

Original Article

# The Use of the Internet and Social Media by Individuals with Ménière's Disease: An Exploratory Survey of Finnish Ménière Federation Members

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**OBJECTIVES:** The present study explored the use of the Internet and social media by individuals with Ménière's disease (MD).

**MATERIALS and METHODS:** This study utilized a retrospective design and included the data of 465 individuals with MD from the Finnish Ménière Federation (FMF) database. Moreover, the participants included 346 females (i.e., approximately 75% of the sample), with roughly 95% of which middle-aged or older adults. An Internet-based survey was used to collect the demographic information and determine the use of the Internet and social media by individuals with MD in order to establish a computer-based peer support program.

**RESULTS:** Based on the findings, more than 90% of the respondents reported using the Internet, 70% used the Internet to gather information about MD, and 47% stated that they trusted the information on the Internet.

**CONCLUSION:** The Internet and social media are frequently used by individuals with MD to gather information about their health conditions. Therefore, it is essential to ensure that appropriate and accurate information is available via Internet websites and social media platforms.

**KEYWORDS:** Ménière's disease, health information, internet use, social media, health communication

## INTRODUCTION

In the past, individuals primarily obtained information from health professionals, their friends and families, and, if necessary, the news media. However, over the last decade, the use of the Internet and social media to gather health information has increased substantially<sup>[1]</sup>. For example, individuals with health conditions are using the Internet for various purposes, including: (1) mapping their symptoms to a health ailment and self-diagnosis; (2) finding coping strategies to self-manage their conditions; (3) gaining knowledge on available treatment strategies and their effectiveness; and (4) understanding the process of seeking help and the costs involved<sup>[2-4]</sup>.

In general, health information on the Internet has been growing at a tremendous rate, as is the number of individuals writing about health ailments on the Internet (e.g., individuals with health problems, health professionals, and marketing professionals selling health products). However, there has been little to no monitoring of such information in regard to its suitability and accuracy. In addition, the sources can vary substantially in their usefulness to patients<sup>[2, 5]</sup>. Hence, it is important to understand the type and accuracy of the information available via the Internet and social media and its usage by individuals with different health conditions.

Although two studies have examined the use of the Internet by individuals with hearing loss,<sup>[6, 7]</sup> limited data exists regarding the use of the Internet and social media by individuals with vestibular disorders. Thus, a recent study addresses this research gap by examining the use of patient magazines, electronic media, and Internet-based peer support by members of the Finnish Ménière Federation (FMF; Suomen Ménière-liitto)<sup>[8]</sup>. The current study explores the use of the Internet and social media by individuals with Ménière's disease (MD), based on the FMF database.

## MATERIALS AND METHODS

### Study Design

This retrospective study utilized the FMF database which included data on an Internet-based survey to establish a computer-based peer support program for individuals with MD. More specifically, the Internet-based survey was used to obtain demographic information and determine the use of the Internet and social media by individuals with MD<sup>[9, 10]</sup>. The overall purpose of the extensive questionnaire was to determine how FMF members gathered and comprehended the digital information related to MD. Permission was obtained from the FMF to anonymously access their registry data (i.e., without collecting the personally identifiable information of subjects). According to Finnish law, this type of survey study, which is conducted in association with patient organizations and involves anonymous data, does not require ethical approval. The participants were provided with detailed information about the study and a consent was obtained electronically prior to gathering the survey data. Finally, the FMF, which includes 1,646 members, sent the questionnaires electronically to 998 members with valid e-mail addresses, after which 465 members replied (46.59% response rate).

### Participants

Table 1 presents the demographic information of the participants. Among the 465 respondents, 346 were female and 119 were male. The participants were classified into three age groups: (1) less than 35 years (n=12); (2) 35 to 63 years (n=227); and (3) older than 63 years (n=226). Since the secondary data gathered by the FMF regarding age was limited to these categories, the exact age of each participant was not available. However, the age and gender of the study sample reflected the distribution of the FMF membership. In addition, more than 60% of the respondents were professionals and/or university-educated, while 23% had a family history of MD.

