The Use of Information and Communication Technology Among Informal Caregivers

Evridiki Papastavrou and Areti Efthymiou

1 Introduction

The number and proportion of people over the age of 60 years is increasing dramatically and, according to the World Health Organization estimations, is expected to increase up to 2.1 billion by the year 2050 (https://www.who.int/health-topics/ageing#tab=tab_1). Aging is often associated with several health conditions, chronic diseases, comorbidities, and frequent limitations that affect the everyday life and reduce the ability of people to live an independent life. As regards patients with cognitive decline that greatly reduces their ability for independent living, an estimated 6.2 million Americans aged 65 and older are living with Alzheimer's dementia today, and this number could grow to 13.8 million by 2060 [1]. Support in managing conditions associated with old age and related diseases, for example, cognitive impairment, is usually provided by the family and people who identify themselves as "informal caregivers." In the United States, and only for patients suffering from Alzheimer's disease, caregivers report about 18 billion hours of unpaid care every year [2] meaning that this number is much higher if informal caregivers of all diseases are added in the equation. Although many informal caregivers find caregiving as rewarding and associated with positive feelings, still providing care to older adults and other patients with chronic disabilities is stressful, and there is evidence of adverse outcomes such as burden, depression, anxiety, family conflicts, and lower quality of life [3–5]. Additionally, most caregivers report that apart from support,

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E. Papastavrou (✉)
Limassol, Cyprus
e-mail: e.papastavrou@cut.ac.cy

A. Efthymiou
Kaisariani, Greece
e-mail: al.efthymiou@edu.cut.ac.cy

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they need more information to manage the care they provide and to cope with the caring challenges and demands [6, 7]. Better caregiver preparation and training is also linked to lower rates of health care utilization and better communication of medical information. In a recent systematic review of the associated literature, it has been shown that caregivers who are more and better prepared for caregiving, demonstrate decrease in the related stress with a one-unit increase in caregiver preparedness connected to a 17% reduction in their stress [8]. The aim of this chapter is to investigate and report the importance and meaning of technological solutions for the informal caregivers of people living with chronic diseases in the community and especially for those caring of people with dementia. The discussion will follow with a scoping review conducted by the authors, aiming to explore e-health literacy of caregivers in relation to older persons and those suffering from dementia, the characteristics of those who are using the internet for the benefit of their patients, what they expect to find, and what they post in the social media.

2 Information and Communication Technology and Informal Caregivers

Information and communication technology (ICT) has emerged as a promising solution in the support of caregivers of chronically ill patients, and many researchers have demonstrated that technology-based interventions can improve outcomes among patients and can reduce burden and emotional strain among caregivers [9]. This type of solution consists of digital and related technologies, including hardware, software, networks, and media that facilitate collecting, capturing, storing, processing, transmitting, exchanging, and presenting information and/or communication [2]. Some examples for caregivers include interactive services, psychoeducational and stress management programs, informal caregivers' platforms, e-learning courses, telemedicine, and telehealth that all have the potential to support informal caregivers in the management of care. The importance of Information and Communication Technology is also recognized by the WHO [10] stating that:

> From technologies that allow people to manage their health more effectively, to better ways of diagnosing disease, to monitoring the impact of policies on population health, digital technologies for health, or digital health, are having a profound effect on how health services are delivered and how health systems are run.

The e-Health solutions targeted on informal caregivers that are most frequently described are mobile applications, web-based portals, and telehealth solutions delivering education, support, and stress management training, multimedia solutions for art viewing or music experiencing targeted at the caregiver–care receiver dyad to facilitate communication and enhance the relationship, or solutions targeting the psychological needs of caregivers [11]. The terms that are often used in the caring literature in recent years are electronic health (eHealth) and mobile health (mHealth), and according to the Global Observatory for eHealth, mHealth is defined as "a medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices." Mobile devices can be of great advantage for informal caregivers as they are widely available and normally easier to use than PCs, they are user-friendly, and they also allow handy access to internet-based applications [10]. WHO defines eHealth as the cost-effective and secure use of information and communication technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge, and research [11].

