Review article

Online information search by people with Multiple Sclerosis: A systematic review

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ABSTRACT

Background: People with Multiple Sclerosis (pwMS) search for information online about various aspects of living with their disease, but details about patterns of searching and outcomes are unclear. This means that opportunities to leverage online resources to support pwMS, and to enhance shared decision making, may be missed. We aimed to do a systematic review of the literature on digital information searching by pwMS.
Methods: We performed a systematic search for studies assessing online information seeking of pwMS in MEDLINE and JSTOR databases. Studies were screened and selected by two investigators. All study designs were included, risk of bias was assessed using the Critical Appraisal Skills Programme qualitative checklist. Reports were assessed for the proportion of patients searching information online about MS, type of information sought, online tools used by patients, perceived quality of the information acquired, and impact of online searching in pwMS.
Results: We identified 5 studies, including 10,090 patients. Most pwMS search for information online (53.8–82 %), which they rarely discuss with physicians. The most common topics are treatment, general disease information, symptoms, lifestyle recommendations, prognosis, and coping strategies. Patients that are younger, have a shorter disease duration, primary progressive MS, and during periods of disease worsening, are more likely to use online resources. Online information is perceived as low quality by pwMS.
Conclusions: Online information search is prevalent among pwMS. Despite concerns with the quality of the available information, only a minority of pwMS will discuss the information found with their physician. These findings highlight the importance of developing and providing quality online information resources for pwMS.

1. Introduction

Multiple Sclerosis (MS) is a chronic inflammatory disorder of the central nervous system most commonly diagnosed in young adults. MS can lead to accrual of disability over time, be it through relapses or through progression independent of relapse activity (Dobson and

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Giovannoni, 2019; Lublin et al., 2022; Thompson et al., 2018a, 2018b). Over time, people with MS (pwMS) may experience different and evolving symptoms, and be faced with questions about various aspects of their disease, including symptoms, diagnosis, disability coping strategies, psychological support, family planning, working and MS, physiotherapy, treatment and/or prognosis (Forbes et al., 2007; Hepworth and Harrison, 2004).

While these questions may be addressed in appointments with general practice physicians, neurologists, MS specialists, or specialist nurses, the frequency of opportunities to contact these professionals depend on the health-care setting (Matti et al., 2010). Furthermore, shared decision making, patient empowerment, and patient and public involvement are valuable growing concepts that require the patients' understanding of complex health information and access to reliable sources. They also serve to bridge the gap between patients and knowledge on their condition (Aboumatar et al., 2013; Frosch and Kaplan, 1999; Greenfield et al., 1985).

Recently, some ruling agencies, such as the National Institute for Health and Care Excellence (NICE) in the United Kingdom, have recommended that doctors should direct pwMS to online resources (National Institute for Health and Care Excellence, 2022). Online resources may be an extremely useful tool for patients to become more informed about MS, and thus more engaged and active on the management of their disease. Nevertheless, information on what pwMS look for in online sources, how they search, the quality of online sources, and how this search impacts their well-being is currently spread across a wide range of unconnected studies, which have yet to be integrated. This means that opportunities to assist pwMS using online resources may be overlooked. We aimed to do a systematic review of the literature to summarise current knowledge on online information use by pwMS, and to identify gaps of knowledge in this area.

2. Methods

2.1. Eligibility criteria

We included studies describing online information seeking behaviour in pwMS. All study designs were accepted. PwMS were defined pragmatically according to local MS criteria or standard McDonald criteria at the time of inclusion in the study. Studies were excluded if they included participants other than pwMS and data were not reported separately for the MS subgroup of participants; or if the full-length report was written in a language other than English, French, Portuguese, or Spanish.

2.2. Outcomes

The review focused on the online information search behaviours of pwMS, and associated outcomes. This included: estimation of the proportion of patients that search for information online on MS (versus patients who don't search for information or use other offline search methods), type of information that patients seek, choice of online tools, perceived quality and trust of the search findings, and impact on patient's well-being. Additionally, we aimed to identify demographic or clinical characteristics of pwMS that influence their online searching behaviour, as these have been shown to significantly impact health-related online information searching in other contexts (Li et al., 2016). As we sought to include all types of study designs, we expected a high degree of heterogeneity of the available outcomes for each included paper.

