

PEER REVIEW HISTORY

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This paper was submitted to a another journal from BMJ but declined for publication following peer review. The authors addressed the reviewers' comments and submitted the revised paper to BMJ Open. The paper was subsequently accepted for publication at BMJ Open.

(This paper received three reviews from its previous journal but only two reviewers agreed to published their review.)

ARTICLE DETAILS

TITLE (PROVISIONAL)	Multiple challenges for people after transitioning to secondary progressive multiple sclerosis: a qualitative study
AUTHORS	Bogosian, Angeliki; Morgan, Myfanwy; Moss-Morris, Rona

VERSION 1 – REVIEW

REVIEWER	Freya Davies Cardiff University, UK
REVIEW RETURNED	02-Oct-2018

GENERAL COMMENTS	<p>Thank you for the opportunity to review this interesting paper. I enjoyed reading it. I hope the minor comments and requests for clarification here will be helpful.</p> <p>Page 5, line 12 - can you clarify that you mean 85-90% of people have RRMS at diagnosis (not prevalence)</p> <p>Page 5 - line 41 - can you clarify the reasons a lack of evidence based treatment leads to delayed diagnosis</p> <p>Page 5 - line 57 - at least one other qualitative study on the topic of transition to SPMS has been published (O'Loughlin et al 2017 doi: 10.1080/09638288.2016.1211760)</p> <p>Page 6 - line 43 - could you explain why a 5 year window was chosen</p> <p>Page 7 - line 12 - could you clarify if you mean age at initial diagnosis or at diagnosis of transition</p> <p>Participants and methods. Could you provide further details about recruitment - how did the process of recruitment and analysis overlap - when did each begin and end? What were the dates of the study period? Were all of the one year follow up interviews at exactly one year or was there variation in the interval between first and second interviews? Were the examples in the second interview guides personalised for each participant based on their previous interview - or were the examples based on experiences of others?</p>
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	<p>Data analysis - could you provide a coding tree to show how you moved from codes to refined categories?</p> <p>Results Arriving at the point of help - did the feeling that health services have nothing to offer relate only to medical treatment. Were there references to the benefits of physiotherapy or occupational therapy for example?</p> <p>Planning activities section - line 51 - could you make it clearer that you mean their inaccurate estimations of coping ability were seen at interview 1 and then disproved at interview 2</p> <p>Emotional regulation section - I wondered if this could be named differently? It seems only to include examples of negative or avoidant type strategies - but there are lots of positive examples of how people managed their emotions too described in the next section. Were any other more positive emotional regulation strategies mentioned?</p> <p>P17 - line 27 - typo - space in word participants and line 29 - should be rapport not report?</p> <p>Limitations section It would be useful to have more discussion about potential limitations of the recruitment methods selecting on the basis of self-report of transition up to 5 yrs ago, and how accurate recall might be after 5 yrs. Self-reported transition might not correlate with clinician-identified transition. People who are not aware of when their transition occurred may not be represented. It would also be useful to discuss the limitations of telephone interviews.</p> <p>Table 1 - it would be helpful to comment on the walking ability of participants and how that correlates with what might be expected (have you recruited a group with more walking difficulties than might be expected soon after transition?) Do you have any details about geographical spread of participants as services provided vary (may be very different in urban and rural settings)?</p> <p>Table 4 - two of the pen pictures suggest participants coping and adapting well to the transition with proactive attitudes- these descriptions don't seem to be as well represented in the main text.</p> <p>Figure 1 - data analysis flow - article suggest analysis started while recruitment ongoing - can you clarify how this fits in the timeline of the analysis</p>
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REVIEWER	Emanuele D'Amico University of Catania
REVIEW RETURNED	18-Oct-2018