2.1 Information and Communication Technology and Informal Caregivers in the Dementia Context

Language and communication problems are present early in almost all types of dementia; they involve speaking, expressing, and conversation, and it is a source of tension for the families and caregivers. The impaired communication skills and memory function may result in tension in the caregiving dyad and the quality of relationship increasing caregiver stress that influence the caregiver well-being, health, quality of life, and their ability to manage care. Communication is considered one of the most challenging caring issues, and the factors that can contribute and explain this problem are described in the conceptual model of Morris et al. [12]. These include difficulties in understanding the changing internal world that affects the memory capacity and the personality of the patient as well as the diminished linguistic resources that do not allow patients to express their needs clearly, leading to informal caregiver frustration [12]. The increased dependence of the patient and the associated role changes, the lack of appreciation to the caregiver's offer, grief due to the "loss" of the person used to be, tension related to the history of long attachment relationships, and practical pressures, fatigue, and isolation may explain the challenges for communication and interaction between the caregiver and the care receiver [12]. Research offers promising findings for the potential of technology to promote communication and relationships in a way that relieves caregiver strain, creates meaningful interactions, and minimizes social isolation [13]. Some systematic reviews are providing interesting results of studies related to ICT-based solutions that have the potential to support informal caregivers in home care settings. Bratches et al. [8], focusing on the impact of technological solutions on the caregiver and patient outcomes, found statistically significant improvements in key outcomes for caregivers receiving visit information, including caregiver happiness, caregiver activation, caregiver preparedness, and caregiver confidence in managing patient health. In their systematic review of ICT interventions for informal caregivers of patients with dementia, Lucero et al. [14] categorized the technology used in telephone, video, and computer interventions and found that a range of these interventions are successful in supporting caregivers and may prevent outcomes such as burden, depression, and anxiety. Other authors describe the emergence of new technologies that can empower and support caregivers, such as the robotics, connected sensors, virtual reality, voice, and interaction of multiple technologies [15]. Yet, several reservations have been expressed by some authors related to challenges such as the design and usability of technology, funding, and sustainability; ethical challenges associated with equity, inclusion, access, autonomy, and privacy of data; and political and regulatory factors [16, 17].

However, although seeking, assessing, evaluating, and understanding health care information is crucial both for caregivers to manage and provide better care and for patients to receive safe and quality care, research findings are not consistent [18–20]. The fact that some studies have found poor informal caregivers e-health literacy and others satisfactory literacy can partly be explained by differences in methodological approaches and the selection of samples, based on the difficulties in deciding who can be better described as a caregiver.

3 Informal Caregivers and Internet Use

Some systematic reviews provided much information on the type of internet use that informal caregivers of different chronic diseases make without any further recommendation regarding the level of eHealth literacy [21–23]. People usually search for information on their suggested treatment, questions that doctors have not replied to and information on healthy habits, and most users consider the information on the internet to be of good quality. Technology tools used by informal caregivers were mainly videoconferencing tools, followed by phone-based technology, and less web-based info or remote monitoring and telemetry. The technology-based interventions for informal caregivers were categorized as follows: (1) education using mainly telephone-based, web-based, and video interventions; (2) consultation using videoconferencing; (3) psychosocial/CBT intervention using the telephone and videoconferencing tools; (4) social support, using videoconferencing tools; (5) data collection/monitoring including response center, sensors, and fall detectors; and (6) clinical care delivery using videoconferences [23]. The interventions reported were befriending and peer support intervention, family support and social network interventions, and support group and remote interventions [27].

Results of the above systematic reviews provided positive outcomes of the use of the web-based interventions for informal caregivers as the improvement in psychological health, well-being (measured with depression measures), sense of competence, decision-making confidence, self-efficacy satisfaction, knowledge, quality of life (QoL), social support, problem-solving skills communication with providers, cost-saving, and physical health. On the other hand, results showed that internet interventions did not affect depression, anxiety, burden, QoL, or social isolation [21, 23, 24]. The outcomes had qualitative results on sharing, companionship, and improved relationships, but there were not any quantitative results supporting this [21]. In the case of randomized trials, mental health has improved [22]. Videoconferencing and online psychological support were promising, providing evidence of enhanced satisfaction, on self-efficacy, and reduced burden, distress and depression [21, 22]. There is a growing research field discussing the type, impact, quality, and implementation of web-based interventions of informal caregivers of PwD to understand the factors that may influence informal caregiver characteristics and needs that would facilitate the internet-based intervention use. On the other hand, there were very few reviews on the type of internet (health-related and dementia-specific) use made by informal caregivers, such as the one reported by Ottaviani et al. (2021) stating that informal caregivers of people living with dementia indicate that internet-based interventions are mostly effective, efficient, and satisfactory. Caregivers also considered these to be informative, relevant, and functional, highlighting the utility and intention of using the resource in the future.

