

Information-Seeking Strategies of People with Multiple Sclerosis in Spain: The INFOSEEK-MS Study

Yolanda Higuera¹Elisa Salas²Virginia Meca-Lallana³Pedro Carrascal Rueda⁴Ofir Rodríguez De la Fuente⁵Rosana Cabello-Moruno²Jorge Maurino²Miguel Ángel Ruiz Díaz⁶

¹Department of Neurology, Instituto de Investigación Sanitaria Gregorio Marañón, Madrid, Spain; ²Medical Department, Roche Pharma, Madrid, Spain; ³Department of Neurology, Hospital Universitario La Princesa, Madrid, Spain; ⁴Esclerosis Múltiple España, Madrid, Spain; ⁵Department of Neurology, Hospital Universitario Puerta de Hierro, Madrid, Spain; ⁶Universidad Autónoma de Madrid, Madrid, Spain

Purpose: Patients with multiple sclerosis (MS) are increasingly demanding access to reliable information regarding their disease. The objective of the INFOSEEK-MS study was to assess what are the strategies people with MS use when searching for information on their disease, including sources, frequency, reliability, and preferred content.

Patients and Methods: A non-interventional, cross-sectional study was conducted. Patients with a diagnosis of MS according to the 2010 McDonald criteria were included. The InfoSeek questionnaire was used to assess patients' strategies when seeking information about the disease. Clinical characteristics and other variables, including disability, quality of life, fatigue, cognition, anxiety and depression, were analysed using the Expanded Disability Status Scale (EDSS), Multiple Sclerosis Impact Scale (MSIS-29), 5-item Modified Fatigue Scale (MFIS-5), Symbol Digit Modalities Test (SDMT), and Hospital Anxiety and Depression Scale (HADS), respectively.

Results: Three hundred and two patients were studied (mean age: 42.3 ± 10 years, 64% female, mean disease duration: 9.6 ± 7.0 years, 90% with relapsing-remitting MS, and mean EDSS score: 2.6 ± 1.9). The internet (either via mobile or computer) is a frequently reported source of information. Lifestyle-related information (67.2%), research and emerging treatments (63.6%), symptom control (49.7%), sharing experiences with other patients (46.4%), and disease prognosis (46.4%) were the most searched topics. Neurologists and nurses were the most trusted source of information. Younger patients and higher SDMT scores were associated with all search resources ($M = 37.7$ and $M = 49.97$, respectively). The frequency of searches was related to the number of relapses ($R^2 = 0.07$), EDSS ($R^2 = 0.14$), MSIS-29 physical and psychological components ($R^2 = 0.132$) and inversely with depression ($R^2 = 0.132$).

Conclusion: Although healthcare professionals are considered the most reliable source of information for people with MS, searching for information on the Internet is very frequent. An individualized information strategy considering the different factors involved is needed.

Keywords: multiple sclerosis, information sources, internet, quality of life, healthcare professionals

Introduction

Multiple sclerosis (MS) is a chronic autoimmune and neurodegenerative disease of the central nervous system that mainly affects young adults.¹

The Pew Research Center conducted a survey among 3015 adults in the US in 2016 to explore how people approach facts and information.² Almost half of the participants (49%) were relatively disinterested and unenthusiastic about the information or the possibility of acquiring further training, especially in relation to digital information. Another 38% had relatively strong interest and trust in information sources and learning. Due to the heterogeneity of MS clinical presentation and

Correspondence: Elisa Salas
Medical Department, Roche Pharma,
Calle Ribera del Loira, 50, Madrid, 28042,
Spain
Tel +34 913248173
Email elisa.salas@roche.com

the unpredictability of the disease course, patients commonly turn to the Internet and social media to better understand their disease.^{3,4} It has been suggested how relevant it is to increase disease-related knowledge, since it is correlated with the decision-making process and better quality of life of people with MS.^{2,5,6}

The aim of the INFOSEEK-MS study is to evaluate the way people with MS search for information and the type and peculiarities of the information preferred by MS patients in Spain. We study other variables that may influence the information sources and search strategies.

Methods

INFOSEEK-MS is a non-interventional, cross-sectional study conducted at 18 hospital-based neuro-immunology units in Spain. Eligibility criteria included adult patients diagnosed with MS according to the 2010 revised McDonald criteria and an EDSS score of 0 to 6.0. Excluded patients were those unable to understand the study questionnaire in the investigator's opinion. The study consisted of a single visit for patient inclusion after signing the informed consent. It was conducted in accordance with the ethical principles of the Declaration of Helsinki and was approved by the institutional review board of the Hospital Universitario Gregorio Marañón (Madrid, Spain).

