of close friends and family members that she saw regularly.  |
| <i>First interview</i>           | She expected to have transitioned to SPMS; it was not a surprise, but her neurologist was reluctant to diagnose transition to SPMS. Her condition has progressed a lot after the transition, especially her mobility, pain and fatigue. She was not sure whether anything could be done with SPMS. She had difficulties coping with the loss of control and uncertainty. | The SPMS diagnosis had not a significant impact on him as he had already lost everything he valued after his initial diagnosis. He reported a lack of sensations, trouble with thinking, very severe pain, tremor and diagnosis of depression. He knew that stress made his symptoms worse but could not do anything to control stress. | She did not expect to transition to SPMS and was shocked. She thought she had a relapse. She reported difficulties with mobility, fatigue and pain. She did yoga and meditation to manage her pain and has learned how to pace to manage her fatigue through workshops organised by her MS nurse. She had a positive outlook that helped her cope with MS. |
| <i>Second interview</i>          | Her pain and fatigue more severe compared to her first interview but mobility remained the same. She was diagnosed with another autoimmune condition and with depression. She felt low and isolated. She was worried about her other condition and was disappointed with the lack of support from health professionals on how to manage her conditions.                  | His fatigue and pain were more severe compared to his first interview, and he lost bladder control. Depression was still present. Feeling isolated and completely depleted of energy. He did not think there was any legal way to manage fatigue or pain or that anyone could help him.   | Her fatigue and pain were worse compared to her first interview, and she was not able to exercise anymore. She was diagnosed with another long-term condition. Her health care team always had good suggestions on how to manage her symptoms for both her conditions.   |



## Transition to secondary progressive MS

Table 5. Examples of self-management and changes over time

| Interview                        | P01  | P05   | P21   |
|----------------------------------|--|---|---|
| <i>Pre-transitioning Context</i> | She was diagnosed with SPMS from the start. Before the MS diagnosis, she had a higher managerial role, which she left after her diagnosis.   | He transitioned to SPMS 6 years after initial diagnosis. Before the MS diagnosis, his job taught him how to anticipate risks and plan accordingly.  | She transitioned to SPMS 23 years after initial diagnosis. Before the SPMS diagnosis, she was diagnosed with depression and other long-term conditions.   |
| <i>First interview</i>           | She reduced her activities, but she was OK with that. She had to change her goals to simpler more achievable ones. She did not need to see a psychologist to help her adjust. She would have liked to volunteer, but she could not commit to it.   | He planned meticulously so he can carry on his usual activities and attended MS self-management workshops. Keeping busy and planning helped him to deal with worries about the future. He was involved with MS charities and MS research to help others and also learn more about MS.   | She tried to plan everything but sometimes planning is too much and it is not worth the trouble. She wanted to exercise and see her friends more, but she was too busy with her health care appointments. She believed that you have to do things for yourself not wait for the scientists to find the cure.  |
| <i>Second interview</i>          | Her MS symptoms and severity progressed a lot compared to her first interview. She reduced her activities even further. Her neurologist referred her to see a psychologist, but she did not want to see one. She avoided seeing friends as they were shocked by her deterioration. She did not want to see health care professionals as it was a waste of hers and their time. | His MS symptoms and severity did not change compared to his first interview. He managed to do most of the things he used to do with some alterations or at a slower pace. He was still very happy with the support from his health care team and how effectively they referred him to appropriate specialists. He still enjoyed volunteering at the local MS centre and taking part in MS-related research. | Her MS symptoms and severity progressed little compared to her first interview. She had to do her research and find out what support is available and how to manage her symptoms and then she would seek the advice from the most appropriate health care professional. The help was not forthcoming. She was not feeling low because of MS but frustrated she could not do certain things. She reported very little social activities. |

Figure 1. Data analysis flow

Transition to secondary progressive MS

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46

For peer review only

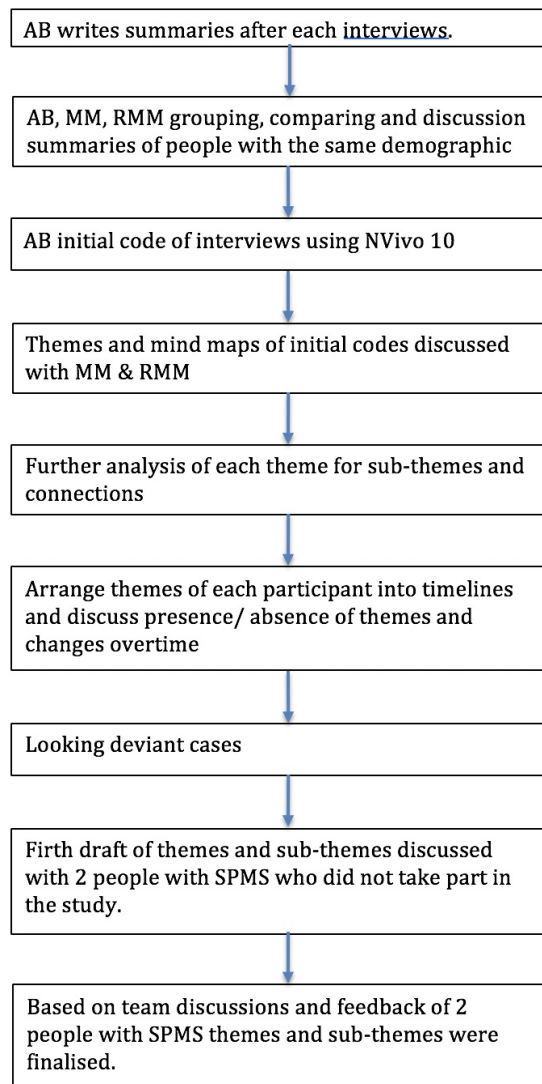


Figure 1. Data analysis flow

Figure 1. Data analysis flow

336x523mm (72 x 72 DPI)

