The Viewpoint of Informal Carers of People with Multiple Sclerosis in Digital Health Research: A Scoping Review

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Abstract. Multiple sclerosis (MS) is a common neurological disease that can impact not only individuals diagnosed with the condition but also their informal carers, i.e. family members and friends. This scoping review aimed to map the role that family members and friends of people with multiple sclerosis have had in digital health research. The scoping review was reported according to PRISMA-ScR. The search was done in Scopus, CINAHL, Pubmed, and Web of Science. A total of 14 studies met the inclusion criteria. These studies were about telemedicine, rehabilitative video games, online education, user research, and development. Usually, family members and friends had a side part in the research. One study focused exclusively on them, and in total, in eight studies family and friends were participants in the study. Otherwise, they were accompanying the person with multiple sclerosis, were seen as possible users of the digital solution or they appeared in results by someone else. In this scoping review, it was seen that informal carers can get support and information from digital sources, they are able to act as informal carers in digital environments, healthcare professionals can receive information from them and family and friends can help in remote assessments, and digital solutions can help informal carers and people with MS to connect in a new or better way. Our results highlight that digital health can bring benefits to family members, people with multiple sclerosis, and healthcare.

Keywords: Digital Health · Digital rehabilitation · Informal carers · Multiple sclerosis · Patient Education · Telehealth · Telemedicine · Telerehabilitation

1 Introduction

There are more than 1,8 million people with multiple sclerosis (pwMS) in the world. Multiple sclerosis (MS) is usually diagnosed in young adulthood, and it is more common in women. It can cause various symptoms that can be disabling [1]. Informal carers, including family and friends (F&F) provide care for their loved ones with long-term

conditions. Informal care is care that is provided by non-professionals. Some of the informal carers get financial compensation for their effort. Among older people informal carers are often the only ones that provide care [2]. About half of the pwMS receive informal care from their F&F [3, 4], on average 10,5 h per week [4]. People with a severe form of MS need most help from F&F, as much as 8 h a day throughout the day. The amount of support pwMS receive from formal care affects how much they need help from their F&F [3].

MS also causes costs for informal carers as a form of absenteeism, presenteeism, early retirement, and productivity loss in volunteer work. In the United States alone this is estimated to cost 4 182 million dollars annually [5]. Informal carers are less likely to work full-time [6] and they have lower socioeconomic status [7]. Informal caregiving can lead to the society receiving less taxes and the informal carers earning smaller pensions [6]. Informal carers of pwMS may also experience carer burden, anxiety, depression, poor quality of life, and poor sleep [8].

Family members and loved ones of a person with a long-term condition do not always see themselves as carers and are concerned that labeling themselves as carers could lead to more responsibilities. People receiving care also might have difficulties accepting their need for support, which is also a reason for avoiding being called a carer. Without a carer identity, people do not necessarily feel that getting support is for them. They might also avoid recognizing how the disease affects them. Sometimes informal carers need outsiders, like healthcare professionals (HCP), to validate them as carers and encourage them to accept support. Responsibilities also can limit carers' opportunities to look for support for themselves [9].

Digital health is a broad umbrella term that covers the use of digital technologies to improve health [10]. Digital health includes for example telehealth, big data, artificial intelligence, and mobile health devices [11]. Through the application of digital health technologies, for example to consumers, there is a possibility to strengthen the health system [10]. Digital health solutions enable sustainable health systems, but to reach this they must respond to health needs [11]. Digital solutions could provide opportunities for family and friends to participate or ease their burden. Digitalization can bring healthcare to home and the daily life of pwMS that they share with their family and friends.

To our knowledge, any kind of review of the role of informal carers of pwMS in digital health research has not been made before. This scoping review was made to map the research that has been done on this topic. Results can guide future research and be used to create more appropriate digital health solutions.

2 Methods

This scoping review was conducted to systematically map the research and to identify possible gaps in knowledge in the literature about the role of informal carers of pwMS in digital health research. This report was written according to the Preferred Reporting Items for Systematics Reviews and Meta-Analyses: Extension for Scoping Reviews (PRISMA-ScR) [12]. This research aimed to explore and summarize how this concept has been studied over time and secondarily to identify knowledge gaps, which makes scoping review a suitable method [13].

Research questions:

1. What roles informal carers of pwMS have had in digital health research?
2. What was the digital health aspect of the included studies?
3. What results do the included studies report related to informal carers of pwMS in digital health?

