



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Multiple Sclerosis Study Public Summary



Executive summary

Multiple sclerosis (MS) is a chronic neurological condition most commonly affecting young adults between 20 to 40 years of age [1]. It is an inflammatory demyelinating disease of the central nervous system (CNS) causing gradual degradation of myelin and transection of neuron axons in the brain and spinal cord via immune-initiated attacks [1]. This damage inhibits the capacity for parts of the CNS to communicate resulting in diverse symptoms [3]. In Australia, an estimated 23,000 people suffer from MS, with 1000 Australians being diagnosed annually, of which 75% are female [4].

Disease progression in MS is variable. In some individuals disease can develop rapidly into disability and in others it can be gradual [5]. Throughout the course of disease, MS patients are confronted with a number of decisions that affect disease maintenance and Quality of Life. With onset of symptoms patients must continually make decisions about treatment options. Clinician and patient communication is an integral component in clarifying treatment options, especially with female MS patients where some DMTs may be more suitable than others [12].

It is well established that patients who are informed about MS are more likely to take control of their own care, make educated decisions and adhere to treatment [13-15]. This study therefore aims to identify how behavioural and psychological aspects of decision-making influence treatment and care decisions.

Method

A literature review was conducted to develop an online questionnaire addressing the aim of this study.

To be eligible for the study, the participants had to be 18 years of age, have MS and be living in Australia.

Participants were recruited via Facebook and through email invitations. Participants completed the questionnaire in September/October 2015.

Participants

53 people with MS consented to participate in the online survey. 16 (30.2%) men and 37 (69.8%) women participated in the study, with most participants having Relapsing Remitting MS (n= 30, 56.6%).

56.6% of respondents stated that they primarily consulted their neurologist to discuss their MS management, while 30.2% stated that they primarily discussed management with their local GP and 13.2% stated 'other' such as the MS society or an MS nurse.

Key points

MS patients in our study commonly reported their current health as 'fair' to 'very good', while not expecting their health to be excellent and also expecting their health to get worse over time. Overall there were relatively few physical or psychological factors that drove participants to seek medical attention and the majority of responses indicated that participants are most likely to do nothing as a result of limitations. This suggests that there may be a need to improve the quality of patient/clinician communication and a need to investigate whether there is a gap in the information available to patients and/or the translation of information into practical applications for MS patients.

- The participants in our study rated both their ability to make decisions at different time points as fair to good, except for 'during remission' that was most frequently rated as good to very good. Motivation to make treatment decisions was most frequently rated as good, with the exception of 'during recurrence' where motivation was more frequently rated as fair. This suggests that in general there is a low level of confidence to make decisions.
 - There are many factors that were identified through the literature as being important to MS patients when making treatment decisions. In our study, the most highly rated and ranked factors tended to be those that focused on the outcome of treatment being effective, safe and tailored, rather than the mode of administration or how the decision was made.
 - The results of this study and others suggest that treatment decision-making for MS patients is a very personal one and less likely to be a shared decision with family members. The need for patient information and clinician/patient conversations that clearly articulate the side effects, safety and demonstrated efficacy are therefore particularly important to MS patients. This may give MS patients more confidence and motivation to engage in discussions about their treatment.
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Appendix 1: Study development

A literature search was conducted using all databases within PubMed to identify relevant topics and terminology as well as items and scales within existing instruments that could be used to measure key influences on treatment options for MS patients. The questionnaire development method used the basic principles for survey design suggested by de Vaus [13].

The search strategy was limited to articles published in the past five years between August 2010 and September 2015, in English, and included the combination of broad keywords “multiple sclerosis” and “patient” and “decision” and “clinician” and “neurologist” in the titles and abstracts of publications. This provided the initial database of articles for the review.

Two reviewers independently reviewed each article, evaluated the relevance of retrieved articles, and recorded the relevant items and findings of each study in a table. Reviewers recorded each article in a table for “inclusion” or “exclusion” based on defined criteria.

Articles were included that used a decision-making instrument or measured decision-satisfaction using a proxy indicator or provided a systematic review of how clinicians present options about treatment and the information patients themselves value or prefer in order to make treatment options. Articles were excluded where individual case studies were reported, and/or the study was not MS-specific, and/or the article did not provide information in relation to treatment decision-making and/or the article was not in English.

Data obtained from each single study were synthesised. The findings were sorted and used to identify existing items and to generate new items that addressed influences on decision-making for MS patients and clinicians.

A draft questionnaire was then tested in a sample of 10 patients. It was planned that items requiring explanation in more than 25% of the sample population would be removed.

Results

The literature review yielded 110 articles of which 76 were included for review. A complete list of articles is available at Appendix 3.

Articles were reviewed and classified according to the main theme within the publication. Nine themes were identified including adherence to treatment (n=5); caregiver considerations (n=1); clinician-driven issues and challenges (n=18); information needs (n=6);

economic considerations (n=6); patient-driven issues and challenges (n=19); patient/clinician communication (n=15); safety (n=2); and quality of life measures (n=4).

From these themes, four series of questions were identified including:

1. Identifying triggers or time points when MS patients consider discussing care or treatment options.
2. Identify and/or prioritise the importance that MS patients place on various clinician-led and patient-led decisions about treatment.
3. Identify a common definition of ‘a good day’ for an MS patient.
4. Identify MS patients’ ability/confidence and motivation to make treatment decisions at different time points.

Validated questionnaires relevant to MS were reviewed and items were selected from the SF 36, MFIS MOD and PDQ-5 questionnaires to address the four series of questions. Additional questions based on the literature were developed in relation to patient and clinician-led considerations when making decisions.

Testing

10 participants tested the questionnaire. As reported, questions that required an explanation more than 25% of the time were removed. As the majority of the questions were taken from validated questionnaires, only one question in relation to fear of making treatment decisions was removed.