

# **The use of digital technologies in the promotion of health literacy and empowerment of informal caregivers: a scoping review**

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# The use of digital technologies in the promotion of health literacy and empowerment of informal caregivers: a scoping review

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## Abstract

**Background:** Informal caregivers play an important role in the community as healthcare providers to people who are dependent. Health literacy contributes to empowering, care and self-management of one's own health and can be enhanced by using digital technologies.

**Objective:** To map scientific evidence about the use of digital technologies to promote health literacy and empowerment of informal caregivers.

**Methods:** A scoping review was carried out following the Joanna Briggs Institute (JBI) methodology. CINAHL, MEDLINE, SCOPUS and PUBMED were the databases searched to find primary studies about the theme. Inclusion criteria were based on the Population, Concept and Context (PCC) logic. To be selected for analysis studies must have involved informal/family caregivers aged 18 or older who provide care to dependent persons and who have access to the Internet and digital devices (computer, smartphone, tablet). Two independent researchers made the screening process.

**Results:** Nine studies were included in the review. The analysis of the studies showed that informal caregivers use digital tools, such as computers and smartphones, with smartphones being the preferred tool. Informal caregivers use the Internet to access information, manage home tasks, and communicate with relatives, their peers, healthcare professionals, and forums. Due to difficulties in leaving their houses, forums are highly valued to preserve human connections.

**Conclusions:** The use of digital technologies to convey clear, objective, reliable, and accessible information is a strategic action for promoting health literacy and for contemplating the variable care needs of informal caregivers. By working with informal caregivers in the development of new technologies, researchers are building a new tool that meets informal caregivers' needs. Clinical Trial: This study is part of a main project which was approved by the Ethics Committee for Health of the Regional Health Administration of Lisbon and Tagus Valley (reference 058/CES/INV/2022).

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## Study Design

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## Abstract

**Background:** Informal caregivers play an important role in the community as healthcare providers of people who are dependent on self-care. Health literacy contributes to empowering, better care and self-management of one's own health and can be developed by using digital technologies.

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difficulties in leaving their houses, forums are highly valued to preserve human connections.

**Conclusions:** The use of digital technologies to convey clear, objective, reliable, and accessible information is a strategic action for promoting health literacy and for contemplating the variable care needs of informal caregivers. By working with informal caregivers in the development of new technologies, researchers are building a new tool that meets informal caregivers' needs.

**Ethic register:** This study is part of a main project which was approved by the Ethics Committee for Health of the Regional Health Administration of Lisbon and Tagus Valley (reference 058/CES/INV/2022).

**Keywords:** Health literacy; Empowerment; Digital Technology; Informal Caregiver; Family Caregiver.

## Introduction

Population aging is a social challenge worldwide. As life expectancy increases, the incidence of chronic and incapacitating diseases also increases [1]. The high levels of dependence and the complex management of health status raise awareness of the increasingly relevant role of informal caregivers (ICs) in terms of care and health promotion of their relatives [2]. The ICs defined as “someone who provides non-remunerated care to a person with a long-term illness, disability or other health need, or long-term care, outside a professional or formal framework”, are considered essential both to the care of people in the community and to the economy of European Union countries [3]. ICs are more and more important to patients, as well as to health care professionals [4]. They play a central role in the planning, training, and provision of services to people with care needs [2-3]. In practical terms, ICs collaborate in providing health care at home to people who show an impairment in self-care, activities of daily living, and instrumental activities of daily living. The needs change over time, as well as the level of dependency of the person cared for [5].

In most situations, ICs are not prepared to play this role. This transition in caregivers' lives brings out



feelings of insecurity due to the unknown and the lack of knowledge and skills to make sure the person cared for is given proper care [5]. This way, ICs' existing and acquired knowledge is extremely important and becomes necessary for the implementation of interventions destined to promote the development of skills and the involvement of relatives in patient trajectories to improve patient outcomes [2-4].

A vital point in health policies is the investment in health literacy (HL) of ICs. Health literacy is central to empowering people, their families, and the communities, promoting greater control over decisions and actions affecting their health [6]. HL is defined as the ability to access, understand, evaluate, and apply information about health care, disease prevention and health promotion to maintain and promote quality of life during life course [7].