Design of the InfoSeek Questionnaire

A multidisciplinary research team of a neuropsychologist, two neurologists, an MS nurse, two research managers, a patient organization representative, and a psychometrician participated in the study design and the development of a specific questionnaire to characterize the information needs and preferred sources among MS patients.⁷ After literature review for content extraction and thorough conceptual discussion, a 17-item version of the self-reported InfoSeek questionnaire was proposed (See Figure 1),

containing 8 main dimensions: 1) MS information channels and search frequency, 2) MS resources frequency of use, 3) Activities related to MS management, 4) Type of information searched, 5) Clinical expert consultation frequency, 6) Involvement with patient groups, 7) MS topic relevance, and 8) Quality of information (see Appendix 1). The instrument was pilot-tested in 15 MS patients to assess acceptability, face validity, and item understanding.⁷

Outcome Measures

The primary outcome was to search strategies, information sources, and communication channels that MS patients use when seeking information about their disease through the InfoSeek questionnaire. The following variables were also assessed:

- **Disability:** The Expanded Disability Status Scale (EDSS) is a clinician-rated instrument to quantify and monitor changes in the level of disability over time.⁸ The EDSS ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability.
- **Cognition:** The Symbol and Digit Modalities Test (SDTM) is a screening tool to measure cognitive impairment, measuring the patient's attention, concentration, and speed of information.⁹ It is a 90-second cognitive test in which patients must quickly indicate the digits that correspond to rows of symbols based on a key of pairings between digits and symbols. Scores are established on the number of correct answers.
- **Fatigue:** The Modified Fatigue Impact Scale Five-Item Version (MFIS-5) is a brief, self-administered questionnaire for assessing the impact of fatigue on cognitive, physical, and psychosocial function during the past four weeks.¹⁰ The MFIS-5 scores each item on a 5-point Likert scale from 0 (never) to four (almost always). The total score ranges from 0 to

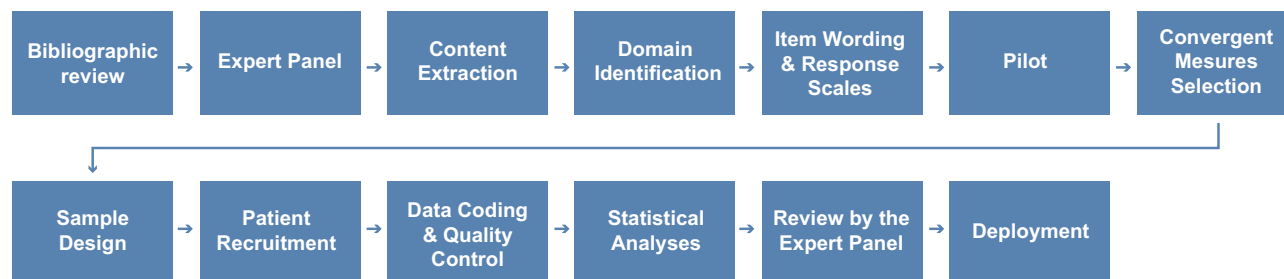


Figure 1 Scheme of the InfoSeek questionnaire construction and validation.

20, with a higher score indicating more severe fatigue.

- **Health-related Quality of Life (HRQoL):** The Multiple Sclerosis Impact Scale (MSIS-29) is a self-report questionnaire for measuring the impact of MS on people's lives, comprising two subscales: a 20-item physical impact and a 9-item psychological impact scale.¹¹ Items are rated using 4-point response categories: not at all, a little, moderately, and significantly. Scores on the physical and the psychological impact scale can range from 20 to 80 and from 9 to 36, respectively. Higher scores indicate a greater impact.
- **Mood and anxiety:** The Hospital Anxiety and Depression Scale (HADS) is a 14-items self-administered questionnaire that provides seven items related to anxiety and seven related to depression, the possible score range from 0 to 21 for either, and it is categorized into non-cases (0 to 7), potential cases (8 to 10), and probable cases (>10).¹²
- **Shared decision-making:** The 9-item Shared Decision-Making Questionnaire (SDM-Q-9) is a self-assessment tool for measuring patients' perceived level of involvement in decision-making related to their treatment and care.¹³ The SDM-Q-9 scores each item on a 6-point Likert scale from 0 (completely disagree) to five (completely agree). The raw total score ranges from 0 to 45. A linear transformation of the scale should be done to obtain a range from 0 to 100, with higher values indicating a greater extent of shared decision-making.