The following scoping review aimed to identify the available literature of the health-related internet use made by informal caregivers of PwD and older people with disabilities or chronic diseases focusing on the type of use those informal caregivers make and the characteristics that may influence this use.

4 Scoping Review on the Dementia Informal Caregivers Internet Use

4.1 Review Methodology

The methodology followed the Preferred Reporting Items for Systematic Reviews and Metanalysis for scoping reviews [25] as well as the five stages of Arksey and O'Malley, [26] on scoping reviews. As part of the research questions, we searched for the characteristics of the informal caregivers that may predict the internet use and dementia-specific internet use, the way that informal caregivers use the internet, available theoretical frameworks for dementia-specific internet use, and the needs of informal caregivers with dementia when using the internet. In the second stage, we identified all relevant studies by searching all available resources: electronic databases, conference proceedings, and gray literature. We have included studies with informal caregivers in general and of older people and PwD, as in this way, we broaden our search, and it was possible to find related information on our topic that was important for us to understand the phenomenon. Based on this, we also included interventional studies, even if not related directly with internet use, as this type of research is an indicator of online service use, and we were also interested in mapping the existing research on online use and services. Additionally, usually in the interventional studies, there is always the usability issue and how ready and friendly the informal caregivers consider this type of technology, which was a question of interest in our research. Studies were excluded if the language was not English and if there was no full paper available. Systematic reviews of the relevant topic were also identified but not included. No type of study design was excluded as the area is new, and we were interested in identifying all possible aspects. The search resulted in 1223 papers, and after reading the titles, we included 208 papers. Through abstracts reading, we included 101 papers, and after full-text reading, we concluded 13 papers. Another six articles were included by the snowball effect. The final number of included papers for review raised to 19 full texts. The reviewers also included a quality appraisal section in the same sector for the selected papers used for qualitative studies (interviews and focus groups), the Consolidated Criteria for Reporting Qualitative research (COREQ), for the observational study Strengthening the Reporting of Observational Studies in Epidemiology Statement (STROBE), and for the online surveys, the Checklist for Reporting Results of Internet E-Surveys (Cherries). All the information regarding the scoping review is shown in Table 1.

Table 1 Results of the scoping review on the Dementia Informal Caregivers Internet Use

Authors, year	Country	Qualitative assessment	Participants	Design	Category	Main outcomes	Theory
(Chiu and Eysenbach, 2010)	CHINA	STROBE 17/22	46 family carers of PwD	Multiphase, longitudinal design, interventional quantitative	Understanding patterns of internet intervention use	Consideration stage (easy technology matters), initiation (acceptance of technology matters), utilisation (frequency of use matters)	Andersen's behavioral model of health service use and Venkatesh's unified theory of acceptance and use of technology
(Chiu and Eysenbach, 2011)	CHINA	COREQ: 12/32	14 family carers of PwD	Qualitative analysis (in depth interviews)	Conceptualization patterns of internet intervention use	Dimension of the web-based intervention use: (a) caregiver needs, influenced by personal capacity, social support, and caregiving belief; (b) information communication technology (ICT) factors (accessibility barriers and perceived efforts) and (c) style of using the technology	Anderson's model of health service utilization, Venkatesh's theory of technology acceptance, and Chatman's and Wilson's information behavior theories
(Kim, 2015)	USA	STROBE = 19/22	450 family carers of PwD	Descriptive correlational design	Internet use	59% identified as internet users. Health-related internet users were younger, more educated, higher income, fewer hours of caregiving. Sociodemographic characteristics and subjective response to stress indicators of health-related internet use, followed by the hours of caregiving	Stress process model