By HL development, conditions are created for individuals to gain knowledge and skills, make informed decisions, and feel motivated to adopt a behaviour that improves their health status and well-being [8].

Considering that HL is a health determinant, mediator, and moderator, it is important to make sure that citizens access reliable, useful and updated health information to help them make the best decisions for their personal health, their family's health, and the community's health [9-11]. Proper access to information allows to promote and increase citizen empowerment so that they participate in their health care, leading to shared responsibility and informed decision-making [12].

As an agent, the health care professional plays a central role in effective communication and in conveying reliable information to the population. User-relative-health care professional communication significantly affects health outcomes and user satisfaction concerning health services [13]. Digital technologies have created an opportunity for health professionals and health organizations to directly communicate with many people in real time. This digital revolution in communication allows to customize information, help people to set health targets and interact in real-time [1].

Information and Communication Technologies (ICTs) is the set of technologies and equipment that, in an integrated manner, allow working and communicating information, including computers and the respective applications, the Internet and telecommunications [14]. They are part of the citizens' routine, with an increasing use of educational platforms. The Internet is considered a privileged means of interaction with the population that needs health care [1].

ICTs improve the quality of life of the elderly and their caregivers and the access to quality care, contributing to improving the social life of caregivers and decreasing their isolation via social activities and intergeneration relationships [15]. These aspects contribute to balanced physical, mental, and emotional health and to the decrease of depressive symptoms and sadness. Digital technologies are considered “a key component and facilitator of sustainable health systems and universal health coverage” [16]. Digital technology is a strategy that can promote accessibility to health care for all citizens. Digital means can be used to increase access to reliable, useful information and to strategies that meet the needs of the highest possible number of ICs, whether in real-time or not [1]. However, accessing and handling these technologies requires digital literacy, which is one of the barriers identified by studies in certain vulnerable groups, such as the elderly. Digital health literacy is the ability of citizens to use digital platforms to manage their health, validate web-accessible health information and communicate with health professionals [17].

In the Portuguese literature, there are only a few scientific studies made by nurses that refer the use of digital technologies as a resource to empower dependent people and family caregivers [1]. The need to know if dependent people and their ICs have access to digital technologies and use them when they have health needs gave rise to the following research question: “Which digital technologies are used for promoting Health Literacy and empowering the Informal Caregiver?”. For the mapping were elaborate the following guiding questions “Do the Informal Caregivers have access to digital technology?”, and “Do the Informal Caregivers use digital technologies to improve

their health literacy and empowerment concerning the care of the person cared for?” To answer these questions, this review aims to map the scientific evidence regarding the use of digital technologies to promote health literacy and empower the Informal Caregiver.

## Methods

This is a scoping review conducted according to the methodology recommended by JBI [18]. Scoping reviews are used to identify knowledge gaps, enhance knowledge described in the literature, clarify concepts, or investigate research conduct [19].

The theme was searched in the JBI Database of Systematic Reviews, CINALH, MEDLINE, SCOPUS, and PUBMED, and no systematic review was found for this same theme. Inclusion criteria were based on the Population, Concept and Context (PCC) logic: the Population included all informal/family caregivers aged 18 or older who provide care to dependent persons and who have access to the Internet and digital devices (computer, smartphone, tablet).

The search was done from 4 to 18 April 2022 and included primary qualitative and quantitative studies and mixed method studies in English, Portuguese, French and Spanish languages, within a period of five years between January 2017 and December 2021, to get the most recent studies published about this theme. Key terms and inclusion criteria were used as a strategy to identify papers that were relevant to the search.

## Study selection, data extraction and analysis

According to JBI's recommendations, the search strategy was done in two steps (18). There was an initial search of the electronic platform EBSCO, in particular the MEDLINE and CINAHL with natural keywords: *informal caregiver, family caregiver, health literacy, empower, digital technology*, and *community*, following the search for the terms of indexing: MH

“Empowerment”. Subsequently, the analysis of the words used in the title, abstract, and terms indexed, and keywords presented in the description of each searched article. Was then made a

second survey in which the indexing terms and keywords were searched in MEDLINE (PubMed), CINAHL (via EBSCO), MEDLINE (via EBSCO), and SCOPUS (Table 1).