Statistical Analysis

An overall description is made for the variables included in the study. Absolute and relative frequency distributions of qualitative variables are presented, as well as measures of central tendency and dispersion (mean, standard deviation, median, minimum, and maximum values) of quantitative variables. Ninety-five percent confidence intervals (CI) are presented for the main quantitative variables of results associated with the primary objective and the main secondary variables. T-Tests are used to compare means for pairs of independent groups on quantitative variables and ANOVA for more than two groups.

Cluster analysis was used to identify profiles within parcels of dichotomous items, like for type of resource used to access the internet. To assess whether different internet resources were used differently by patients to search for information on MS, and exploratory factor

analysis was carried out with questions corresponding to the frequency of information search in each resource. Linear regression models were used to identify predictors of internet resources usage.

The sample size was determined by the number of items included in the InfoSeek questionnaire (10–20 items). The psychometric literature recommends a minimum of 4 to 15 subjects per item in the questionnaire.¹⁴ In our case, a maximum length of 20 items has been settled, and a sample size between 80 and 300 subjects would be recommended; it was also deemed necessary for a sample composed by 150–300 individuals to obtain solid estimates of item loadings, item variances and covariances, and the structural solution.¹⁵

Results

A total of 302 patients were included. Socio-demographic and clinical characteristics of the participants are shown in [Table 1](#).

Internet Use

Only 2.6% of participants did not have access to or did not use the Internet. The most frequent access types were mobile phones (86.1%) and personal computers (PC) (79.1%), while 11.9% used public sites. Twenty-two percent of participants did not use the Internet for MS related topics, and from those who did, a 39.1% consulted yearly, 22.8% monthly, 11.9% weekly, and 3.3% daily.

Information Sources

Two types of information sources used for the search of MS were explored: the first related to the use of the Internet and the second to healthcare professionals consulted. Concerning the first one, 17.2% of MS patients did not use any source, while the other 82.8% used between one and eight, being one source (23.5%) and two sources (24.2%) the most common. Sources more frequently used for MS information were browsers (70.9%), social networks (37.4%), and patient association web pages (38.4%). Fewer patients used discussion groups or forum (23.5%), newsletters (21.5%), pharmaceutical web pages for patients (10.9%), and online communities (10.9%). Additionally, 9.6% manifest to use other sources for gathering information about MS.

Regarding the frequency of use, general web-searchers were used monthly or yearly (57%) by most patients followed by daily/weekly (13.9%), while 29.5% never used them. For the rest of the sources, such as online communities, social networks, discussion forums or patients' organizations, the most common frequency

Table 1 Sociodemographic and Clinical Characteristics

(N=302)	Value
Age: mean (SD)	42.3 (10.1)
Sex, female: n (%)	194 (64.2)
Years since diagnosis: mean (SD)	9.6 (7.0)
Disease: n (%)	
Relapsing remitting	273 (90.4)
Primary progressive	13 (4.3)
Secondary progressive	16 (5.3)
Education: n (%)	
Primary education	43 (14.2)
Secondary education	110 (36.4)
Higher education	112 (37.1)
Unknown	37 (12.3)
Marital Status: n (%)	
Single	83 (27.5)
Married	150 (49.6)
Divorced	17 (5.6)
Widowed	2 (0.7)
Other	2 (0.7)
Unknown	48 (15.9)
Living Condition: n (%)	
Alone	28 (9.3)
With couple	176 (58.3)
With family	41 (13.6)
Other	5 (1.7)
Unknown	52 (17.2)
Working Status: n (%)	
Employed	137 (45.4)
Unemployed	44 (14.6)
Retired	11 (3.6)
Disabled	40 (13.3)
Other	23 (7.6)
Unknown	47 (15.6)
Relapses: mean (SD), n=283	3.6 (3.8)
Relapses last year: mean (SD)	0.3 (0.4)
Disability: mean score (SD), n=299	
EDSS	2.6 (1.9)
Cognition: mean score (SD), n=302	
SDMT	44.0 (12)
Fatigue: mean score (SD), n=299	
MFIS-5	49.0 (27.8)
Health-related Quality of Life: mean score (SD), n=300	
MSIS-29	
Physical component	31.7 (27.2)
Psychological component	37.1 (27.7)

(Continued)

Table 1 (Continued).

