**TREATMENT INFORMATION-SEEKING BY PEOPLE WITH MULTIPLE SCLEROSIS IN THE INTERNET AGE: STAGE 1 FINDINGS OF THE IN-DEEP PROJECT**

**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 vital to 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, attitudes 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.

**METHODS**

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 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.ii 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**

Participants withMS rated their disability level. Family members rated disability level (0-3, “None” equates to EDSS 0-2, “Mild” equates to EDSS 3-4, “Moderate” equates to EDSS 4.5-6, “Severe” equates to EDSS 6.5-9 [4]).

**Participant characteristics**

In Australia, 60 participants (47 females; 13 males, 51 people with MS; 9 family members) took part in either a focus group (27/80) 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 (41/80) 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, [8%] 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.**

**Participant with MS, Australian focus group**

**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.**

**Participant with MS, Australian online forum**

**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.

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**REFERENCES**