GENERAL COMMENTS	<p>I have some concerns about this work. First I got confusion about the inclusion criteria of the enrolled population. Which classification criteria was used for defining a person as suffering from SPMS? Lublin criteria? Moreover, why it was used the cut off of five years? The literature about the transitioning phase has changed.</p>
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	I do not know if the paper in such status is suitable for an audience of MSologist.
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REVIEWER	Antonino Giordano San Raffaele Scientific Institute, Milan, Italy
REVIEW RETURNED	02-Nov-2018

GENERAL COMMENTS	The study has been conducted very precisely, but the aim does not emerge clearly from the manuscript. No answers to specific scientific questions have been given. The whole methodology seems pretty weak, no statistic methods have been adopted. Patients selection is unclear (e.g. no information about EDSS of the sample, which is the internationally accepted scale for disability in people with MS; moreover the term "progression" is too general: criteria followed to establish the diagnosis of SP-MS are various and there is no mention of which ones have been used by the clinicians and this can influence the results). Probably, the manuscript would fit better in a more "psychology-focused" journal.
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

- 1. Page 5, line 12 - can you clarify that you mean 85-90% of people have RRMS at diagnosis (not prevalence)**

The clarification is added, page 5, line 64

- 2. Page 5 - line 41 - can you clarify the reasons a lack of evidence based treatment leads to delayed diagnosis**

The lack of treatment could increase participants' anxieties, this brief explanation, has now been added, page 5, line 76.

- 3. Page 5 - line 57 - at least one other qualitative study on the topic of transition to SPMS has been published (O'Loughlin et al 2017 doi: 10.1080/09638288.2016.1211760)**

The O'Loughlin et al., 2017 paper has now been added in the introduction, page 6, lines 88-91

- 4. Page 6 - line 43 - could you explain why a 5 year window was chosen**

There are no guidelines as to what defines an early diagnosis period. Previous studies looking at psychological adjustment or interventions in chronic illness have included participants that have been diagnosed between 6 months-10 years (Dennison et al., 2010, Moss-Morris et al., 2013; Bleiker et al., 2000; Mehrabi et al., 2015) and defined that as early diagnosis. We considered 5 years to be soon enough after a diagnosis for the participants to be able to reflect on the effects of the diagnosis given but also long enough for participants to have started forming management strategies (page 7, line 106).

- 5. Page 7 - line 12 - could you clarify if you mean age at initial diagnosis or at diagnosis of transition**

That is the age at the time of the interview. The clarification has now been added, page 9, line 152.

Participants and methods.

- 6. Could you provide further details about recruitment - how did the process of recruitment and analysis overlap - when did each begin and end?**

The analysis was conducted in parallel with data collection (page 11, line 201), the analysis was finalised after all interviews were conducted this clarification is now added (page 11, line 202).

- 7. What were the dates of the study period?**

Dates of data collection have been added, page 9, line 170 and page 10, line 175.

- 8. Were all of the one year follow up interviews at exactly one year or was there variation in the interval between first and second interviews?**

There was some variation between first and second interviews and that is now described on page 10, 176-179.

- 9. Were the examples in the second interview guides personalised for each participant based on their previous interview - or were the examples based on experiences of others?**

the interview guide was personalised for each participant based on their previous interview. This clarification has now been added.

- 10. Data analysis - could you provide a coding tree to show how you moved from codes to refined categories?**

A coding tree has now been added on table 3

Results

- 11. Arriving at the point of help - did the feeling that health services have nothing to offer relate only to medical treatment. Were there references to the benefits of physiotherapy or occupational therapy for example?**

Physiotherapy was mentioned in some cases but always with the qualifier that what you get from NHS is very limited and it's expensive privately. This clarification is now added in the manuscript, page 13, lines 262-263.

- 12. Planning activities section - line 51 - could you make it clearer that you mean their inaccurate estimations of coping ability were seen at interview 1 and then disproved at interview 2**

This clarification has now been added, page 15, lines 287-288.

- 13. Emotional regulation section - I wondered if this could be named differently? It seems only to include examples of negative or avoidant type strategies - but there are lots of positive examples of how people managed their emotions too described in the next section. Were any other more positive emotional regulation strategies mentioned?**

The more positive strategies are the positive reframing that was mentioned in the section and we also added seeking support from the partners, which was also something frequently discussed in the interviews, see page 16, lines 311-313.