(N=302)	Value
Mood and anxiety: mean score (SD), n=301	
HADS	
Anxiety component	8.1 (3.2)
Depression component	8.4 (2.1)
Patient-Physician Relationship: mean score (SD), n=300	
SDM-Q-9	78.0 (23.4)
Under DMTs: n (%)	267 (88.4)
Number DMTs: mean (SD)	1.85 (1.10)

Abbreviations: DMTs, Disease Modifying Therapies; EDSS, The Expanded Disability Status Scale; HADS, Hospital Anxiety and Depression Scale; MFIS-5, Modified Fatigue Impact Scale 5-Item version; MSIS-29, Multiple Sclerosis Impact Scale 29-Item; N, total of patients; n, number of responders; SD, standard deviation; SDM-Q-9, 9-item Shared Decision-Making Questionnaire; SDMT, Symbol Digital Modalities Test.

participants informed was “not use them at all” (between 61.6% and 89.1%), while those using them reported monthly or yearly frequency most commonly (7.6–27.1%) (See Figure 2).

Related to the specialized sources rated with at least sufficient quality, the most consulted is the one offered by the neurologist (100%), followed by a nurse (67.4%), an ophthalmologist (40.2%), online information (44.9%) and psychologist (36.9%). Less consulted were patients' organizations (25.2%), rehabilitation physicians (23.9%), physiotherapist (21.6%), and other MS patients or support groups (20.6%). Likewise, around 22% of MS patients received or had access to a specialized periodical publication, although the 78% did not consult them.

Type of Information Searched

The results showed that most of the participants searched for three (12.6%) and four (10.6%) different topics about MS. It is worth pointing out that 12.9% of participants indicated that they searched no topics at all.

The most consulted topics were as follows: information about healthy habits (67.2%), new treatments and MS research (63.6%), symptom control (49.7%), other patient experiences (46.4%), and disease prognosis (46.4%). The most frequent periodicity for refreshing information is once a year (13–31%) and monthly (10–21%), depending on the topic. In relation to this search frequency, topics most recently updated with daily searchers were healthy habits (6%), social experiences from other patients (4.6%), new treatment options (4%), and