Inclusion criteria for this scoping review were: the research explored aspects about family or friends of pwMS, is about digital health, is original research, research is peer-reviewed and the full text is in English. Exclusion criteria were: no family or friends of pwMS, not about digital health, or the article was protocol, editorial, comment, or review.

The search was done in four databases: Pubmed, Web of Science, Scopus, and CINAHL in November 2022. No time limit or other limitations were set. Search words used in databases are presented in Table 1. Words in each search word group were combined with the Boolean operator "OR" and groups were attached with the Boolean operator "AND".

Table 1. Words used in the search

Search word 1	Search word 2	Search word 3
digital*	"multiple sclerosis"	informal
ehealth	"ms-disease"	famil*
"e-health"		spous*
mhealth		partner*
"mobile health"		couple*
telemedicine		child*
telemedicine		parent*
telerehabilitation		friend*
"health informatics"		relative*
		caregiv*

One researcher (TY) executed the title, abstract, and full-text screening based on the inclusion and exclusion criteria. The identification of included studies is represented in Fig. 1. Included full texts were then discussed by two researchers (TY, VM). Two researchers (TY, VM) independently read the included articles, wrote information about the included studies to the Google Sheets file, and then discussed the findings and synthesized the results.

3 Results

The search in the databases resulted in a total of 723 results. Search results were uploaded to Covidence [14]. Covidence identified 189 duplicates, which were removed. A total of 534 search results ended in title and abstract screening. 45 of them continued to full-text screening, but one full-text was not available. A total of 14 articles were included in this review. The study identification process is described in Fig. 1.
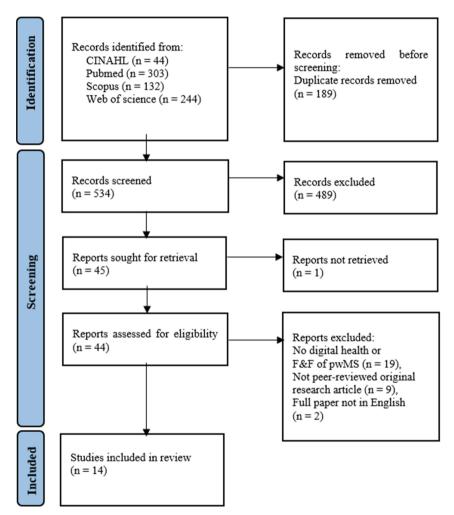

Fig. 1. Preferred Reporting Items for Systematics Reviews and Meta-Analyses Flow diagram of identification of studies

3.1 Characteristics of Included Studies

One article was published in 2014 [15], two in 2016 [16, 17], one in 2018 [18], three in 2020 [19–21], four in 2021 [22–25] and three in 2022 [26–28]. Six of the included studies were conducted in the United States [18–21, 24, 27], two in Australia with international participants (the educational intervention was in English) [23, 26], two in Italy [25, 28], one in Spain [16], one in Germany [22], one in Belgium [15] and one in the United Kingdom [17].

Most of the included studies concentrated on adults with multiple sclerosis and their F&F. Only one research, [19] had participants with pediatric multiple sclerosis and their carers. It was not specified who these carers were but since the participants were 6 to 20 years old (mean 13.1), it is assumed that most of them were their parents or guardians. Summaries and study participants of the included studies are described in Table 2.

Table 2. Characteristics of included studies

Authors	Summary	Participants
Abbatemarco., Hartman, McGinley, Bermel, Boissy, Chizmadia, Sullivan & Rensel [24]	Evaluation of satisfaction with the online clinic experience of pwMS. The physical clinic experience transferred online due to COVID. Survey of satisfaction physical vs digital	PwMS. Family members sometimes accompanied pwMS in the video meeting with HCP[a]
Bergamaschi, Tronconi, Bosone, Mastretti, Jommi, Bassano, Turrini, Benati, Volpe, Franzini, Allodi & Mallucci [25]	Development and evaluation of a protocol for managing pwMS by HCP[a]. Virtual appointment, usability assessed by survey. F&F helped with cognitive assessment	25 pwMS, their carers accompanied in all virtual visits
Bove, Garcha, Bevan, Crabtree-Hartman, Green & Gelfand [18]	Evaluation of video appointments for understanding if they reduced provider and pwMS burden	150 People with MS or other neuroinflammatory disorders. 27% had a companion (usually a spouse or partner) with them
Claflin, Campbell, Doherty, Farrow, Bessing & Taylor [23]	Evaluation of a MOOC[b] education program about participant engagement and measures of satisfaction, appropriateness, and burden	3518 participants, 1549 of whom completed the feedback survey: 862 formal or informal carers, 928 pwMS, 664 F&F
Claflin, Mainsbridge, Campbell, Klekociuk & Taylor [26]	Evaluation of the impact of an online course on the participants' behavior regarding eating and exercising habits of pwMS. Survey of self-reported behavior change after education	560 participants: 213 pwMS, 144 carers
Haase, Voigt, Scholz, Schlieter, Benedict, Susky, Dillenseger & Ziemssen [22]	Survey on the use of information technology, barriers, needs, requirements, and adopting technology solutions for MS	185 pwMS, 25 informal carers, 24 Healthcare professionals