*Table 1 – Search strategy according to database searched*

Database	Search strategy
MEDLINE (via PubMed)	((informal caregivers) OR (family caregivers) AND (community) AND (“health literacy”) OR (empowerment) OR ((digital education) OR (digital technology) OR (digital era) OR (digital platforms) OR (digital sources) OR (Information and communication technology))) in the last 5 years
CINAHL complete (via EBSCO)	<b>S1</b> informal caregivers <b>S2</b> family caregivers <b>S3</b> S1 or S2 <b>S4</b> community <b>S5</b> health literacy <b>S6</b> empowerment <b>S7</b> MH"empowerment" <b>S8</b> empower* <b>S9</b> digital technology <b>S10</b> digital era <b>S11</b> digital health literacy <b>S12</b> digital sources, <b>S13</b> digital education <b>S14</b> digital platforms <b>S15</b> Information Communication Technology <b>S16</b> S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 <b>S17</b> S3 and S4 and S16
MEDLINE (via EBSCO)	<b>S1</b> informal caregivers <b>S2</b> family caregivers <b>S3</b> S1 or S2 <b>S4</b> community <b>S5</b> health literacy <b>S6</b> empowerment <b>S7</b> MH"empowerment" <b>S8</b> empower* <b>S9</b> digital technology <b>S10</b> digital era <b>S11</b> digital health literacy <b>S12</b> digital sources,

	<b>S13</b> digital education <b>S14</b> digital platforms <b>S15</b> Information Communication Technology <b>S16</b> S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 <b>S17</b> S3 and S4 and S16
Scopus	(TITLE-ABS-KEY ("informal caregivers") AND PUBYEAR > 2016) OR (TITLE-ABS-KEY ("family caregivers") AND PUBYEAR > 2016 AND PUBYEAR < 2023) (TITLE-ABS-KEY (community) AND > 2016 AND PUBYEAR < 2023) (TITLE-ABS-KEY ("health literacy") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("empower*") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("empowerment") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("mh empowerment") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital technology") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital era") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital sources") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital health literacy") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital education") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("digital platforms") AND PUBYEAR > 2016 AND PUBYEAR < 2023) OR (TITLE-ABS-KEY ("information and communication technology") AND PUBYEAR > 2016 AND PUBYEAR < 2023) (TITLE-ABS-KEY (#3 AND #4 AND #16) AND PUBYEAR > 2016 AND PUBYEAR < 2023 AND (LIMIT TO (LANGUAGE, "English") OR LIMIT TO (LANGUAGE, "Spanish") OR LIMIT TO (LANGUAGE, "French") OR LIMIT TO (LANGUAGE, "Portuguese")))

Two independent reviewers analysed the relevance of papers using the information included in the title and abstract, considering that the study population must be defined, and the goal must be associated with digital tools.