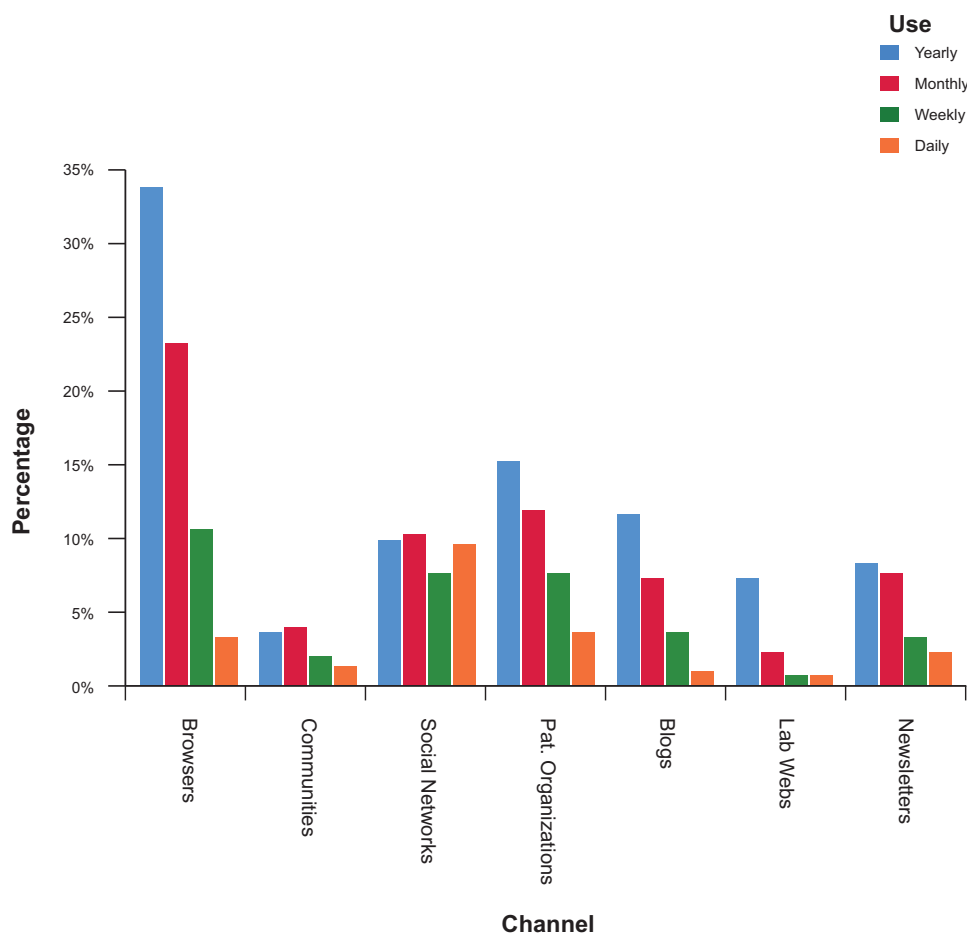


Figure 2 Internet channels frequency of use for multiple sclerosis information search (never used excluded).

psychological health management (2.6%) (See [Figure 3](#)). However, the most frequent option was not to seek information, ranging from 36% for seeking new treatments to 68% for administrative procedures and 71% for opinions about existing treatments. Reasons for not searching for any information about the disease ($n = 176$) were not finding reliable information (36.4%) and not wanting to know more about the condition (30.7%). Some delegated on other family members (9%) or could not find what they needed (8%) in scarce cases.

Importance of the Information

Quality of life (81%), emerging treatments and research (79%), current treatments (75%), disease progression (64%), disease prognosis (56%), physiotherapy (55%) and symptom control (52%) were the most relevant topics.

Information Reliability

Resource reliability was a relevant aspect for almost half of patients, usually searching for different sources to increase reliability (49%) or not using sources they would not

consider reliable (44%). Participants were rated as “excellent quality information”, the information provided by neurologists (66.6%), followed by nurses (38.7%) and psychologists (19.2%). Online information was only rated as “sufficient” by 25.8% of the participants (see [Figure 4](#)).

Patient Organizations

Approximately one in five participants (22.5%) regularly attended a patient organization. These people ($n = 67$) sought to improve their quality of life (70%), use physiotherapy services (63%) and psychological support (49%). Other less frequent reasons were seeking information about the disease (36%), awareness and advocacy (28%) and help in finding a job (13%).

Lack of awareness of the services offered and the fear of encountering people with severe disability were the main reasons not to turning to patients' organizations ($n = 231$). Half of the participants consulted would like to engage in self-support groups online and 33% in person, while 31% do not manifest to have interest in these activities.