Table 2. (*continued*)

Authors	Summary	Participants
Halstead, Leavitt, Fiore & Mueser [21]	A feasibility study of an online resilience education program for pwMS and their family	62 participants, 31 dyads: 28 pwMS and partners, 3 parent-child dyads
Harder, Hernandez, Hague, Neumann, McCreary, Cullum & Greenberg [19]	Comparison between the home-based pediatric videoconference and in-person neuropsychology assessment. Evaluation of user satisfaction and validity	95 participants, ages 9–20 years, and their carers. 24% have MS or clinically isolated syndrome
Octavia & Coninx [15]	Evaluation of the impact of adaptive, personalized, collaborative games for rehabilitation	9 pwMS and therapist. A game was designed to play with for example family members, but it was not studied with family members
Palacios-Ceña, Ortiz-Gutiérrez, Buesa-Estellez, Galán-Del-Río, Cachón-Pérez, MartÍnez-Piedrola, Velarde-García & Cano-De-La-Cuerda [16]	Exploring the experience of pwMS on the virtual home exercise program and its impact. Video games were used as a rehabilitation tool	24pwMS received treatment using Kinect, control group (25pwMS) received physiotherapy twice a week. Family and friends had joined Kinect games with pwMS
Roth, Minden, Maloni, Miles & Wallin [27]	Interviewing participants to understand their perspectives about telemedicine for provision of MS care	20pwMS, 15 HCP[a], 15 payers and policy experts (from health insurance companies)
Schleimer, Pearce, Barnecut, Rowles, Lizee, Klein, Block, Santaniello, Renschen, Gomez, Keshavan, Gelfand, Henry, Hauser & Bove [20]	Expanding the design of a medical digital platform to have an interface for pwMS, where they can monitor and understand their health condition to make meaningful decisions. Designing and testing the solution	Phase I: 6 clinicians, 12 pwMS (with family, friend, carer), industry and advocacy experts. Phase II: 10 pwMS, MS support group. Phase III: MS support group, 15 pwMS advocacy group for feedback & 24 pwMS for testing
Sillence, Hardy, Briggs & Harris [17]	Study of F&F impressions and needs of online support and information forums	20 F&F of pwMS. In all but one case pwMS was their spouse
Toscano, Patti, Grazia Chisari, Arena, Finocchiaro, Schillaci & Zappia [28]	Evaluation of reliability and satisfaction of televisits	76 pwMS, 23 F&F

[a] HCP: healthcare professional, [b] MOOC: Massive open online course

3.2 Role of Family and Friends of PwMS in Included Studies

Role of family members and friends varied greatly in the included studies. One of the 14 included studies had their main focus solely on the F&F of pwMS [17] and two had them in a significant role [19, 21]. Harder et al. were the only ones studying pediatric pwMS and their informal carers. In their study carers made the necessary arrangements but they were not allowed to be in the room with the child patient during testing. Informal carers also filled out the satisfaction survey [19]. Figure 2 represents how centric roles informal carers had in different studies.
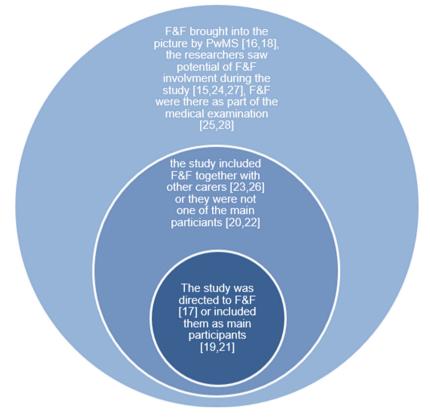
Fig. 2. The role of informal carers in the included studies

In two studies F&F had been mentioned as possible users in the methods section but they were not part of the study, and they were not separately discussed in the results [15, 20]. In one study, it was planned that family members would be using the solution with pwMS, but they ended up testing it with HCP only [15] and in one study it was recognized that the user could finally be the patient's informal carer [20]. Some studies had not written about F&F participating in their methods, but F&F had appeared in the study [16, 18, 27]. In Claflin et al. [23, 26] studies, they did not define any group specifically as participants. They invited all people who had registered for their multiple sclerosis course or completed it. Table 3. Represents in what part of the research article informal carers were mentioned.