(Larner, 2003)	UK	STROBE = 5/22	104 carers of people with cognitive decline	Descriptive study	Use of internet and NHS help line of patients and carers	More than 50% of patients and families/carers had internet access; 27% had accessed relevant information. 82% expressed interest in, or willingness to access, websites with relevant medical information if these were suggested by the clinic doctor. Although 61% had heard of the NHS Direct telephone helpline, only 10% of all patients had used this service	N/A
(Blackburn et al., 2005)	UK	STROBE = 16/22	3198 carers	Cross-sectional survey	Internet use	Half (50%) of all carers had previously used the Internet. Of this group, 61% had used it once a week or more frequently. Factors significantly associated with having previously used the Internet were carer's age, employment status, housing tenure and number of hours per week they spent caring. Frequency of Internet use was significantly associated with carer's age, sex, employment status and number of hours spent caring	N/A
(Alwan et al., 2011)	USA	REPORT	1000 carers of adults with mental, physical illness	Quantitative online study	Usability and needs met by 12 technologies	Reported benefits of web-based use: saving time, facilitating caring, safety, self-efficacy and reduction of stress	N/A

(continued)

Table 1 (continued)

Authors, year	Country	Qualitative assessment	Participants	Design	Category	Main outcomes	Theory
(Kernisan et al., 2010)	USA	COREQ: 14/20 OR CHERRIES 30/30	2161 carers (50% caring for parents of elders	Five questions pop up survey	Internet use	People visiting a caregiving-related website search for general information on caring, specific assistance (custoial, medical, emotional and financial), training, disease progression and symptoms, caring support, peer support	N/A
(Lam and Lam, 2009)	AUST RALIA	STROBE: 16/20	784 carers of older adults over 60 with disability	National health survey	Internet use	Significant association between use of internet and better mental health status	N/A
(Fox and Brenner, 2012)	USA	REPORT	860 carers of adults	National telephone survey	Internet use	Caring is associated with being online and with online e-health behaviors. Carers are active health care consumers	N/A
(Kim, 2012)	USA	DISSERTATION	752 family carers of PwD	Telephone surveys	Internet use	Carers' stress may predict carers' perception of poor health status. Health-related Internet use did not mediate this relationship effectively	N/A
(Li, 2015)	USA	STROBE: 19/22	800 carers of older adults over 65		Internet use	Carers search for care receivers' conditions or treatments (77.2%), available services for care receivers (52.7%), and care facilities (35.3%). Only a small percentage search for support for themselves	Wilson's model of information-seeking behavior

(Anderson et al., 2017)	USA	COREQ 18/21	3245 carers' posts of PwD	Descriptive study/ qualitative research/ analysing samples of blogs	Internet use	Themes derived from carers' posting social support through communication and engagement, information gathering and seeking, reminiscing and legacy building, altruism	N/A
(Werner et al., 2017)	USA	COREQ 18/32	26 carers of PwD	Qualitative (4 focus groups)	Information needs assessment/internet use?	Authors find three critical information needs: (1) timely access to information, (2) access to information that is tailored to caregiver's needs and (3) usable information that can directly inform how caregivers' manage behaviors	System engineering initiative for patient safety
(Yoo et al., 2010)	USA	COREQ 9/21	798 carers' messages of PwD	Qualitative study/content analysis	Socio-affective regulation (SAR) and goods-and information acquisition (GIA)	The results indicated that Korean caregivers expressed more family burden than US caregivers. Also, the Korean caregivers expressed more negative emotions than the US caregivers	N/A
(Jeong et al., 2018)	USA / South Korea	STROBE = 16/22	104 dementia carers	Descriptive correlational design	Information seeking and forwarding-cybercoping	Information seeking is associated with the affective coping and physical coping than information forwarding. Information seeking is associated with problem focused coping	Chiu and Eysenbach, 2011 and Lazarus (emotion based and problem-based coping)

(continued)

Table 1 (continued)