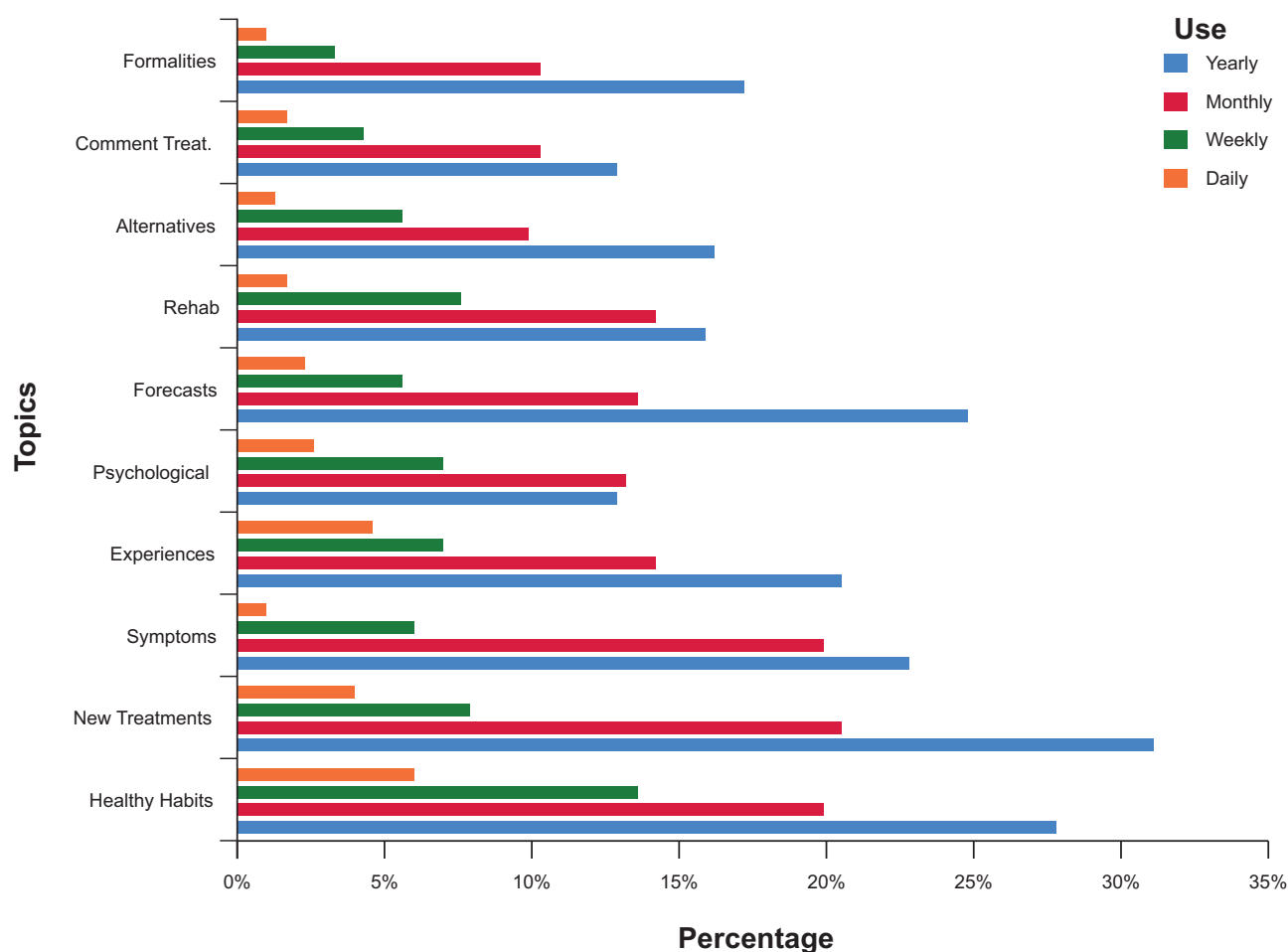


Figure 3 Frequency of use on different multiple sclerosis topics.

Healthcare Support

Ninety-nine percent of participants were managed by a neurologist, and 57% were also seen by general practitioners. In 62% of cases, a telephone or e-mail service was available to patients at the health service they visited. More details are summarized in [Table 2](#).

Relationship Between Patient Characteristics and Information-Seeking Strategies

Internet Access and Use

Five different patterns have been identified concerning access to the Internet: a) 58% use all available resources simultaneously, including public access, b) 17% only use mobile phone, c) 10% only use PC, d) 10% use mobile and PC indistinctively, and e) 4% did not use Internet at all.

Age

There was a relationship between age and the type of

Internet access ($F = 5.17$, $p < 0.001$). The group that did not use the Internet was older ($M = 49.7$) but similar to those using only PC ($M = 46.3$). Those using all the available methods were younger ($M = 37.3$) but only differed from those who barely used it. Possibly due to the mediating effect of age, a similar pattern was found for disease duration.

Relapses and Disability

The number of relapses was not statistically related to the type of Internet access, with the only difference of a single case with four relapses and not using the Internet. There was no relation between the Internet access and the EDSS score ($F = 1.26$, $p = 0.287$).

Emotional Status, Quality of Life, and Fatigue

The type of Internet access was not related to other health indicators: anxiety ($p = 0.199$), depression ($p = 0.449$), health-related quality of life ($p = 0.488$), mental component ($p = 0.184$), and fatigue ($p = 0.725$).