2.3. Information sources, search, selection, and collection strategies

We searched MEDLINE and JSTOR from inception until December 2022. In addition, reference lists from identified records were manually cross-checked for any further potentially eligible studies. Due to the expected high heterogeneity between studies, the research strategy developed for all databases was inclusive, and combined the terms: 'multiple sclerosis' and ('internet' or 'online information' or 'digital information' or 'social media'). Titles and abstracts yielded by the search were independently screened against the inclusion and exclusion criteria and full text reports were analysed for inclusion by two reviewers (DB, MLR). Disagreements were solved by consensus or by another reviewer. The motives for exclusion at this stage were recorded. Data were collected onto a previously piloted spreadsheet, considering the defined outcomes.

2.4. Risk of bias assessment

As this review focuses on studies with varying designs and settings, risk of bias was assessed using the Critical Appraisal Skills Programme (CASP) (2018) tool (Critical Appraisal Skills Programme 2018, Accessed: 03.03.2023). All included studies were independently assessed by two raters (DB, MLR) and disagreements were solved by consensus between the authors.

2.5. Additional details

This systematic review is reported according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 statement (Liberati et al., 2009; Page et al., 2021). Data extracted from included studies and used for analyses can be made available upon request.

3. Results

3.1. Study selection and characteristics

The electronic database search yielded 1347 records, of which 17 full-text records were reviewed according to the flowchart presented in Fig. 1. Another 2 records were identified from manual checking of reference lists. After full-text analysis, we included 5 studies in the review, comprising a total of 10,090 patients (Hay et al., 2008; Higueras et al., 2022; Lejbkowicz et al., 2010; Marrie et al., 2013; Potemkowski et al., 2019).