Authors, year	Country	Qualitative assessment	Participants	Design	Category	Main outcomes	Theory
(Allen et al., 2018)	UK	CHERRIES 13/30	212 dementia carers	Online and postal survey (questions adapted from the US health and services 2014)	Dementia information seeking, access and understand	Source of information accessed: First source: Internet (almost all except 2 people)- 82% search dementia specific information, 57% accessed the web through mobile. Second source: health and social care professionals Factors related to frequency of use: Age in majority, they were searching info by dementia charities websites Relational information source: GP and friends and family Friends and family most popular information resource for emotional support Passive information resources: Newspapers, television and internet Health and social care professional as most inaccessible sources and internet as the most accessible source followed by the published material Most important characteristic of information source: trustworthiness, accessibility and answer questions	N/A

(Lucero et al., 2018)	USA	COREQ21/32	20 carers and 11 caregiving counselors	Qualitative (6 focus groups of 4–6 people)/ exploratory study	Effectiveness of family-HIMS intervention	Three tasks and six skills were presented in the analysis: Tasks: medical management, role management and emotional management. Emotional management and resource utilization mentioned more often, by carers and counsellors, medical management more often by the caregivers. 6 self-management skills: (1) Problem-solving (2) Decision-making (3) Resource utilization (4) The formation of patient-provider partnership (5) Action planning (6) Self tailoring	*Chronic disease self-management program framework: Improvements in health status and outcome are result of an individual's knowledge ability and confidence in practicing self-management*
(Ruggiano et al., 2018)	USA	COREQ 14/32	36 dementia carers	Beta test interviews for care IT	Use of technology and an app	Current technology use: all had access to internet, spouses less active on the internet in comparison with children. They do not use the technology for caregiving activities. Only three people use apps for caregiving. Importance to the usefulness of the technology to generate interest to use: social networking, and personalized technology Half of the participants support that IT would be helpful for medication management information	Technology acceptance model

(continued)

Table 1 (continued)

Authors, year	Country	Qualitative assessment	Participants	Design	Category	Main outcomes	Theory
(Scharett et al., 2017)	USA	COREQ 11/19	250 posts and related responses (randomly selected) of dementia carers	Post qualitative analysis	Emotions of problems stated and given solutions	Categories from initial analysis of 500 posts: Problem categorization: Carers feelings/Symptoms/Doctors and nursing homes/physical safety/basic hygiene/general info/medicines/conflicts/solutions/ethics. Solution categories: informational resources for carers, contact professional assistance, assisted care facilities, doctor consultations, caregivers well-being, patients well-being, memory problems, safety, medication, bathing and sanitation, anxiety or depression, hallucinations, home care	Linguistic inquiry and word count system: provide an emotional rating 0 to 100 (0 negative emotion and 100 positive emotion)

4.2 Characteristics of the Studies Reviewed

Much of the internet use research among informal caregivers was based in the United States, with 11 out of 19 papers developed in the United States. Other countries of research were the United Kingdom (*n* = 4), China (*n* = 2), Australia (*n* = 1), and South Korea (*n* = 1). The total number of the study sample was 10,091, with five papers using a sample under 50 informal caregivers [1, 19, 34–36]. Furthermore, three research papers analyzed 3393 posts on social media and forums to understand how informal caregivers of PwD post online [20, 21, 37]. Most of the papers focused on informal caregivers of PwD (*n* = 13). In other cases, the research focused on informal caregivers of older people (*n* = 3), informal caregivers of adults (*n* = 1), informal caregivers without defining (*n* = 1), and informal caregivers of adults of mental and physical diseases (*n* = 1).