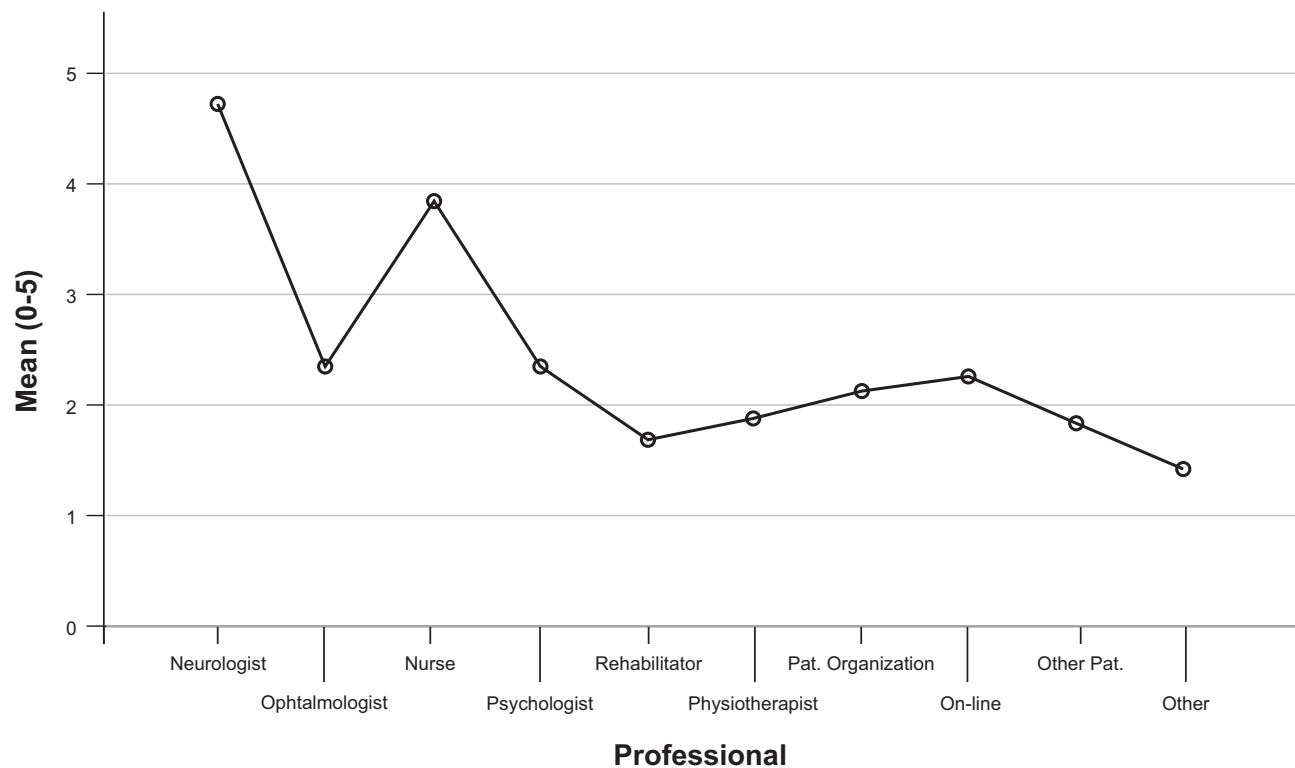


Figure 4 Average quality attributed to different specialized sources.

Cognition

We found statistically significant differences in mental processing speed as measured by the SDMT between usage profiles ($F = 13.59$, $p < 0.001$), although all groups scored above the cut-off point on average. The group that did not use the Internet scored lower on the SDMT ($M = 30.9$). Those using only mobile phone ($M = 38.0$) or PC ($M = 41.6$) had similar scores, and those using all available resources scored higher ($M = 49.97$).

Older age ($p = 0.005$) and longer disease duration ($p = 0.020$) were associated with not using the internet for information seeking. Physical ($p = 0.033$) and psychological ($p = 0.017$) components score of the MSIS-29 and MFIS-5 score ($p = 0.042$) were associated with information seeking.

Type of Resources and Frequency of Use

Two clusters of information resources were identified with relatively high correlation ($r = 0.469$). The first cluster grouped specialized resources (patient webs, on-line communities, discussion boards, patient associations) and the second one grouped more general resources (search engines, social networks, and general internet).

The variables that were associated with the most frequent use of specialized resources were the number of relapses ($p = 0.0039$, $R^2=0.06$), and the physical component score of the MSIS-29 ($p < 0.001$, $R^2=0.084$). On the other hand, the predictor variables for the frequency of general resource use were the number of relapses ($p = 0.010$, $R^2=0.07$), EDSS score ($p = 0.022$, $R^2=0.14$), MSIS-29 physical ($p = 0.004$, $R^2=0.132$) and psychological components scores ($p = 0.022$, $R^2=0.132$) and with negative sign depressive symptoms ($p = 0.022$, $R^2=0.132$).