14. P17 - line 27 - typo - space in word participants and line 29 - should be rapport not report?

Typo is now corrected (page 19, line 391).

Limitations section

15. It would be useful to have more discussion about potential limitations of the recruitment methods selecting on the basis of self-report of transition up to 5 yrs ago, and how accurate recall might be after 5 yrs. Self-reported transition might not correlate with clinician-identified transition.

The limitations suggested by the reviewer have now been added to the limitation section, page 20, lines 401-405.

16. People who are not aware of when their transition occurred may not be represented.

This is true, but it was not added as a limitation of this study as the aim was to explore the experiences of people who knew they have been transitioned and how they manage with this knowledge. Therefore, experiences of people unaware of their transitioning to SPMS were beyond the scope of this study.

17. It would also be useful to discuss the limitations of telephone interviews.

Advantages and disadvantages of telephone versus face to face interviews are now discussed, page 20, lines 405-410.

18. Table 1 - it would be helpful to comment on the walking ability of participants and how that correlates with what might be expected (have you recruited a group with more walking difficulties than might be expected soon after transition?)

SPMS corresponds with more severe disability. A comment on disability expected with SPMS has now been added in the 'participants and methods' section, page 9, lines 154-157.

19. Do you have any details about geographical spread of participants as services provided vary (may be very different in urban and rural settings)?

We do have geographical details of participants. Participants came from a wide range of locations in the UK, including rural (small towns) and urban areas; therefore, accessing different services. This is now explained under the participants and methods section, page 8, lines 145-147.

20. Table 4 - two of the pen pictures suggest participants coping and adapting well to the transition with proactive attitudes- these descriptions don't seem to be as well represented in the main text.

Thank you for bringing this to our attention. More details about people attending self-management courses have been added under 'arriving at the point of no help' theme (page 14, lines 269-271), more details about planning ahead have been added under 'planning activities or scaling down activities' (page 14, lines 283-285), participation in MS research has been added under the 'being social, fitting in and being of use' theme (page 16, line 327).

21. Figure 1 - data analysis flow - article suggest analysis started while recruitment ongoing - can you clarify how this fits in the timeline of the analysis

Data collection and analysis overlapped, this has now been clarified, see response on comment 6.

Reviewer: 2

- 22. First I got confusion about the inclusion criteria of the enrolled population. Which classification criteria was used for defining a person as suffering from SPMS? Lublin criteria?**

Researchers of the study did not determine whether someone has transitioned to SPMS. Participants who self-reported that they had received a SPMS diagnosis from their neurologist or MS nurse were included. This clarification has now been added under participants and methods (page 8, line 136), limitations of this method of inclusion have also been added (page 20, lines 401-404).

- 23. Moreover, why It was used the cut off of five years? The literature about the transitioning phase has changed.**

Please see respond on comment 4, above.

Reviewer: 3

- 24. The study has been conducted very precisely, but the aim does not emerge clearly from the manuscript.**

The aims of the study were re-phrased to add more clarity and details, page 6, lines 99-101.

- 25. No answers to specific scientific questions have been given. The whole methodology seems pretty weak, no statistic methods have been adopted.**

This was a qualitative methodology study, the use of research hypotheses and statistical methods were not appropriate for a qualitative methodology design.

- 26. Patients selection is unclear (e.g. no information about EDSS of the sample, which is the internationally accepted scale for disability in people with MS**

Although, EDSS questionnaires were not completed in full, participants were only asked about walking ability (first subscale of the EDSS), which can indicate the EDSS disability score, which have now been added in table 1.

- 27. moreover the term "progression" is too general: criteria followed to establish the diagnosis of SP-MS are various and there is no mention of which ones have been used by the clinicians and this can influence the results).**

Please see response to comment 22.