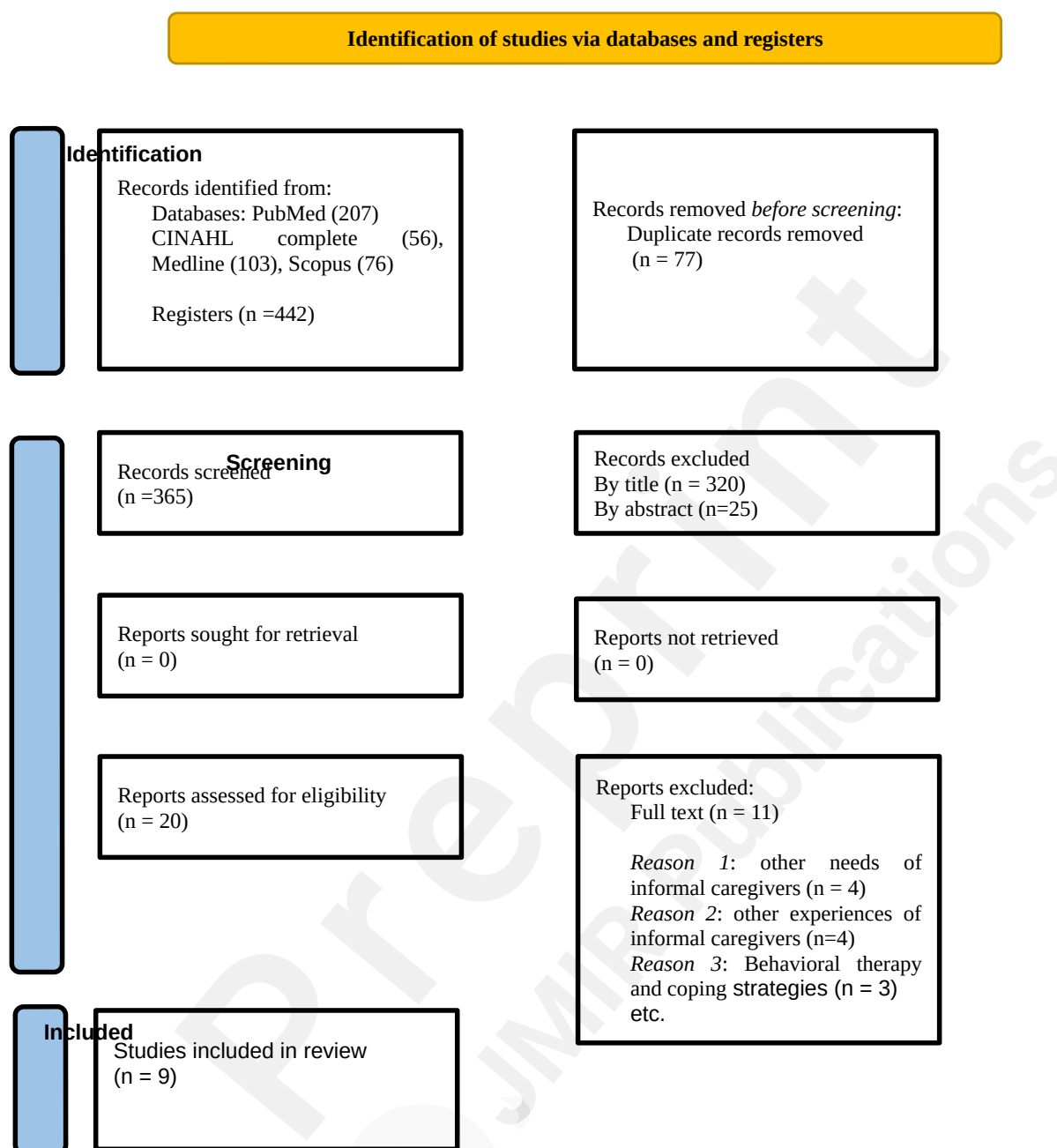
It was necessary to retrieve papers after reading the abstract. Full papers were obtained for all studies with inclusion criteria. A table was filled with defined criteria. Considering the goals and results of the study that would answer the research question. After reading the full text,

two papers showed a divergent opinion. This situation was discussed and resolved without the need to speak to a third reviewer.

The screening process identified 442 studies. Of these, 77 were duplicated and so were excluded. From the remaining 365 studies, 320 were excluded for their titles and 25 for their abstracts, based on the inclusion criteria that had determined their eligibility. In the second step, there were 20 papers for full-text review. Eleven were eliminated because of the following reasons: their goals did not relate to the technological needs of ICs, but to the person cared for ( $n=4$ ); they were about another type of non-technological experiences ( $n=4$ ); and they were about behavioural therapies and coping strategies ( $n=3$ ). Figure 1 shows the PRISMA flowchart of the paper's identification and selection.

A data collection instrument was made to extract information from the selected studies, including the following items: author, country, year of publication, study goal, study type and methodology used, population, sample, types of interventions, main results, and conclusion. Results were analysed based on their content and were organized according to the research question and goals.

Figure 1 – PRISMA Flowchart



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

## Results

Nine studies were included in this review as result of the search. According to JBI's guidelines, after the selection, the studies were organized based on their research question and goals (Table 2 and 3).

As to the year of publication, the studies were published in 2017 ( $n=1$ ), 2019 ( $n=1$ ), 2020 ( $n=4$ ), and 2021 ( $n=3$ ). They were made in the following countries: Canada ( $n=4$ ), United States of America ( $n=2$ ), Scotland ( $n=1$ ), Singapore ( $n=1$ ), and Spain ( $n=1$ ). Three studies followed a qualitative approach, four followed a mixed approach, one was observational, and one was a quasi-experiment.