The 5 selected studies assessed online information search by pwMS. Table 1 summarises the main characteristics of each study, including study design, patient demographics, diagnosis, and outcomes assessed in each study. Two studies were conducted in North America (Hay et al., 2008; Marrie et al., 2013), one in Israel (Lejbkowicz et al., 2010), and the remaining two in Europe (Poland, Potemkowski et al. 2019 and Spain, Higueras et al. 2022). One study was based on semi-structured interviews, and the remaining ones on self-completion questionnaires. Sample size varied between 65 and 8586 patients, and although most included patients with an established diagnosis of MS (mean or median disease duration or time since diagnosis between 7.1 and 18.1 years), one study focused on newly diagnosed patients (median time since diagnosis of 0.2 years). Age at time of inclusion in the study and proportion of female patients were similar across studies, and followed the expected demographics of an MS population sample. Most studies did not mention ethnicity of their population; though, in the study by Marrie et al. (2013), most patients were identified as White (95 %). Level of education of participants was assessed in all studies, which reported a prevalence of higher education ranging between 37.1 % and 81 %. Additionally, annual income information was also assessed in the two American studies, which found 14.3 % and 34.4 % of the participants had a high income (> \$100,000/year). Two of the studies did not report MS phenotype; on the remaining, relapse remitting phenotype was the most common diagnosis (38.8–90.4 %), followed by secondary progressive (5.3–37.5 %) and primary progressive (4.3–23.7 %).
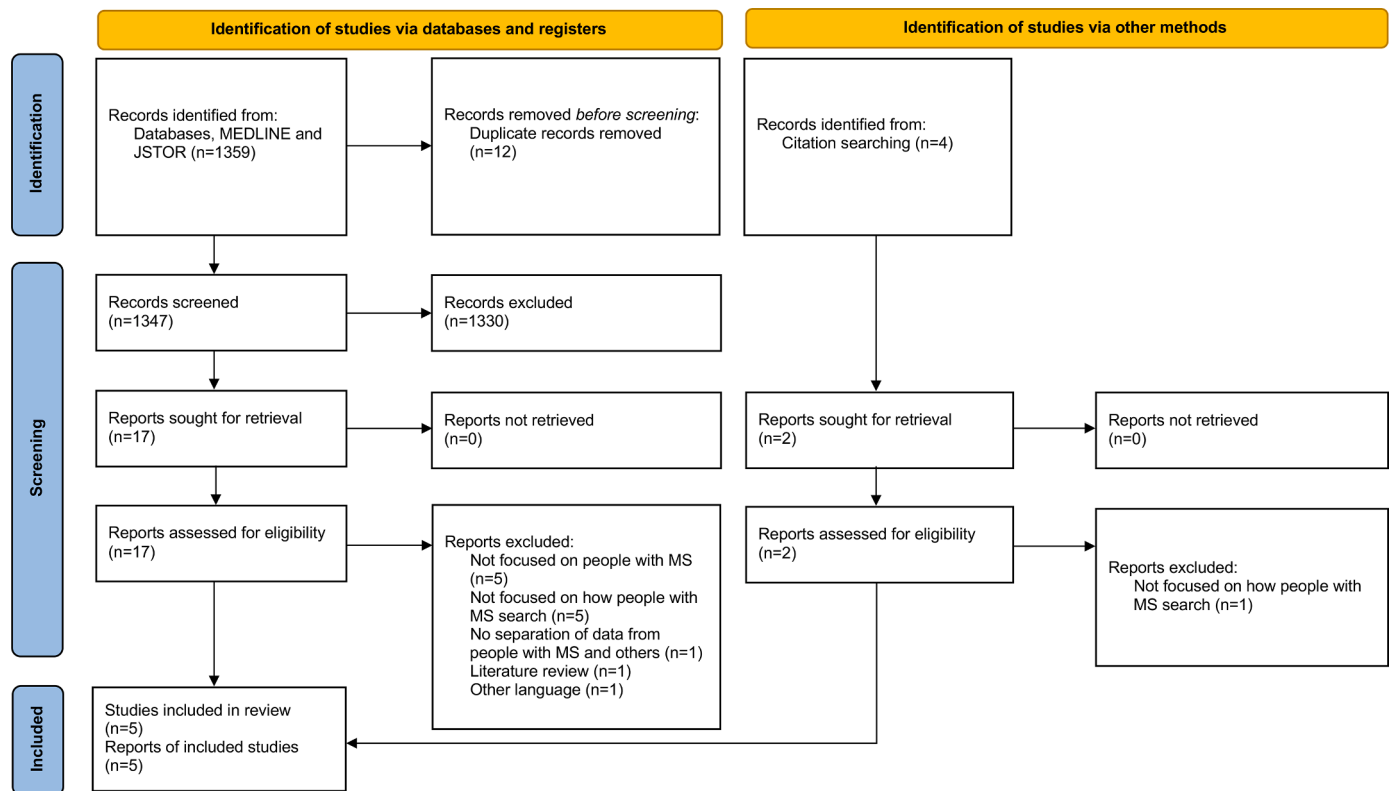
Fig. 1. PRISMA flow diagram.

3.2. Risk of bias in studies

All the selected studies met the quality screening criteria, scoring above 7 points and being deemed 'valuable' to the research question in the quality checklist. CASP assessments are detailed in Table 2.

3.3. Outcomes

3.3.1. Preferred sources of information

All studies found that a high proportion of pwMS search online for information about MS (53.8–82 %). Table 3 summarises the proportion of online searching, type of resources consulted, non-digital sources of information, and information sought online. The population from the Hay et al. (2008) study was different from the other 4 studies, including people newly diagnosed with MS and focusing on information seeking behaviour before a first MS appointment. In this sample of patients, 82 % of pwMS looked for MS information online before a first appointment. Importantly, in Marrie et al.'s large north-american cohort (Marrie et al., 2013), the way questionnaires were presented influenced responses on information seeking behaviour, with participants who completed the survey online being more likely to say they seek general health and MS specific information online than participants who completed a paper-based survey.

Two studies looked at the specific online sources of information, however there were marked differences in the sources mentioned between them (Higueras et al., 2022; Lejbkowicz et al., 2010). For instance, in the more recent study from Higueras et al. (2022), search engines and social networks were the dominant sources of information, which are not mentioned in the older study from Lejbkowicz et al. (2010) These findings likely reflect differences in data collection: Lejbkowicz et al. only reported websites visited, whereas Higueras et al. included other information searching strategies, namely the prevalence of proactive (search engines) and social (social networks, online communities,...) channels, over institutional ones. Nevertheless, both

studies indicate a clear preference for patients' associations websites over those from pharmaceutical companies. Other non-online sources of MS information varied across studies and are detailed in Table 3.