1. Quality of the studies

   In the analysis, nine qualitative studies and ten quantitative studies (including two reports and one dissertation) were included. In the case of the qualitative studies, three of them analyzed and discussed the findings from the text that was already uploaded on the internet by the informal caregivers of older people through related websites or open online support groups as ALZConnected.org and other blogs. In most of the qualitative studies, the authors did not provide information on the personal characteristics of the interviewers or moderators or the relationship that was established during and before the study. Information regarding methodology orientation, sampling, and data collection as well as the consistency of data and findings and presentation of major and minor themes were always included. On the other hand, authors usually did not provide information on data saturation, setting of data collection, involvement of the participants in the transcription and findings, and nonparticipation rates. The three papers that used online posted material and messages were the most difficult to be assessed as in COREQ most items were not related as in the case of the relationship with participants, nonparticipation, method of approach, presence of nonparticipants, setting, interview guide, duration, and transcription. In this case, we used items 1–5 regarding the characteristics of the coders, theoretical framework, participant (posts) selection, description of the sample, data collection, analysis, and findings items. Only in one case did the authors discuss this regarding the terminology of posts and if posts considered being handled as "participants" [27]. In six of the seven studies, the assessment of the observational studies was high with minimum score 16/22 and maximum 19/22. Only in one study did we find a low score of STROBE 5/22 including only items 3, 5, 13, 14, and 18. In this study, the topic discussed the use of the internet and NHS telephone line from people with cognitive disorders and was the first study that we included chronologically in the area, followed by Blackburn [28].

2. Theoretical underpinning of the studies reviewed

   Most of the studies were not based on a certain theory, and only in nine out of the 19 papers, a theoretical framework supported the findings, although all studies used a different theoretical approach. In total, nine theories were presented:

   The "Andersen's Behavioral Model of Health Service use: Model explaining service use including three main dimensions, predisposing, enabling and needs factors."

   The Venkatesh's unified theory of acceptance and use of technology: intention to use information technology with four core dimensions—performance and effort expectancy, social influence, and facilitators.

   The "Chatman's and Wilson's information behavior theories: dynamic relation among the user, information system and information resources."

   The "Stress Process model" developed by Pearlin.

   The "System Engineering Initiative for Patient Safety: sociotechnical system model."

   "Lazarus coping strategies: primary and secondary appraisal, coping processes and coping styles: problem-focused and emotion-focused."

   "Law of Attrition" by Eysenbach—stages of use: consideration, initiation of use, attrition or continuation of use, and outcomes."

   "Chronic disease self-management program framework: improvements in health status and outcomes are a result of an individual's knowledge, ability and confidence in practicing self-management."

   "Linguistic inquiry and word count system (to analyze the emotional level of posts online)."

5 Results of the Scoping Review

5.1 The Profile of the Caregivers Who Use the Internet for Caregiving

Caregivers' characteristics that affect the use of the internet for health-related or caregiving topics Internet access and use by informal caregivers seemed to be influenced by socioeconomic factors. The age of the informal caregivers and the age of the person cared for, gender, employment status, living conditions, and hours of care are factors associated with internet access and frequency of use. Being over 55 years old and with more hours of care was related to limited internet access and less frequent use. Being not in paid employment was also connected with not having use the internet. Being a female was the strongest predictor for using the internet less than once a week [28]. The health-related internet use was also related with sociodemographic characteristics of informal caregivers, such as age, education, income, hours of caregiving and relationship with the cared-for person, age of care recipient and instrumental of daily living (IADL) level of dependency, chronic condition, and having a recent crisis in health. More specifically, younger informal caregivers (children and grandchildren) more educated, with higher income, more financial hardships, and fewer hours of caregiving were most likely to be health-related internet users [29, 30]. Dementia-specific internet use was also associated with being informal caregivers or not [30]. Internet use was associated with better mental health after adjusting for confounders such as the age of the informal caregiver, being a primary informal caregiver and caring for a disabled person significant [31]. The frequency of internet searches for caregiving information was related to the informal caregivers' service needs, being or not a primary informal caregiver, informal caregivers' strain, and health status. The higher the service needs for informal caregivers, being a secondary informal caregiver, reporting better health status and higher caregiving strain, the more likely it was for informal caregivers to search the internet [32]. The percentages of internet use and access differed according to the study. Blackburn, Read, and Hughes [28] found that 61% were frequent users and almost half had internet access, and Kim [29] found that 59% of the informal caregivers used the internet for health-related reasons and caregiving information.