The results of the studies allowed answering the guiding questions. On the question “Does the Informal Caregiver have access to digital technology?”, the studies show that ICs have access to and use digital technology [27, 28]. They describe which type of technological resources are used more frequently by them, smartphones with mobile apps and Internet access. The Internet is the source of choice for accessing health information and learning about self-management techniques, with the importance of reliable websites being emphasized [22, 26, 28]. Smartphones are used to make calls, send SMS and e-mails, and access the Internet [28]. Apps are used to manage the appointments and medical information of the person cared for and to access specific information that allows ICs to share and discuss to commit to the caregiving relationship (28). The aesthetic dimension, easiness of configuration and nice interface are app features that are valued by informal caregivers [22, 28].

Privacy and security issues seem to be a factor that limits the use of technologies because users feel insecure due to the risk of sharing personal information [24, 19]. Struggling to identify relevant, reliable information is also a factor that causes apprehension when it comes to Internet use [22]. The degree of trust when accessing digital information seems to be related to the health literacy level of users [29]. Users with low health literacy levels who did not use the technology that was being analysed had little experience using computers, no training, and no Internet access at home. Those who used the portal showed increased interest in learning and practising with the new technologies [29]. This fact reinforces the need for specific training for the use of digital technologies to gain trust [29].



Regarding the question “Does the Informal Caregiver use digital technology to improve their health literacy and their training in caring for the person cared for?”, the studies show that the use of digital technology can benefit the population as well as caregivers [21, 22, 24, 28,29].

ICTs lower information access barriers and provide relevant information that is enabled when there is the need to gain new knowledge [21, 22]. ITCs are perceived as giving the ICs the opportunity to guide themselves and interact with other caregivers, which allows them to get to know their peers and feel less lonely [23,25].

Caregivers say that, by using digital technologies, they can get basic information about the disease, such as symptoms and treatment options, and about existing resources and equipment, which makes them feel less lonely in this role [21, 26-27]. With the support of digital tools, caregivers felt recognized and heard and could express their uncertainties, stories, and suggestions, which increased their commitment to care provision [26]. Technology also keeps their caring ability and allows them to develop coping strategies [25].

The use of technology is also referred to as an intermediary for an improved quality of life [21, 23]. This perception of the improvement of the quality of life is boosted when the technology that is used includes multiple resources, such as the fact that there is a public forum for community discussion with other ICs in the same region without having to leave home; a market to purchase and sell materials and equipment that is needed for providing care; and an alert system or information trackers [22, 24]. The integration of the multiple resources that are needed by caregivers daily in an app that is easy to use allows them to save time and provides help to browse without problems [24].

Another aspect referred to by the studies concerns suggestions or factors that can improve the experience of informal caregivers when using digital technologies. There is a study describing that new technologies that are only focused on the task can lose their value, as they lose the capacity to provide information that is relevant to caregivers’ needs [21]. It is important that

ICs collaborate in the development of technologies because their deep knowledge of the needs and existing gaps contribute to technological innovation, which allows them to overcome the existing technological barriers and learn facilitator mechanisms [27].

The expectations of ICs as to digital technologies also seemed like an important aspect to consider, because they can increase technology used. ICs hope that technologies can provide emotional and psychological support, informative support from the family, training and education, and health care follow-up [22,27]. In a more practical way, ICs suggested that there should be resources that helped them with their mental health, namely: relaxation techniques and motivational quotes and guides that would help them remember to take care of themselves [24].