3.3.2. Type of information sought

Regarding what information pwMS looked for online, responses varied across studies possibly due to differences in prompt questions (variability in wording, open vs. closed/multiple choice, interview vs online/paper-based questionnaire, etc.). Still, across all studies there were some recurrent themes. Information on MS treatments was sought by a significant proportion of patients, including current treatments/drugs or drug efficacy (5 out of 5 studies, 49.1 % to around 90 %), new or innovative treatments (2 out of 5 studies, 34.4–67.8 %), complementary and alternative therapies (2 out of 5 studies, 22.2 to around 60 %), and stem-cell treatments or research (1 out of 5 studies, 23.2 %). General understanding of the disease (3 out of 5 studies, 62.5 % to around 90 %) and disease course or prognosis (4 out of 5 studies, 36.9–46.4 %) were also common enquiries. Hay et al. (2008) found that information about disease course, symptoms, and treatment were the most researched topics by pwMS (56 %) in their interview-based study of newly diagnosed patients.

Lifestyle information including diet, nutrition, exercise, or healthy habits was also frequently sought after (3 out of 5 studies, 0.6–67.6 %). Most patients reported using online sources to find strategies to cope with the disease (3 out of 5 studies, 55.2 % to around 60 %) or to find groups of other pwMS, MS organizations or support groups (4 out of 5 studies, around 30 % to around 60 %). Interestingly, Higueras et al. (2022) reported that around 80 % of patients found that online information contributed to their quality of life, and in Hay et al.'s study (Hay et al., 2008) information obtained online was reported as providing social support.

Lastly, patients also report using online sources to know more about MS physicians, find or interact with physicians, or find information or reviews on MS centres (3 out of 5 studies, 19 % to around 40 %).

Table 1

Characteristics of selected studies. MS: Multiple Sclerosis; NA: not applicable; PPMS: primary progressive Multiple Sclerosis; PRMS: progressive-relapsing Multiple Sclerosis; RRMS: relapse-remitting Multiple Sclerosis; SPMS: secondary progressive Multiple Sclerosis.

Study	Country	Study design and setting	Questionnaire administration	Response rate	No. Of patients included	Age at time of the study (mean (SD)) unless otherwise specified	Years since diagnosis (mean (SD)) unless otherwise specified	Female sex (%, N)	Diagnosis	Outcomes assessed
Hay et al. (2008)	United States of America	Semi-structured interviews, new patients at tertiary MS clinics	NA	NA	61	<30 – 11 (18 %) 30 to 50 – 33 (55 %) >50 – 16 (27 %)	0.2 (5.5)	80.3 (49)	Multiple sclerosis: 32 RRMS (52.5 %), 6 SPMS (9.8 %), 3 PPMS (4.9 %), 1 PRMS (1.6 %), 2 Devic (3.3 %)	Percentage of patients using internet, association with clinical and demographic patient characteristics, most searched subjects, reasons patients go online, patients' approach to information and discussion with clinicians
Lejbkowicz et al. (2010)	Israel	Distributed questionnaires, patients followed at a tertiary MS clinic	Self-filled, not specified if online or paper-based	93 %	96	43.2	7.7 (mean disease duration)	70.8 (68)	Multiple sclerosis (phenotype distribution not reported)	Percentage of patients using internet, sources of information, association of patient characteristics (age, marital status, computer ownership, disease duration, disability), most searched subjects, browsing habits, patients' approach to information and discussion with clinicians
Marrie et al. (2013)	United States of America	Distributed questionnaires, voluntary self-report registry (NARCOMS Registry)	Self-filled, online (65.63 %) or paper (34.37 %)	66.2 %	8586	56.6 (10.5)	18.1	77.6 (6649)	Multiple sclerosis (phenotype distribution not reported)	Information sources, type of health information sought, internet use, satisfaction and trust in the information, association with clinical and demographic patient characteristics
Potemkowski et al. (2019)	Poland	Distributed questionnaires, outpatients and patients enrolled in clinical studies	Self-filled, paper	NA	1045	40.65 (11.06)	9.08 (6.97) (mean disease duration)	70.0 (731)	Multiple sclerosis: 405 RRMS (38.8 %), 392 SPMS (37.5 %), 248 PPMS (23.7 %)	Percentage of patients using internet, most searched subjects, type of health information sought, patients' approach to information, impact of patient clinical and demographic characteristics, perceived credibility of different sources
Higueras et al. (2022)	Spain	Distributed questionnaires,	Assessed by researcher and	NA	302	42.3 (10.1)	9.6 (7.0)	64.2 (194)	Multiple sclerosis: 273	Search strategies, information