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

| No. Item                                       | Guide questions/description                             | Reported on Page #   |
|--|---|--|
| <b>Domain 1: Research team and reflexivity</b> |   |  |
| <i>Personal Characteristics</i>                |   |  |
| 1. Interviewer/facilitator                     | Which author/s conducted the inter view or focus group? | Angeliki Bogosian<br><br>Page 9, line 165  |
| 2. Credentials                                 | What were the researcher's credentials?<br>E.g. PhD, MD | Angeliki Bogosian<br>PhD, Senior lecturer<br><br>Myfanwy Morgan<br>PhD, Emeritus<br>Professor<br><br>Rona Moss-Morris<br>PhD, Professor<br><br>Page 1 (title page) |
| 3. Occupation                                  | What was their occupation at the time of the study?     | Angeliki Bogosian<br>Research fellow<br><br>Myfanwy Morgan<br>Professor<br><br>Rona Moss-Morris<br>Professor<br><br>Page 1 (title page) &<br>7 (line 126-127)      |
| 4. Gender                                      | Was the researcher male or female?                      | Female<br><br>Page 9, line 165   |
| 5. Experience and training                     | What experience or training did the researcher have?    | Data analysis<br><br>Page 10, line 190-<br>198   |
| <i>Relationship with participants</i>          |   |  |

|   |   |   |
|---|---|---|
| 6. Relationship established                 | Was a relationship established prior to study commencement?   | Interviews<br>Page 9, line 161                    |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research                                  | Participants and methods<br>Page 8, lines 133-136 |
| 8. Interviewer characteristics              | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Interviews<br>Page 9, lines 164-169               |

|  |  |   |
|--|--|---|
| <b>Domain 2: study design</b>            |  |   |
| <i>Theoretical framework</i>             |  |   |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Data analysis<br><br>Page 10, line185   |
| <i>Participant selection</i>             |  |   |
| 10. Sampling                             | How were participants selected? e.g. purposive, convenience, consecutive, snowball   | Participants and Methods<br><br>Page 8, lines 143-144                             |
| 11. Method of approach                   | How were participants approached? e.g. face-to-face, telephone, mail, email  | Participants and Methods<br><br>Page 8, lines 129-133                             |
| 12. Sample size                          | How many participants were in the study?   | Participants and Methods<br><br>Page 8, line 149                                  |
| 13. Non-participation                    | How many people refused to participate or dropped out? Reasons?  | Participants and Methods<br><br>Pages 8 (lines 144-145) & 9 (line 159)            |
| <i>Setting</i>                           |  |   |
| 14. Setting of data collection           | Where was the data collected? e.g. home, clinic, workplace   | Interviews<br><br>Pages 9, line 163 & lines 172-173                               |
| 15. Presence of non-participants         | Was anyone else present besides the participants and researchers?  | Interviews<br><br>Page 9, line 173-174  |
| 16. Description of sample                | What are the important characteristics of the sample? e.g. demographic data, date  | Participants and Methods<br>Table 1<br><br>Pages 8 (line 151) & 9 (lines 152-155) |
| <i>Data collection</i>                   |  |   |

|  |   |   |
|--|---|---|
| 17. Interview guide                    | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Table 2, Patient & involvement, Interviews<br><br>Pages 7 (line 113) & 10 (lines 179-182) |
| 18. Repeat interviews                  | Were repeat interviews carried out? If yes, how many?                         | Participants and methods<br><br>Pages 9 (lines 157-159)                                   |
| 19. Audio/visual recording             | Did the research use audio or visual recording to collect the data?           | Interviews<br><br>Page 10, line 182   |
| 20. Field notes                        | Were field notes made during and/or after the inter view or focus group?      | Data analysis<br><br>Page 11, lines 211-214   |
| 21. Duration                           | What was the duration of the inter views or focus group?                      | Interviews<br><br>Page 9, line 164 & line 171   |
| 22. Data saturation                    | Was data saturation discussed?  | Participants and Methods<br><br>Page 8, lines 147-149                                     |
| 23. Transcripts returned               | Were transcripts returned to participants for comment and/or correction?      | Interviews<br><br>Page 10, line 183   |
| <b>Domain 3: analysis and findings</b> |   |   |
| <i>Data analysis</i>                   |   |   |
| 24. Number of data coders              | How many data coders coded the data?  | Data analysis<br><br>Page 10, lines 189-190   |
| 25. Description of the coding tree     | Did authors provide a description of the coding tree?                         | Table 3   |
| 26. Derivation of themes               | Were themes identified in advance or derived from the data?                   | Data analysis<br><br>Page 10, lines 185-186   |
| 27. Software                           | What software, if applicable, was used to manage the data?                    | Data analysis<br><br>Page 11, line 200  |
| 28. Participant checking               | Did participants provide feedback on the findings?                            | Patient and public involvement  |

|                                  |   |   |
|----------------------------------|---|---|
|                                  |   | Page 7, lines 123-124   |
| <i>Reporting</i>                 |   |   |
| 29. Quotations presented         | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Results<br>Pages 12-17, lines 221-341   |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings?  | Results<br>Pages 12-17, lines 221-341   |
| 31. Clarity of major themes      | Were major themes clearly presented in the findings?  | Results<br>Pages 12-17, lines: 216-220, 223-231, 240-244, 246-250, 255-258, 260-261, 264, 274-279, 282-289, 297-300, 308-314, 322-330 |
| 32. Clarity of minor themes      | Is there a description of diverse cases or discussion of minor themes?  | Results<br>Pages 12-17, lines: 231-233, 244-246, 262-263, 269-273, 314-315, 319-320   |