### Statistical Analysis

The statistical analysis was conducted using the Statistical Packages for the Social Sciences (SPSS) software program version 24 (IBM Corp.; Armonk, NY, USA), while descriptive statistics were used to examine the answers to the majority of the questions. Since the data for many of the variables were in categorical form, a Chi-square test was performed to examine the association between the demographic variables (i.e., gender, age, work status, education, duration of MD, and family history of MD) and weekly Internet use. Finally, an alpha level of <0.05 was used for statistical significance interpretation.

**Table 1.** Demographic information of the participants (n=465)

Variables	N (%)
<b>Age</b>	
• Less than 35 years	12 (2.6)
• 35 to 63 years	227 (48.8)
• Over 63 years	226 (48.6)
<b>Gender</b>	
• Male	119 (25.6)
• Female	346 (74.4)
<b>Work</b>	
• Student	6 (1.3)
• Unemployed	24 (5.2)
• Full-time work	141 (30.3)
• Part-time work	30 (6.5)
• Part-time work pension	27 (5.8)
• Full-disease pension	21 (4.5)
• Retired	216 (46.5)
<b>Education</b>	
• Secondary school	102 (21.9)
• High school	25 (5.4)
• Basic professional education or applied science education	257 (55.3)
• University	81 (17.4)
<b>Duration of MD</b>	
• 0 to 5 years	112 (26.9)
• 6 to 10 years	119 (25.6)
• 11 to 20 years	106 (22.8)
• Over 20 years	118 (25.4)
<b>Family history of MD</b>	
• Yes	109 (23.4)
• No	356 (76.6)