Table 1 (*continued*)

Study	Country	Study design and setting	Questionnaire administration	Response rate	No. Of patients included	Age at time of the study (mean (SD)) unless otherwise specified	Years since diagnosis (mean (SD)) unless otherwise specified	Female sex (%, N)	Diagnosis	Outcomes assessed
		patients at 18 hospital-based neuroimmunology units	excluded patients who did not understand questionnaire. Not specified if online or paper-based						RRMS (90.4 %), 16 SPMS (5.3 %), 13 PPMS (4.3 %)	sources, association with clinical patient characteristics, most searched subjects, information reliability of different sources

Table 2
Risk of bias assessment according to the CASP tool.

Study	Section A						Section B			Section C
	Aims	Methodology	Research design	Recruitment	Data collection	Researcher/. Participant	Ethical issues	Data analysis	Findings	Valuable
Hay et al. (2008)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Lejbkowicz et al. (2010)	Yes	Yes	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes
Marrie et al. (2013)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes
Potemkowski et al. (2019)	Yes	Yes	Yes	Cannot tell	Cannot tell	No	Yes	Yes	Yes	Yes
Higueras et al. (2022)	Yes	Yes	Yes	Cannot tell	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes

3.3.3. Perceived quality and trust of online information

Information acquired online was difficult to triage according to Marrie et al. (2013), with 28 % of patients reporting that they felt frustrated during searches and that getting information required a lot of effort, and 21 % saying that information acquired was difficult to understand. Additionally, 40 % of patients were concerned with the quality of the information. Considering all studies, the degree of trust in the information obtained varied according to the type of source. Overall, physicians were considered the most trusted source of information (3 out of 5 studies). Marrie et al. (2013) reported that 80 % trusted 'a lot' the information obtained from a physician, which dropped substantially to only 22 % giving the same reliability to information obtained from the internet. Likewise, Hay et al. (2008) reported that 36 % of participants stopped using the internet for information seeking, with 44 % of them pointing to misleading or wrong online information as the cause for cessation.

One study evaluated perceived credibility of websites dealing with MS (Potemkowski et al., 2019) and reported MS communities' websites as the most credible, followed by blogs written by pwMS, MS services' websites, doctors' blogs or websites, and lastly foreign websites.

3.3.4. Correlation with demographics, socioeconomic measures, and disease characteristics

Three of 4 studies (Higueras et al., 2022; Lejbkowicz et al., 2010; Potemkowski et al., 2019) that assessed the influence of age on online search behaviours reported a significant association between the two, with younger people more likely to resort to online information search about MS ($p = 0.01$ (Lejbkowicz et al., 2010); $p < 0.001$ (Higueras et al., 2022); OR 0.08, 95 CI 0.03–0.18, $p < 0.001$ (Potemkowski et al., 2019)). Additionally, Marrie et al. (2013) found an association between younger age and increased trust in the internet as a source of information. Four studies (Hay et al., 2008; Higueras et al., 2022; Lejbkowicz et al., 2010; Potemkowski et al., 2019) reported no association between sex and online information seeking; Marrie et al. (2013) found that female sex was associated with increased use of mass media for information seeking