5.2 How Do Informal Caregivers Use the Internet?

Informal caregivers of older people visiting a caregiving website mostly looked for health information, practical issues, and legal and financial issues [33]. These preferences were directed from the type of caregiving. Informal caregivers also searched online to communicate and receive support by other informal caregivers, health professionals, and eHealth solutions. Kernisan et al.'s [33] group replies in four categories: (a) caring for a parent, (b) caring for themselves only, (c) other caregiving situations, and (d) unknown caregiving situations. In the case of the informal caregivers of older people, practical issues were the most frequently searched. According to Lam and Lam [31], the most common use of the internet among informal caregivers in Australia included chat sites and emails. This related to the informal caregivers needs to communicate. Furthermore, informal caregivers used the internet for information and for accessing government services, to pay bills. Informal caregivers who used the internet 12 months before the study had better mental health in comparison with the informal caregivers who had not used the internet during that period. In another study by Li [32], using secondary data of 812 informal caregivers from the US caregiver survey, informal caregivers searched for disease-specific information (77.2%) and services for the patients (52.7%), and only 11% searched for information for themselves. In the report by Pew Research Center "Family Caregivers Online" [30], 860 informal caregivers participated in the survey about internet use among informal caregivers in the United States. From most of the sample, 79% used the internet at home, 88% searched for health information online, and 55% had a laptop or another mobile device. Informal caregivers were more likely to search for health information for someone else, use social media for communication, and read clinicians, medical facilities, and drug reviews. They also considered the internet as useful when searching for health- related issues. In other research on information-seeking among the family of PwD, 171 out of 214 informal caregivers replied that they were searching for information mainly through dementia association websites (82%) and that 38% rated the information that they found on the internet about dementia as low quality [34]. The internet together with newspapers and television was considered as passive information sources, and the internet was considered the most accessible source (86%) and was the first source of the search for information followed by health professionals. Informal caregivers also considered access to online sources as important for the knowledge and skills of health self-management [2]. Informal caregivers considered technology use as important for networking and personalized care, being most useful for information management [35]. In the same study, spouses made less frequent use than children who cared for a parent with dementia, and only three informal caregivers used applications for caregiving.

5.3 What Do Informal Caregivers Post Online?

In the case of the research by Anderson et al. [27], 2345 posts were analyzed by nine websites and were categorized in four categories: (a) social support–communication and inclusion, (b) the search for information, (c) sharing of memories with the person with dementia, and (d) information to other informal caregivers and advocacy. In another study by Yoo et al. [36], 798 messages were analyzed by informal caregivers from South Korea, and they found that informal caregivers expressed mostly negative feelings in comparison with informal caregivers in the United States, and they looked for emotional support to online communities. More recently, 500 posts of the Alzheimer Association forum were categorized in ten categories: feelings, symptoms, doctors and services, physical safety, hygiene, general info, medicine, conflicts, solutions, and ethics. Another 250 posts randomly selected included their solutions and were included in the below categories. The problems were mostly negative, and solutions provided by other informal caregivers or moderators were neutral. The solutions were also categorized into six categories: information, communication with experts, assisted care facilities, memory problems, safety and care at home [37], and information search and coping, a model developed to associate information seeking and information forwarding among informal caregivers of PwD and coping strategies online. Information seeking was associated more with problem-solving techniques and information forwarding with emotion-based techniques [38]. Needs and benefit among informal caregivers of PwD informal caregivers considered as important elements for using the technology to have on-time access to related tailored information and be able to receive information online for direct behavioral management [39]. According to the American National Alliance for Caregiving [40], benefits for accessing online health-related information were: (a) time-saving, (b) support with caregiving, (c) safety of the person receiving care, and (d) a sense that the caregiver is effective.

6 Conclusions of the Internet Use Among Informal Caregivers Systematic Scoping Review

The scoping review searched all available published research of health-related or dementia-related internet use among informal caregivers of PwD, elderly, and adults with mental or physical chronic conditions. In the papers included, the importance of internet use was identified, and predictors of the use are reported such as age, relationship with the patient, education, socioeconomic position, and other characteristics. Informal caregivers searched online for dementia information and services, and they tried to communicate with other informal caregivers or health professionals. eHealth literacy was not reported in any of the above published papers of the search period (2000–2018) neither as a theory or as survey concept, even if in many cases, the related questions may have been part of the concept of eHealth literacy.

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