MD: Ménière's disease

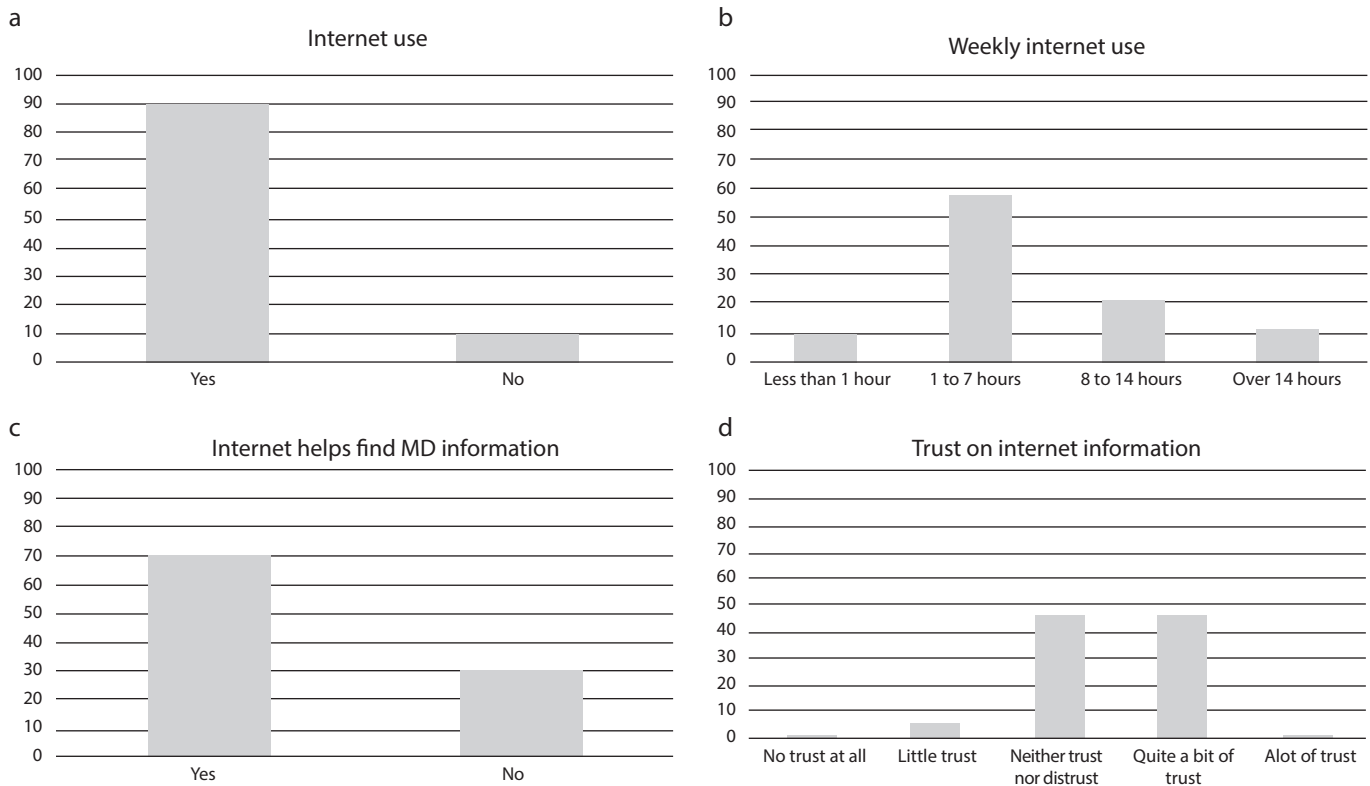
## RESULTS

### Internet Use

Figure 1 presents the use of the Internet for general purposes by individuals with MD. More than 90% of the respondents reported using the Internet (Figure 1a), while weekly Internet use included: less than 1 hour by 9.5% of the respondents; 1 to 7 hours by 57.7% of the respondents; 8 to 14 hours by 21.8% of the respondents; and more than 14 hours by 11% of the respondents (Figure 1b). In addition, approximately 70% of the respondents stated that the Internet helped them obtain information about MD (Figure 1c). Interestingly, 6% of the respondents reported having no or little trust of such information, 46% neither trusted nor distrusted the information, 46% had quite a bit of trust, and 1% had complete trust of the information (Figure 1d).

### MAIN POINTS

- The Internet and social media are frequently used by individuals with various health conditions including those of MD to gather information about their health conditions.
- The current study suggests that more than 90% of the MD patients reported using the Internet, 70% used the Internet to gather information about MD, and 47% stated that they trusted the information on the Internet.
- It is essential to ensure that appropriate and accurate health information is available via Internet websites and social media platforms.



**Figure 1.a-d.** The use of the Internet by individuals with Ménière's disease. a) internet use, b) weekly internet use, c) internet helps find MD information, d) trust on internet information.

A Chi-square test was performed to examine the relationship between the demographic variables (i.e., gender, age, work status, education, duration of MD, and family history of MD) and weekly Internet use. In this case, there was no association between weekly Internet use and gender (Chi-square=5.3,  $p=0.26$ ) and duration of MD (Chi-square=13.9,  $p=0.3$ ). However, a significant association was found between weekly Internet use by age (Chi-square=25.1,  $p<0.001$ ), work (Chi-square=51.1,  $p<0.001$ ), education (Chi-square=27.9,  $p=0.03$ ), and family history of MD (Chi-square=13.4,  $p=0.009$ ). These results suggest that the variables of age, education, and family history of MD influence the use of the use of the Internet, although the reasons for this association are unknown.