($p = 0.005$), although an association with specific use of online sources was not reported. One study (Potemkowski et al., 2019) found that pwMS living with partners or married had higher odds of using online MS information than divorced or widowed people (OR 0.12, 95 % CI 0.05–0.31, $p < 0.001$); however, Lejbkowicz et al. (2010) and Hay et al. (2008) found no association between marital status and internet usage. Regarding socioeconomic measures, higher education had an association with online MS information searching in pwMS in 2 out of 3 studies that assessed this outcome ($p = 0.04$, Lejbkowicz et al. 2010; OR 8.64, 95 % CI 3.31–22.57; $p < 0.001$, Potemkowski et al. 2019). Additionally, pwMS of higher income brackets may have more frequent online information seeking behaviours compared to low income brackets, although this did not reach statistical significance in the only study that assessed this outcome (Hay et al., 2008); a higher income was associated with being married and with higher education levels, though neither of these was directly associated with online information seeking.

Disease characteristics also influenced online information seeking. Namely, a shorter disease duration was associated with more usage of online resources ($p = 0.02$, Lejbkowicz et al. 2010; OR 0.48, 95 % CI 0.27–0.87, $p < 0.001$, Potemkowski et al. 2019), although this was not corrected for age or other possible confounding factors. MS phenotype had no effect in one study (Hay et al., 2008), but Potemkowski et al. (2019) reported that patients with relapsing-remitting MS were 2 times less likely to use the internet for MS searches compared to patients with primary progressive MS (OR 0.47, 95 % CI 0.29–0.75, $p = 0.002$). There were three studies that assessed the relationship with disability, and while one (Lejbkowicz et al., 2010) found no association with number of relapses or disability as measured by EDSS, Potemkowski et al. (2019) reported that patients who needed assistance for walking were less likely to resort to online search on MS (OR 0.53, 95 % CI 0.31–0.89, $p = 0.02$). Marrie et al. (2013) reported that patients with mild degrees of disability had a higher odds of using mass media (including online resources) for information on MS compared with severe disability (OR 1.44 95 % CI 1.12–1.86) . Interestingly, Lejbkowicz et al. (2010) found no association between EDSS disability with internet usage, but reported that patients

Table 3
Summary of online information seeking patterns in the included studies.

Study	N*	Proportion of pwMS using online resources / internet	Proportion of pwMS using online sources for MS	Types of online sources used for MS information	Other sources of information on MS	Information sought online
Hay et al. (2008)	61	Not applicable	82 %	Not reported	Magazines, journals, books (13.1 %)	Background information, information that may save time during the appointment, check physician competency, find social support, find MS physician
Lejbkowicz et al. (2010)**	96	82 %	63 %	Patients' associations sites (73 %), academic sites (69 %), commercial medical sites (51 %), pharmaceutical companies' sites (46 %), health maintenance organizations (36 %), hospital sites (26 %)	Physician and nurse, leaflets, newspapers, television	Understanding the disease (around 90 %), search for treatment (around 90 %), research/news (around 80 %), understanding drugs activity (around 70 %), alternative medicine (around 60 %), nutrition (around 60 %), coping with the disease (around 60 %), physical activity (around 50 %), interaction with specialists (around 40 %), support groups (around 30 %)
Marrie et al. (2013)	8586	86.1 %	59 %***	Not reported	Doctor or health care provider (8.5 %), national MS society (5.5 %), books (3.7 %), magazines (1.9 %), brochures/pamphlets (1.4 %), family (1.1 %), consortium of MS centres (0.5 %), telephone information number (0.7 %), newspapers (0.5 %), complementary or alternative practitioner (0.5 %), friend/co-worker (0.4 %), library (0.3 %), other (1.6 %)	Treatment for MS (78.9 %), general information about MS (62.5 %), symptoms of MS (55.8 %), coping with MS (55.2 %), complementary and alternative therapies (46.2 %), MS organizations (42.5 %), cause of MS (40.4 %), prognosis (36.9 %), diagnosis of MS (19.1 %), other information about MS (25.9 %)
Potemkowski et al. (2019)	1045	89.2 %	53.8 %	Not reported	Not reported	Innovative treatments (67.8 %), course of MS (62.7 %), medication efficiency (49.1 %), diagnostic methods (41.9 %), prognosis and lifespan (41.9 %), diagnosis criteria (39.1 %), new medication (34.4 %), MS treatment centre reviews (28.7 %), MS doctors reviews (23.6 %), stem cells treatment results (23.2 %), alternative methods reviews (22.2 %), MS and pregnancy (19.1 %), treatment centre using stem cells (19.1 %), MS and marriage (12.6 %), MS and sexuality (11.7 %), raising children (11.6 %), MS and chronic venous insufficiency (6.5 %), MS and diet (0.6 %)
Higueras et al. (2022)	302	97.4 %	78 %	Browsers (70.9 %), social networks (37.4 %), patient associations webpages (38.4 %), discussion groups or forums (23.5 %), newsletters (21.5 %), pharmaceutical webpages for patients (10.9 %), online communities (10.9 %), others (9.6 %)	Not reported	Information about healthy habits (67.2 %), new treatments and MS research (63.6 %), symptom control (49.7 %), other patient experiences (46.4 %), disease prognosis (46.4 %)