Table 3. Informal carers in included studies

	Yes	No
F&F were mentioned in the methods section of the research	7 studies [15, 17, 20–25, 28]	6 studies [16, 18, 19, 26, 27]
F&F were participants in the study	8 studies [17, 19, 21–23, 26, 28]	6 studies [15, 16, 18, 20, 24, 25, 27]
F&F accompanied pwMS during the research	8 studies [16, 18, 20, 21, 24, 25, 27, 28]	6 studies [15, 17, 19, 22, 23, 26]
F&F appeared in the results or discussion section of the research	11 studies [16–19, 21–28]	2 studies [15, 20]

3.3   The Digital Health Aspect of the Included Studies

Telemedicine. Six out of 14 included studies were about telemedicine, meaning they arranged video appointments instead or in addition to in-person appointments at the clinic [18, 19, 24, 25, 27, 28]. Video appointment was organized with Zoom [18], VSee [19], Express Care Online telemedicine platform [24], or Skype [25, 28]. In one study software that was used in telemedicine was not mentioned [27]. Telemedicine made it possible for F&F to attend appointments from a third location [18, 27] and in some cases, pwMS did not need to leave the workplace to attend the appointment[18]. F&F often accompanied their cared ones with multiple sclerosis during their video appointment [18, 24, 25, 27, 28]. F&F also helped in arrangements or health assessments [19, 25, 28].

Online Education Course. Three of the included studies were about online education targeted to increase awareness or knowledge about MS [21, 23, 26]. In Claflin et al. studies [23, 26] they arranged it by Massive open online course (MOOC). Halstead et al. [21] had a web-based portal called MS hub, that was developed for their study. It was used for resilience intervention for pwMS and their partners.

Telerehabilitation with Video Games. In the included studies, there were two that studied telerehabilitation, in these cases digital rehabilitative games. Neither of them had F&F as participants in their study [15, 16]. Octavia et al. [15] had created a rehabilitative game that pwMS could play together with their family members but tested it in their research with HCP. They used individualized technology-supported and robot-assisted virtual learning environments (I-TRAVALE) and MOOG HapticMaster, a haptic robot, while the healthy co-player uses a WiiMote. They had developed games for individual and collaborative use. They thought that collaborative rehabilitation would have a positive effect on pwMS motivation, and it could provide social support, sympathy, and empathy [15]. Palacios-Ceña et al. [16] used for rehabilitative purposes pre-existing games for Xbox360 with Microsoft Kinect that were monitored with videoconference. They used the Kinect Virtual Home-Exercise Programme and the games they used were Kinect Joy Ride, Kinect Adventures, and Kinect Sports. During testing, F&F had joined a game with their loved one with MS [16].

User research and Software Development. In Sillence et al. [17] study F&F selected and used websites of their interest from a list. Websites contained information and experiences of MS and carers. Haase et al. [22] studied the use of information technology, barriers, needs, and requirements for eHealth solutions for a user-centered development process for a care portal for MS. Schleimer et al. [20] developed and studied the development of an app version of a data infrastructure platform called MS BioScreen that gathers data from various sources and visualizes the disease course.

3.4 Family- and Friend-Related Results of Included Studies

Two of the included studies did report F&F-related results [15, 20]. In one article family and friends' answers were combined with pwMS answers [22] and in two articles participants without MS were divided into two groups based on whether they identified themselves as carers. Informal and formal carers were combined in one group and another group was people who did not identify as carers [23, 26]. These results were not included in this section as F&F-related results could not be specified. Nine of the included articles reported F&F-related results.

Support and Information from Digital Sources. Especially those F&F whose loved ones had been recently diagnosed with MS wanted to find information about the condition. Those who had lived with the condition for a longer time were also interested in carers' experiences, especially in ideas on how to tackle everyday problems. People share their difficult experiences online more openly than in face-to-face support groups, but not all want to be reminded of difficulties [17].