### Social Media Use

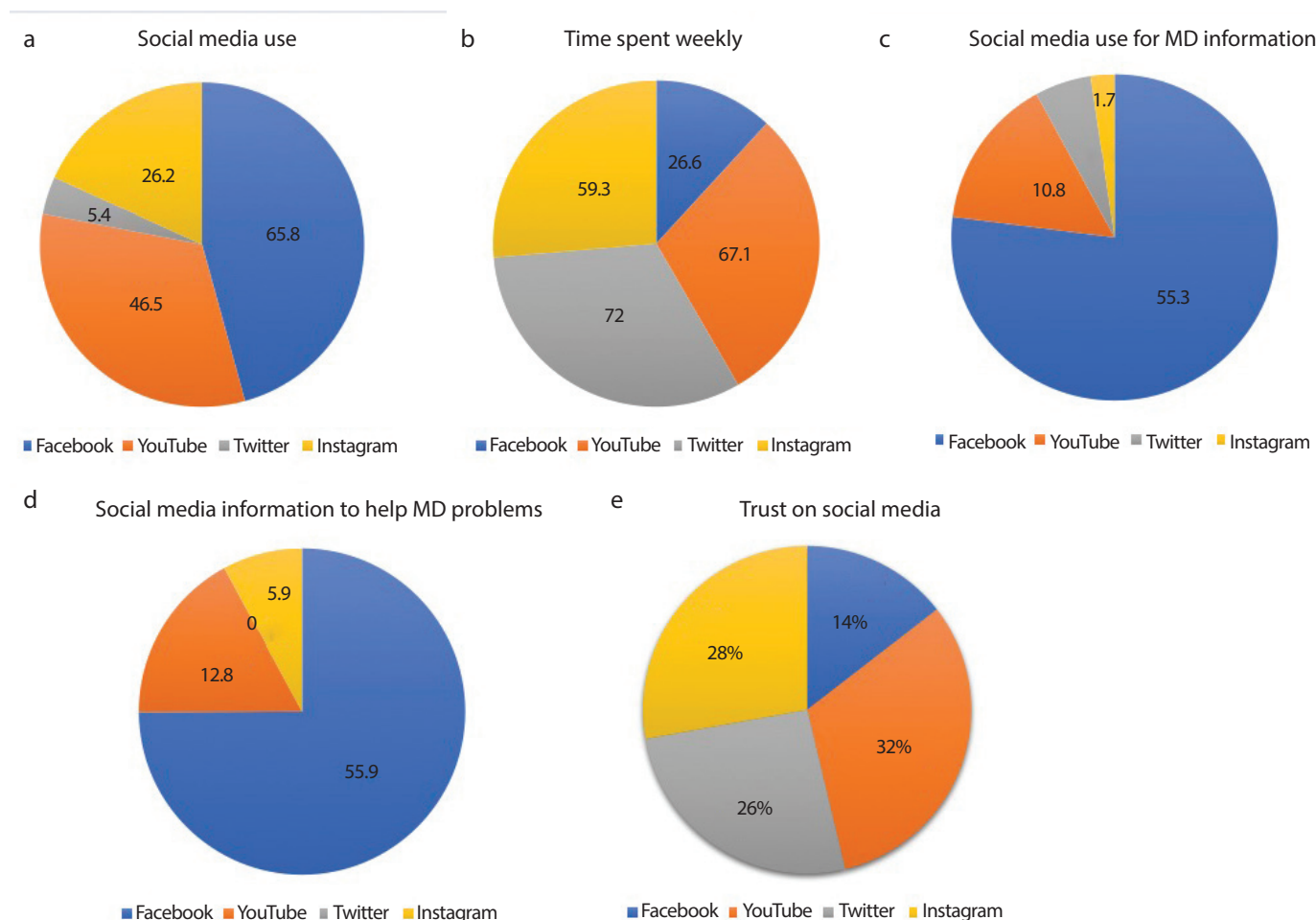
Figure 2 presents the use of social media by individuals with MD. In this regard, Facebook, YouTube, Instagram, and Twitter were used by 66%, 47%, 36%, and 5% of the respondents, respectively (Figure 2a). More specifically, Facebook and Instagram were used more than 1 hour by 73% and 34% of the respondents, respectively, whereas YouTube and Twitter were used more than one hour by less than 30% of the respondents (Figure 2b). Overall, Facebook was the most frequently used (55%) social media platform for obtaining information about MD, followed by YouTube (11%). Conversely, Twitter and Instagram were rarely used by the respondents (less than 2%) (Figure 2c). Moreover, a number of respondents stated that Facebook (56%) and YouTube (13%) offered useful information about MD (Figure 2d). Although the respondents reported using social media to gather information, the data suggests that they did not find the information trustworthy. For example, more than 55% of the respondents report-

ed using Facebook to find information, but only 14% stated that the information was highly trustworthy. (Figure 2e).

