The liminal self in people with Multiple Sclerosis: 
an interpretive phenomenological exploration of the experience of being diagnosed with Multiple Sclerosis

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Aim of the study

• The aim of this study was to explore the biographical impact of newly diagnosed Multiple Sclerosis (MS) on the individual and their support person(s) and how this impacts on how the person manages the transition to living with MS.
Research Questions

- What impact does a new diagnosis of MS have on how a person views the ‘self’?
- How has the onset of MS affected how the person goes about their daily life?
- How has MS affected close relationships?
- How have those affected by MS managed the physical and emotional changes during the transition to living with a confirmed diagnosis?
- What support have people found helpful / lacking?
- What are the experiences of MS nursing support and intervention from people with MS and their support person during the initial stages of being diagnosed?
## Participants

<table>
<thead>
<tr>
<th>PWMS Participant Identifier</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Support Person Participant Identifier</th>
<th>Pseudonym</th>
<th>Age Bracket</th>
<th>Relationship to PWMS</th>
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<tbody>
<tr>
<td>P1F</td>
<td>Julia</td>
<td>25</td>
<td>SP1M</td>
<td>Richard</td>
<td>25-30</td>
<td>Partner</td>
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<tr>
<td>P2M</td>
<td>Billy</td>
<td>35</td>
<td>SP2F</td>
<td>Jean</td>
<td>50-60</td>
<td>Mother</td>
</tr>
<tr>
<td>P3F</td>
<td>Ruth</td>
<td>42</td>
<td>SP3M</td>
<td>Brian</td>
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<tr>
<td>P4M</td>
<td>Steven</td>
<td>36</td>
<td>SP4F</td>
<td>Judy</td>
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<td>Partner</td>
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<td>P5F</td>
<td>Sheila</td>
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<td>SP5F</td>
<td>Maggie</td>
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<td>Mother</td>
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<td>P6F</td>
<td>Janice</td>
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<td>P7F</td>
<td>Lynne</td>
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<td>P8F</td>
<td>Lorna</td>
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<td>SP8F</td>
<td>Nic</td>
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<td>P9F</td>
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<td>Danny</td>
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<tr>
<td>P10F</td>
<td>Nancy</td>
<td>44</td>
<td>None</td>
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</table>
Methods of data collection

• Focus group interview with specialist MS nurses
• Interviews with person with MS and their support person
  – One soon after diagnosis
  – Follow up 6-12 months later
  – Interviews conducted individually or as couples
The qualitative research process

1. Literature review
2. Interview guide
3. Key issues from interview
4. Developing emergent themes
5. Looking for patterns
6. Developing conceptual framework

- Topic guide
- Analysis
- Analysis
- Interpretative phenomenological analysis
- Reflexive thoughts on process

- Focus group with nurses
- 1st stage interviews with PWMS & SP
- 2nd stage interviews with PWMS & SP
- Moving through each case
- Returning to the literature
- Discussing in context of existing knowledge
Key steps in Interpretative Phenomenological Analysis

- Descriptive analysis
- Linguistic analysis
- Conceptual analysis

(Smith, Flowers & Larkin, 2009)
Themes

• The three superordinate themes:

• “road to diagnosis”
• “the liminal self”
• “learning to live with MS: an uncertain future”.
Road to diagnosis

• “So I was never away from the doctors actually. I even took an AIDS test because I was that worried about what it was. And all of my blood tests were coming back negative, healthy. Blood pressure healthy everything was healthy yeah? And I was just looking for an answer and that’s why I took an AIDS test. Because I thought there must be something wrong with me.” (Steven, PWMS, int 1)
The liminal self

- “I don’t think I’ll ever be the same person I was kind of thing. You get stuff that you wouldn’t have thought anything about before. I mean MS I didn’t know what it was and you’ve now got all that experience. I mean I still try and be me kind of thing at the end of it but you still come across things that you never had before and find I can’t always do the same amount I used to do.” (Julia, PWMS, int 1)
The anticipatory carer

• “I have had to think about it from the point of view that I may, at some point, be in a position of being a central carer in Lorna’s life and that initially was a big mental shift. But then I had to think about well yes, but Lorna does what she can for herself now, so she's not there yet and she may never be there and if she is we'll support her to do as much as she can for herself.” (Nic, SP, int 1)
Learning to live with MS: an uncertain future

• “You don’t know what’s going to happen. There could be nothing for the next X amount of years or there could be something next week, you don’t know. So I think it would just be take it as it comes.”

(Janice, PWMS, int 1)
Conceptual framework: the liminal self in MS

- **Preliminal self**
  - Person with MS:
    - Knowing one’s body: knowing one’s self
    - Embodied experience: early encounter with symptoms
  - Common characteristics:
    - Road to diagnosis
    - Prior to diagnosis
    - Rites of separation
  - Support person:
    - Support person experience
    - A shared journey

- **Threshold concept: Being diagnosed**
  - Demarcation of the self as a person with MS
  - Threshold moment: Epistemological shift

- **The liminal self**
  - Stigma
    - A self disrupted
    - Rites of transition
    - Betwixt and between the selves
    - Ontological shift
    - Disruption to roles and relationships

- **The Post-liminal self**
  - Living with MS in daily life
  - Negotiating healthcare
    - Transformation of the biography of the self
    - Rites of reincorporation
    - Continued ontological shift
    - Uncertainty of future
  - Support for anticipatory carer

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Implications for practice

• Health care professionals involved in neurological clinics where the diagnosis of MS is usually given should consider highlighting in appointment letters that the person may wish to bring a support person with them to the consultation.

• Consideration needs to be given to how the diagnosis is communicated.

• Consideration should be given to the nature and amount of information that is given to people when early symptoms present which may indicate MS is present. Communication and consultation with the person are paramount in determining if they wish to have fuller explanation of the possible causes for their symptoms.

• Specialist services should consider the complement of participants in the programmes for newly diagnosed people e.g. Getting to Grips courses. Wherever possible participants should be attending with people who are experiencing similar levels of physical impairment.

• Health care professionals should consider providing a greater focus on living well with MS rather than waiting for symptoms.

• Psychological support should be readily available for people who are newly diagnosed and express a wish for support, regardless of physical symptom profile.

• Health care professionals need to consider the wider impact of MS for the support person, and consider their role in providing support, or being able to refer to additional sources of support.
Implications for further research

• The conceptual framework requires further exploration and refinement. In particular, a more longitudinal study may help to further illustrate the post-liminal experience.

• The concept of the anticipatory carer which was relevant to the support persons in this study would benefit from further research to add further depth of understanding into this lived experience.

• A similar study focusing on the experience of biographical disruption in fathers would be useful and would allow comparison with the experience of mothers in this study.

• An evaluation study to explore the usefulness of the framework for health care professionals involved in the care of people with MS should be undertaken.