Family Members and Friends as Carers. Some pwMS rely on their carer being with them in the appointment taking notes and asking questions. Telemedicine can make it easier for F&F to attend [27]. Telemedicine can also reduce carer burden as F&F can avoid taking time off from work [18]. F&F did not always see themselves as carers. Instead, some considered that they were going through things together with pwMS [17]. It can also happen that the person who usually drives pwMS to appointments does not attend remote appointments [27]. In Bove [18] et al. study, they also found that F&F attended not so often remote appointments than in-person appointments at the clinic. In Harder et al. [19] pediatric patients' carers arranged the remote appointments and 94% of them were satisfied with the videoconference health testing session and most of them considered it as acceptable as in-person health testing. 21% would rather choose an in-person assessment and 16% would rather use videoconference [19].

Family Members and Friends as a Source of Information for Healthcare Professionals. Telemedicine gives HCPs the possibility to meet informal carers of pwMS who maybe would not come to in-person appointments. This provides HCPs an opportunity to see who at home provides support for pwMS [27]. Meeting with the members of the household sometimes gave a different perspective of pwMS needs and status [24]. Toscano et al. [28] compared remote and in-person appointments' inter-rater agreement and in most health tests, it was better when informal carers accompanied patients. In visual assessment, carers made it possible to do the assessment properly. In

Bergamaschi et al. [25] research F&F's presence was considered important, especially in remote cognitive assessment.

Connecting People. Playing the Xbox Kinect game gave pwMS a new type of opportunity to connect with their family members as it was something that they could do together even though pwMS had limitations with their mobility. Instead of suffering treatments, pwMS were able to have fun with F&F by playing with them with Kinect [16]. Online education intervention was found to increase family members' satisfaction with their relationship with pwMS and improve their communication [21].

4   Discussion

In this scoping review, we identified 14 studies that had some information about family members and friends of pwMS in digital health research. Even though there was no time limit, the oldest research was from the year 2014 [15]. Most of the included articles, 10 out of 14 were from this decade, from the years 2020–2022 [19–28]. Only one of the 14 included studies had their main focus on the informal carers of pwMS [17] and two had them as one of the main participants [19, 21]. In Harder et al. [19] study patients were children and the research could not have happened without their guardians. All the other studies had adult participants.

Digital health aspects of the research were telemedicine, online education, telerehabilitation with video games, user research, and development. Telemedicine was the most common type of digital health, and it was examined in six out of 14 included studies. In most of these F&F were accompanying pwMS during their remote appointment with HCP [18, 24, 25, 27, 28]. In one study F&F arranged a remote appointment for a child but were not in the same room during the appointment [19].

11 out of 14 included studies had outcomes related to F&F [16–19, 21–23, 25–28]. Overall, in the included studies, there were not many outcomes considering F&F, but the results related to F&F were positive toward digital health. In this scoping review was seen that F&F can get support and information from digital sources, they are able to act as a carer in digital environments, HCP can receive information from them, and with their help and digital solutions can help F&F and pwMS to connect in a new or better way. In some studies, results related to F&F were reported by an HCP [24, 25, 27] or pwMS [16, 18, 27]. In one of the included studies, one reason for adding mental health services to telemedicine was that HCPs had noticed an increase in domestic violence during the COVID-19 epidemic [24]. It is good to keep in mind that families can also have interactions that can have a negative impact.

52 million people take care of their loved ones with disabilities in the EU weekly. In addition to taking their time and causing a financial burden, it affects their mental health [6]. Digital health has the potential to ease carers' burden. For example, transportation is one of the most common things F&F helps pwMS with [8]. One of the benefits of telemedicine is that pwMS and F&F can avoid traveling to a clinic that can be far away. Sometimes pwMS could travel by themselves but they need their F&F to accompany them at the appointment and for example to ask necessary questions [27]. In earlier studies, web-based interventions have decreased the stress, anxiety, and depression of informal carers [29, 30].

There were possible limitations in this study. Due to the resources, only one researcher did the screening, it would have been more reliable if it had been made independently by two researchers. It is a limitation that studies were only sought and included studies reported in English. Most of the included studies were from English-speaking countries and it might be explained by language limitation. Also, two articles were excluded in the full-text stage because they were not in English.

Currently, there is a limited body of evidence addressing the F&F of pwMS in digital health research. F&F may be often overlooked when designing digital health and its research. As populations in numerous countries age and health challenges become more prevalent, healthcare resources are becoming increasingly scarce. The rise of informal caregiving is anticipated across various health conditions, including multiple sclerosis. There is significant potential for digital health to aid informal carers in effectively caring for both their loved ones and themselves, thereby saving time and resources for everyone involved. This research shows that there is a lack of research on the inclusion of F&F of pwMS in digital health. Further research is imperative to fully understand and harness the benefits of digital health.

Disclosure of Interests. The authors have no competing interests to declare that are relevant to the content of this article.

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