Discussion

The INFOSEEK-MS study allowed us to gather data about search strategies, information sources, and communication channels that MS patients usually use when seeking information on their health condition using the *ad-hoc* InfoSeek questionnaire. We found that, in a representative sample of MS patients in Spain, they frequently used the web to search. The majority utilized both a mobile phone and a PC to access the web less than once a month. Interestingly, 13% of participants declared they searched nothing about MS on the web; the reasons were their feelings about the lack of reliability of website information and/or the lack of

Table 2 Healthcare Support

(N=302)	n (%)
Medical assistance	
Neurologist	300 (99.3)
Biannually	176 (58.6)
Quarterly	89 (29.8)
General practitioner	172 (57.0)
Yearly	33 (19.2)
Nurses	150 (49.7)
Biannually	22 (14.9)
Quarterly	21 (14.2)
Ophthalmologist	141 (46.7)
Yearly	54 (38.1)
Psychologist/Neuropsychologist	103 (34.1)
Yearly	11 (11.3)
Physiotherapist	96 (31.8)
Monthly	16 (16.6)
Other health professional	44 (14.6)
Interested in disease details	
Patients prefer to make the questions	190 (62.9)
Patients prefer being interrogated by health-providers	99 (32.8)
Patients prefer not to receive information	7 (2.3)
Patients prefer to search their own information	4 (1.3)
Not responders	2 (0.7)
Telemedicine (n=292)	
Access	187 (64.0)
Not Access	105 (36.0)
Call service usefulness, mean (SD) (n=183) (scale 1–10)	8.5 (2.1)

Abbreviations: N, total of patients; n, number of responders; SD, standard deviation.

interest to know more about MS. This aspect must raise a red flag about data quality on the web and lead professionals toward reliable website-sharing resources. An excellent example is the creation of SMsocialnetwork.com, a medically supervised Italian web community that filters the quality of information.¹⁶ Lavorgna et al reported that patients found this resource very useful because they found only verified medical information and helped participants to better cope with health-related problems.^{16,17}

Regarding the contents of the search, our patients focused on healthy habits, information about new treatments and how to deal with MS symptoms. These results are in line with those previously published.^{5,18–20} Brigo et al assessed search behaviour associated with the term MS in English-speaking countries using Google Trends.¹⁹ Most searches were related to causes and symptoms, and most peaks in search volume corresponded to news of celebrities having MS.

Based on the type of Internet access, we defined five groups. There was a relationship between age, Internet access and disease duration, being the youngest and fewer years from diagnosis who used all types of access (mobile and PC) and the oldest and longer years from diagnosis those who did not use Internet or only use PC. The type of Internet access was related to cognitive status. Those with higher SDMT scores used all resources for searching, whereas those with lower scores did not search the Internet. A predictive model based on frequency of use of information resources showed that patients with higher disease progression (number of relapses, EDSS score) tend to use resources more frequently. Patients with a greater impact on their quality of life (either physical or psychological) tend to search for information more frequently, except for subjects with a higher degree of depression, who tend to search less frequently.

Participants consulted an MS professional, almost all of them with a neurologist and at least twice a year. When they did, 32.8% did not ask questions and prefer the medical team to inform them about the disease. Out of the neurologist consultancy, most patients had another way to contact their medical group (ie, e-mail and/or telephone line), perceived as a helpful resource. Only a quarter of the participants visited patients' organizations regularly.

Although most people today use the Internet as a source of health information, people with MS considered the neurologist offers excellent quality information and were concerned about the reliability of the data obtained in other ways. When asked about the importance they provide to specific topics, the most relevant was quality of life, following current and future treatments for MS and how to deal with the disease. Similar findings were found by Chi et al²¹ where laypeople searched for information about MS on the web only if they considered the data had a low impact on their lives, otherwise they still trusted healthcare professionals to get information with a high impact.

This study has limitations inherent to its observational design. However, to reduce selection bias and to have a representative sample, the patient's inclusion was consecutive and unselected in neurology units throughout Spain. Although the sample size was reached, not all patients provided complete information on all the study questions and variables. The treatment of missing values by pairwise comparison made it possible to take advantage of the maximum information available in each analysis. The INFOSEEK-MS study is the first approach on information preferences for MS patients in Spain, and further research is needed.

Conclusions

The INFOSEEK-MS study showed that healthcare providers are the first and most trustworthy source of information and the Internet is a widely used tool by the MS population in Spain. Multidisciplinary teams managing MS should be involved in ensuring quality and truthful content on the internet and networks. Individualized information given by healthcare professionals may help patient's management of the disease.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in

drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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