* Number of patients for calculation of each percentage may varies according to response rate to each question; MS: Multiple Sclerosis.
** Proportions for 'Information sought online' obtained from Lejbkowicz et al. (2010) were extracted from a bar chart figure and exact percentages were not available.
*** Proportion of pwMS that search online as a first information source (proportion of overall use of online sources for MS is not reported).

that use the internet are more likely to search information about MS when the disease worsens, both online and through other sources.

3.3.5. Discussion of findings with MS physician

Hay et al. (2008) reported that patients were motivated to seek information to prepare for clinical appointments, in order to use the limited time with the physician more efficiently. However, Hay et al. (2008) also reported that only 36 % discussed their information searches

with physicians. Similarly, Lejbkowicz et al. (2010) found that only one third of patients talked with their physicians about their searches for information online; and Potemkowski et al. (2019) reported that 53 % of patients did not discuss their online research with physicians during appointments.

4. Discussion

Online information search by pwMS about their disease is frequent and the internet is often the most common source of information used by patients. Our review found that between 53.8 and 82 % of pwMS use online resources to search about MS information. This is in line with previous studies on general health information seeking behaviours (Bujnowska-Fedak et al., 2019; Clarke et al., 2016; Jia et al., 2021). Likewise, other studies in people with neurological, psychiatric, or other systemic immune mediated disorders also showed that most patients use the internet to seek information about their conditions (Lim et al., 2022; van der Vaart et al., 2013; Zaja et al., 2022). The search for information about MS was widespread across patients in different geographic locations and was more common in younger patients, patients with higher education levels, and in higher income brackets, which is in line with other health-related online information seeking behaviours (Li et al., 2016). Clinical characteristics were also associated with internet usage in some studies, namely a more recent diagnosis, shorter disease duration, having a primary progressive phenotype of MS, and periods of disease worsening were associated with increased online information seeking behaviour. This link between medical history and health-related information searching has also been found in other studies, where patients with more complex medical histories tended to search more for information online (Li et al., 2016).

The only study in our sample that discussed channels used for information search (Higueras et al., 2022), identified search engines as the dominant strategy. While this is in line with overall health information search behaviours (Maon, 2017), it does leave pwMS vulnerable to harm from misinformation as the unregulated nature of the Internet results in a substantial proportion of health information being misleading or inaccurate (Eysenbach and Diepgen, 1998; Li et al., 2016; McLeod, 1998). The Higueras et al. (2022) study also showed the popularity of social media channels, such as online social networks, discussion forums, and online communities as sources of information for pwMS. Social media are increasingly popular communication channels and, therefore, it is not surprising to see them emerge as important sources of information for pwMS. However, social media have been shown to increase health-related information overload and, consequently, information anxiety (Soroya et al., 2021). Whether cognitive impairment related to MS impacts the way this information is dealt with by pwMS is, at this point, unknown.

The most common topics searched for by pwMS relate to understanding the disease (including prognosis or symptoms), lifestyle recommendations (including nutrition, exercise, and healthy habits), and associated treatments. In other disorders and in previous studies in MS "infodemiology", the main search topics were also related to information about the disease, treatment, and prognosis (Bragazzi, 2013; Brigo et al., 2014; Lim et al., 2022; Serrazina et al., 2022; van der Vaart et al., 2013). The interest in novel treatments and alternative therapies revealed in some of the studies may reflect the type of person that tends to look for health information online (Li et al., 2016). Namely, patients that search for information online tend to have high education and income levels.

