

# THE INTERNET AND TREATMENT INFORMATION-SEEKING BY PEOPLE WITH MS

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## BACKGROUND

Access to timely and appropriate information is a critical component of informed decision-making for people with multiple sclerosis (MS) and may facilitate shared decision making between doctors and patients [1-2]. Yet, the unmet information needs of people with MS remain well documented [1, 3-4]. Much of this research has focussed on information needs at diagnosis, and patient-doctor communication issues, with the doctor as the central information provider. While specialists remain the preferred source for many, the Internet is rapidly becoming the primary information source for people with MS aged under 40 [5]. In fact, between 64%-82% of people with MS seek health-information online [5-6]. As the Internet has grown in prominence, and given the increasing array of therapies and interventions to manage MS, how has the information-seeking landscape changed?

## OBJECTIVE

To explore the experiences of people with MS in finding, assessing and integrating research-based health information from the Internet.

## METHOD

We conducted focus groups and an online discussion forum based on the focus group format.

## Participants

Participants, recruited via purposive sampling, had to be diagnosed with MS or a family member of a person with MS. 60 participants (47 females; 13 males, 51 people with MS; 9 family members) took part in either a focus group (27/60) or the online forum (33/60) (see Table 1).

## Procedure

Four focus groups, stratified according to time since diagnosis and participant type (people with MS or family member), were conducted in two metropolitan cities in Victoria and Tasmania, Australia. AS and SH facilitated the groups, which were audio-recorded and transcribed verbatim. An online forum, held over four weeks, was open to participants from across Victoria and Tasmania. Participants were provided with an anonymous user name and password. All participants provided written informed consent, following institutional ethics committee approval.

Focus group and online forum participants addressed the questions: (1) where do you get reliable information on the evidence of treatments for MS, (2) what kinds of information do you need, and how do these needs change over time, (3) how do you use the Internet to access information about treatments for MS, and (4) how do you assess the quality and usefulness of this information?

## Data Analysis

We analysed focus group and online forum transcripts using a phenomenological framework and grounded theory method. AS and KG independently read the transcripts and identified emerging themes, in consultation with SH. Agreed codes were categorised into themes using NVivo software. Keeping a research journal, engaging in multiple reads and using multiple researchers enhanced the trustworthiness of the analysis.

## RESULTS

### The Internet and...

While most participants described using the Internet to gain information about MS treatments, it was rarely used as the sole source. Most described integrating their Internet searching with information from health professionals, MS Societies and family and friends.

Participants described searching on the Internet for factual information about treatments, experiential information about treatments from other people with MS, or both. The main uses for the Internet were to (1) conduct pre-research before visiting a health professional or considering a treatment option, (2) "fill in the blanks" from information provided by another source (predominantly health professionals or MS Societies) and (3) connect with other people with MS.

### Too much information

Many described being inundated with information, not just information available online, but from the media, family and friends, health professionals and pharmaceutical companies. Some participants described reaching information overload.

*It is up to us to filter through and go with information that we are comfortable with (...) because we just get it thrown at us every day constantly.*

Focus group participant

*I reached a point of over-saturation. I snapped at the end of it because it was just too much information and just too overbearing to handle.*

Focus group participant

### Unbiased, up to date, personally applicable

Most participants expressed a strong desire for unbiased information from independent sources that was up to date and personally applicable to their circumstances. There were sceptical about the quality of information available online although the Internet was seen as an up to date source. Some said it was hard to find personally applicable information on the Internet.

*So much information out there is in the guise of a plug for some or other "cure", so it's not impartial.*

Online forum participant

*In general, MS is too complex and varies too much for each person for me to apply info[rmation] I find online to myself.*

Online forum participant

*These days I will use the Internet solely to read about any new breakthroughs in research.*

Online forum participant

### Pros and cons of the Internet

Participants described that searching for information online can often be overwhelming, confusing and sometimes scary. Some, but not all, participants described interactive websites such as forums and blogs as particularly negative. For others, the Internet was a vast, invaluable resource and they were confident in their ability to seek out high quality and meaningful information.

### Self-regulation of information

Participants described a range of information-seeking strategies to address their comfort levels with the amount of information they receive, their information preferences, attitudes about reliability and their attitudes towards the Internet. We term this concept self-regulation.

Self-regulation included strategies related to: volume of information (maximise sources, minimise sources), frequency of searching (high searching, infrequent searching or only in response to a new event or information), quality acceptability (only using trusted websites or comparative checking with Internet and non-Internet sources), content of information (factual versus experiential information or both) and using a delegated searcher (such as a family member or pooling information resources with other people with MS). A small number of participants had opted out of Internet use.

*I'm careful about the websites I go to, I only trial with the medical type ones or natural therapy type ones but not just any Joe Blogs, I just don't read any of that.*

Focus group participant

*I only fully trust the information I find after I have chatted to my neuro[logist], chatted to family and friends and find satisfactory findings, e.g. people's success stories.*

Online forum participant

*Now I tend to read new stuff to see if it applies to me and if it doesn't I will just put [it] in the back of my mind.*

Online forum participant

*I (...) try to seek information [online] on a fortnightly basis to minimise the effect on emotion and depression.*

Online forum participant

Table 1. Participant characteristics

	ALL PARTICIPANTS			ALL PARTICIPANTS			
	People with MS (n=)	Family members (n=)	TOTAL (n=)	Age in years (mean +/- SD)	Years with MS* (mean +/- SD)	Modified Disease Steps Score**	Internet use for MS health info
Focus groups	21 (16F:5M)	6 (5F:1M)	27 (21F:6M)	48.6 +/- 11.6 (median = 52) (range 27-66)	11.7 +/- 9.9 (median = 10) (range 1-39)	Mild = 11 (48%) Moderate = 10 (38%) Severe = 6 (14%) Unclassifiable = 0	Yes = 24 (89%) No = 3 (11%)
Online forum	30 (24F:6M)	3 (2F:1M)	33 (26F:7M)	51.1 +/- 12.3 (median = 52) (range 22-73)	11.1 +/- 9.1 (median = 7) (range 1-33)	Mild = 9 (26%) Moderate = 17 (50%) Severe = 4 (12%) Unclassifiable = 4 (12%)	Yes = 30 (91%) No = 3 (9%)

\*Participants with MS reported the year in which they were diagnosed with MS. Family members reported the year in which their family member with MS was diagnosed.

\*\*Participants with MS rated their own disease severity using a modified disease steps questionnaire[7]. Family members rated the disease severity of their family member with MS. 'Mild' equates to EDSS 0-1, 'Moderate' equates to EDSS 4-6, 'Severe' equates to EDSS 6.5-9 [7]. One online forum participant had two immediate family members with MS and gave separate scores for each.

## CONCLUSION

The Internet is an important source of information for many, yet equally scepticism exists about the trustworthiness of many websites. While invaluable to some for fact-checking and to connect with people with MS, it can also be overwhelming, scary and negative. Relating online information to personal circumstances was difficult for some.

People with MS and their family members are using a range of self-regulation strategies to filter information from the Internet and to integrate with other sources. The findings suggest that with the advent of the Internet the MS health information landscape has moved from unmet need to information overload.

## ACKNOWLEDGEMENTS

We gratefully acknowledge funding provided by Multiple Sclerosis Research Australia (MSRA) and Multiple Sclerosis Limited (MSL) ACT/NSW/VIC.

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