### DISCUSSION

The use of the Internet and social media has grown exponentially over the last decade<sup>[1, 11]</sup>. The reasons for this change include the easy availability of digital information and the fact that it is cost-free. As for individuals with MD, the Internet is frequently used to gather information about their conditions, despite the fact that some of the information is untrustworthy. In the present study, the variables of age, work, education, and family history of MD were associated with weekly Internet use, although the reasons for this association are unknown. Moreover, Facebook (66%) and YouTube (47%) were the most frequently used social media platforms, although Facebook was the only source used to gather information about MD. In this case, 55% of the respondents rated the platform favorably for its usefulness. However, all types of social media were rated as less trustworthy by the majority of the respondents<sup>[5]</sup>.

In general, there are several advantages of using the Internet and social media to gather health information. First, the information is free and easily accessible. Second, regardless of whether they are correct, patients feel that the information is bias-free, since it is shared by service users. Third, patients can search for specific information that interests them, instead of relying on whatever information their healthcare professionals offer during their clinical consultations. However, the information derived from these sources is not always suitable, as shown in previous studies in which there is a high percentage of misinformation on the Internet, especially in social media<sup>[5]</sup>. According



**Figure 2. a-e.** The use of social media by individuals with Ménière's disease. a) social media use, b) time spent weekly, c) social media use for MD information, d) social media information to help MD problems, e) trust on social media.

to some of the respondents in this study, they were somewhat aware of this issue. Thus, it is important that healthcare professionals ensure that their patients do not solely rely on digital media and refer them to more credible sources.

As the number of individuals using the Internet and social media rapidly increase, they are more likely to consume information, instead of contributing to the overall dialogue. Hence, it is important that users in social media are monitored by individuals with relevant expertise (e.g., healthcare professionals and/or members of service user organizations). In other words, these channels can become a collaborative space for communicating and exchanging important health information. Moreover, Internet-based peer support, monitored by healthcare and technology professionals, can be developed to assist service users [9, 10].

In future studies, it would be useful to examine how information from the Internet and social media contributes to the self-management of individuals with MD. It would also be useful to determine which keywords are used when they search for information via the Internet and social media. Moreover, future studies should examine the relationship between the information gathered by various sources and health outcomes (i.e., help-seeking, rehabilitation uptake and use, satisfaction from rehabilitation) among individuals with MD. Al-

though a platform currently exists as a MD self-help program, it can be further explored in relation to outcome indicators [9, 10]. Finally, future studies should address the "coldness" of technology, especially in situations in which a human approach is more effective. In other words, communication between healthcare professionals and their patients involve an exchange of emotions, warmth, and support. In order to address this challenge and to develop effective Internet-based diagnostic and therapeutic programs, [8] a possible solution is to increase the information shared through patient association magazines and newsletters.

## CONCLUSION

This retrospective study explored the use of the Internet and social media by individuals with MD. Based on the results, more than 90% of the respondents reported using the Internet, 70% used the Internet to gather information about MD, and 47% stated that they trusted the information on the Internet. Moreover, the Internet and social media were frequently used by individuals with MD to gather information about their conditions. Therefore, it is important to ensure that appropriate and accurate information is available via Internet websites and social media platforms.

**Ethics Committee Approval:** The study was conducted in collaboration with Finnish Ménière Federation. Under Finnish law, this kind of survey study con-

ducted in association with patient association does not require ethical approval.

**Informed Consent:** The participants were provided with detailed information about the study and a consent was obtained electronically before gathering the survey data.

**Peer-review:** Externally peer-reviewed.

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**Conflict of Interest:** The authors have no conflict of interest to declare.

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