It is unclear why some pwMS reported low confidence and concerns with the quality of information found on the internet, which prompted some patients to stop seeking information online. It is also unclear if other factors, such as difficulty in finding and understanding the information found could have contributed to this. Problems in processing the information pwMS find online could have adverse implications in their psychological wellbeing (Matthes et al., 2020; Soroya et al., 2021). This could be a problem for the safety of pwMS, and the quality of any subsequent decision making, if the online sources of legitimate MS information are deemed to be more confusing than those that provide less accurate information regarding treatments and other topics of interest to pwMS. Perceived quality of the information found is also a concern in other disorders, and it is quoted as the most common reason to prevent

search usefulness (Kalckreuth et al., 2014; Lim et al., 2022), similar to our findings.

Patients described a higher perceived quality and trust in information obtained from healthcare professionals than from other sources (Higueras et al., 2022; Marrie et al., 2013; Matti et al., 2010; Potemkowski et al., 2019). However, the included studies consistently found that information sought online was rarely discussed with physicians. Additionally, despite evidence supporting the increased participation of patients in their own disease management (Frosch and Kaplan, 1999; Greenfield et al., 1985), guidance for pwMS through their information searches is missing. It is unknown in our sample what guidance was provided by clinicians to pwMS on their online information searches. The gap between the use of internet for information search about MS and the discussion with physician magnifies the concerns with trust in online content reported by pwMS in the included studies, as potentially inaccurate information is not corrected, and clinicians may not be aware of the need to provide direction to patients (Ball and Lillis, 2001; Potts and Wyatt, 2002). Given the high proportion of pwMS using online resources to obtain information and the widely beneficial impact of the internet as a tool for information dissemination and accessibility, clinicians should pre-emptively provide their patients with adequate guidance and direction to online information resources (Lode et al., 2007).

Finally, given the indication that different sources of health information may have differential impacts on health-related anxiety (Soroya et al., 2021), further research is needed about the link between online channels of information used by pwMS and their emotional wellbeing. There is a need for additional studies to better understand patient information needs and how healthcare professionals may provide better personalized support to pwMS in their online searching, considering the specificities of a chronic central nervous system disease like MS. Therefore, it is important for sources of legitimate MS related information to evaluate the extent to which their websites are pwMS-friendly, and to find ways of improving the readability and ease of use of their content. In turn, this requires understanding how the information is accessed and presented interacts with pwMS's ability to use it, and which devices are better suited to search for information online (Ghahramani and Wang, 2020).

Our review has several limitations. There was a high heterogeneity in the included studies, namely in the sample size, disease phenotypes, and duration of disease, which could limit comparison across studies and generalizability. The included studies also spanned a significant time interval (2008 to 2022) during which internet usage and digital information presence evolved and became more widespread. As for limitations associated with the use of self-filled questionnaires, some studies reported low response rates and one study applied predominantly online questionnaires, which may lead to a selection bias towards pwMS that use the internet. We also did not have access to the questions used for the questionnaires or length of questionnaire, and wording likely differed between studies, so a high variability in the reported outcomes was expected. The included studies only performed univariate analysis to assess the correlation of demographic and clinical characteristics with internet usage and no corrections were performed for possible confounders. Despite these limitations, the consistent findings across studies, with similar clinical and demographic factors associated with information seeking, strengthens our findings.

5. Conclusion

Healthcare professionals should be aware that most of their patients will refer to online resources to get information about the disease and that, despite concerns with quality of the available contents, only a minority will discuss the results of their search with their physician (Hay et al., 2008; Lejbkowicz et al., 2010; Potemkowski et al., 2019). These findings highlight the importance of making information available and accessible to pwMS, supporting previous studies indicating that digital resources should be given to patients at the time of diagnosis

([Lode et al., 2007](#)). Additionally, the high proportion of patients using the internet for health information highlights the importance of providing pwMS with adequate and trusted online resources. The impact of this information seeking pattern on the wellbeing of pwMS is still to be evaluated.

Declaration of Competing Interest

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