

Treatment information-seeking by people with multiple sclerosis in the Internet age: Stage 1 findings of the IN-DEEP project

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BACKGROUND

Multiple Sclerosis (MS) is an inflammatory disease of the central nervous system, commonly diagnosed in young adulthood, for which both a cure and the cause remain elusive. High quality information is vitally important for people with MS and their families to make informed decisions, solve problems and manage their health [1-2].

The IN-DEEP project (Integrating and deriving evidence, experiences and preferences: developing research-based health information applicable to decision making and self-management by people with MS) is a collaborative, four-stage, mixed methods project between two Cochrane Review Groups, each operating in partnership with consumers with MS and the Australian and Italian MS Societies. Here, we report on the results of Stage 1.

OBJECTIVE

To document and analyse the experiences of people with MS in finding, assessing and integrating research-based health information from the internet, along with personal preferences and values, to make decisions and manage their health.

METHOD

The IN-DEEP project is running in parallel in Australia and Italy. In both countries, we conducted focus groups and an online discussion forum.

Participants

Participants included people with MS and close family members (partner, parent, or adult child or sibling) of people with MS. A sampling frame was used with the aim of achieving a representative and broad sample of the MS population. Recruitment was conducted via the networks of the national MS Societies (Australia and Italy) and via neurologists (Italy). All participants provided written informed consent, following institutional ethics committee approval.

Procedure

In Australia, four focus groups were conducted in two metropolitan cities in Victoria and Tasmania. In Italy, six focus groups were conducted in metropolitan cities in northern, central and southern Italy. All focus groups were conducted by two experienced focus group facilitators, audio-recorded and transcribed verbatim. Each project team also held an online forum over four weeks. Participants were provided with an anonymous user name and password and invited to log in and post responses to a series of questions.

All participants were asked questions that addressed the following topics: (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 the transcripts using thematic analysis with NVivo software (Australia) and Atlas.ti software (Italy). In Australia, two researchers independently read the transcripts and identified emerging themes, in consultation with a third. In Italy, the facilitator read the transcripts and identified emerging themes, in consultation with the assistant facilitator.

RESULTS

Participant characteristics

In Australia, 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). In Italy, 60 participants (42 females; 18 males, 40 people with MS; 20 family members) took part in either a focus group (41/60) or the online forum (19/60) (see Table 1).

MS treatment information needs

Many Australian and Italian participants described searching for the latest information about currently available medications and those in clinical trials and other experimental therapies. Participants in both countries also identified complementary and alternative therapies and diet as two important information topics. While many Australian participants described looking for practical strategies that people with MS can use to manage symptoms, Italian participants described looking for information about how and where to access tests and treatments and how to read MS diagnostic tests.

Attitudes towards the Internet

The Internet was acknowledged by Australian and Italian participants as a vast and up to date resource, yet the amount of information was overwhelming for some. Many participants identified that they need a process to filter this information.

When you Google something, you try to filter it out, [it's] trial and error, and you might have a couple of hundred [websites] and you'll find that only two or three are relevant to anything, so you've got to learn how to just dismiss them.

Person with MS, Australian focus group

Participants in both countries were highly sceptical about the quality of health information online. Many expressed uncertainty about their ability to assess the quality of online health information and sought the assistance of health professionals or trusted MS organisations. On the whole, Australian participants were more confident information seekers.

The Internet and reliability

Participants identified a number of factors that help them to decide if the information they find online is reliable. Websites that are run by those not seeking economic gain (i.e. free of advertising and not funded by pharmaceutical companies), such as medical experts or other trusted groups, such as official MS organisations, governments and health organisations were identified as important by many.

I would only use official resources such as PubMed, MS Society website, etc. Drug company websites are probably the worst place to go to. Patients need unbiased information to make an informed decision.

Person with MS, Australian online forum

Australian participants who were confident information-seekers said that reliable information presents both the positives and negatives of treatments and therapies including scientific data. Similarly, Italian participants said that websites which provide links to source documents are a marker of reliability. Some Italian participants described that they trust their instincts to decide if a website is reliable, a concept not discussed by Australian participants. In both countries there was disagreement about the reliability about information provided by other people with MS on online forums and blogs.

Strategies to improve reliability

Australian and Italian participants identified a number of strategies they used to increase the reliability of the information they found online, such as only using 'trusted' websites, and cross-checking their information with health professionals. Australians participants identified more strategies than Italian participants. Italian participants in particular, described opting out of Internet use, particularly those living with MS for longer, and preferred to rely on health professionals, commonly their neurologist.

As time passed I researched more over the internet (...). I make final decisions after chatting to my neurologist and family/friends, checking the MS Australia website and also [deciding] what works for me and fits into my lifestyle.

Person with MS, Australian online forum

Awareness of The Cochrane Library

While not a central question of the research, only one Australian focus group participant thought they 'might have heard' of The Cochrane Library and one Italian focus group participant mentioned 'The Cochrane Foundation' as a source of reliable information.

CONCLUSION

Australian and Italian MS consumers have a desire for high quality, independent health information. Most consumers are highly sceptical about the quality of online health information, with many uncertain about how to assess this. Australian MS consumers described greater confidence in online health information-seeking and a greater number of strategies to improve reliability.

As health professionals and MS Societies are seen as reliable sources of information by many consumers with MS, their endorsement of health information websites (such as The Cochrane Library) is important. Partnerships with trusted MS organisations provide an opportunity to introduce consumers to Cochrane reviews.

TABLE 1. PARTICIPANT CHARACTERISTICS

	PwMS (n=)	Family (n=)	Age (mean +/- SD)	Highest educational level	Years with MS* (mean +/- SD)	Self-reported disability level**	Internet use for MS health info
AUSTRALIA	51 (40F:11M)	9 (7F:2M)	50.0 +/- 12 (median 52) (range 22-73)	Primary = 0 (0%) Secondary = 10 (17%) Diploma = 21(37%) University = 28 (45%) Missing = 1 (2%)	11.4 +/- 9.4 (median 8.5) (range 1-39)	Mild = 20 (33%) Moderate = 27 (44%) Severe = 10 (16%) Unclassifiable = 4 (7%)	Yes = 54 (90%) No = 6 (10%)
	Total = 60 (47F:13M)						
ITALY	40 (31F:9M)	20 (11F:9M)	43.2 +/-10.6 (median 43) (range 24-67) Missing = 3 (5%)	Primary = 15 (25%) Middle = 6 (10%) Secondary = 27 (45%) University = 11(18%) Missing = 1 (2%)	11.4 +/-9.5 (median 10) (range 0-36) Missing =1 (1.6%)	Median = 3** (range 0-9) missing = 5 (8%)	N/A***
	Total = 60 (42F:18M)						

* 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 disability level. Family members rated the disability level of their family member with MS. Italian participants completed the Expanded Disability Status Scale (EDSS). An EDSS score of 3 equates to 'moderate' disability level, but still ambulant[3]. Australian participants completed a modified EDSS, where 'Mild' equates to EDSS 0-3, 'Moderate' equates to EDSS 4-6, 'Severe' equates to EDSS 6.5-9[4]. One Australian participant had two immediate family members with MS and gave separate scores for each.

*** In Italy Internet use was an eligibility criterion to participate.

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