*Table 2 – Summary of study characteristics*

Paper title	Authors Country Year	Goal	Type of study and Methodology	Population and sample
What is “care quality” and can it be improved by information and communication technology? A typology of family caregivers’ perspectives	Leslie;M.,Gray;R., Mahani; A.(a) Canada 2020	To determine how ITCs can support family caregivers who play the caregiver role.	Qualitative study Method: Focus Group	Family caregivers (FC) of elderly people. Sample: 25
Effect of an innovative model of complexity care on family Caregiver experience Qualitative study in family practice.	Nickell, L.; Tracy, S.; Bell, S.; Upshur,R. (b) Canada 2020	To learn about the experiences of family caregivers of elderly people with complex needs, using the IMPACT model.	Qualitative study Method: Individual interviews	Family caregivers (FC) of elderly people with complex needs. Sample: 20
Building a Research Roadmap for Caregivers Innovation: Finding from a Multi-Stakeholder Consultation and Evaluation	Egan, K.; McMillan, M.; Lennon,M.; McCann,L.; Maguire, R. Scotland 2021	To explore a future roadmap for innovation from informal caregiver participation.	Mixed study Method: - Interview. - Questionnaire.	Informal caregivers (112) Professionals /researchers (62)
The care capacity goals of family carers and the role of technology in achieving them	Leslie, M.;Gray, R.; Eales,J.; Fast, A. & J.;Magnaye, A. & Mahani, A.(b)	To identify the goals of Family Caregivers (FC) when caring for the elderly and how technology can help	Mixed study Method - Focus Group. - Questionnaire.	Family caregivers. Sample: 25

Canada 2020		achieve those goals.		
Mobile Support for Older Adults and Their Caregivers: Dyad Usability Study	Quinn, C., Staub, S., Barr, E., Baldini, A. USA 2019	To determine the usability of a mobile app within the elderly population and in their relationship with informal caregivers.	Observational study.  Method: - Questionnaires.	Elderly people and informal caregivers (IC). Sample: 24 (dyad 12)
Preferences for using a Mobile App in Sickle cell Disease Self-management: descriptive Qualitative study	Gamble, T.; Quasie-Woode, D.; Erves, J.; Rollins, M. <i>et al</i> Canada 2020	To explore health preferences for using an app in the process of facilitating the self-management of adults with sickle cell disease and their caregivers who live in urban and rural communities.	Qualitative study.  Method: - Focus Group.	Adults with sickle cell disease and caregivers.  Sample: 43
A Digital Mobile Community App for Caregivers in Singapore: predevelopment and Usability Study	Lwin, M.; Sheldenkar, A.; PanchapaKesan, C. Singapore 2021	To understand the implementation the app in a community network app "Caregiver's circle" and to get to know user's opinion.	Qualitative study.  Method: - In-person interviews. - Questionnaire.	Informal caregivers Sample: 103
Improving the Quality of Life of Family Caregivers of People with Alzheimer's Disease through Virtual Communities of Practice: A Quasiexperimental Study	Romero-Mas, M.; Ramon-Aribau, A.; Souza, D.; Cox, A.; Zúniga, B. Spain 2021	To describe the relation between the quality of life of ICs of people with Alzheimer's Disease and their participation in a VcoP (virtual community with the exchange of knowledge and an emotional support and collaboration culture).  To determine the impact of ICs' health literacy in the quality of life and involvement in the VcoP.	Quasi-experimental study.  Method: - phone calls and in-person contact. - Focus group. - Evaluation scales. - control group with and without VcoP intervention. Questionnaire.	Informal caregivers of people with Alzheimer's disease.  Sample: 38 pre-test and 37 post-test.
Patient Portals as a Tool for health Care Engagement: A Mixed-Method Study of older Adults with Varying Levels of Health Literacy and Prior Patient Portal Use	Irizarry, T.; Shoemake, J.; Nilsen, M.; Czaja, S.; Beach, S.; Dabbs, A.; Faan, R. USA 2017	To explore attitudes in relation to choosing the portal and its utility as a tool to involve healthcare with difference levels of health literacy.	Mixed study.  Method: - Phone interview. - Focus group.	Elderly people Sample: 100

Table 3 – Summary of study results

Types of interventions	Main findings	Conclusion
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Intervention made with 10 focus groups from 05/2017 to 8/2018. Each session took 2 hours. Bottom-up approach, with thematic content analysis.	Technologies that are only focused on the task can lose their value, as they lose capacity to provide information that is relevant to caregivers' needs. ITCs, as the intermediary for an improvement in quality of life and as providers of relevant information that are enabled with knowledge and caregiver needs' change. Smartphones can be an extension of access to software.	ITC product development supported by ICs should focus on human relationships and expand a facilitating communication, allowing their participation in decision making and that they express their concerns and goals. Technology appears as a support to receive information that is relevant to caregivers' needs, and also to establish human connections.
Individual interviews to 13 family caregivers about the caregiver role and their (physical and emotional) well-being. The patient and the caregiver are encouraged to play a more active role in the process of their disease, by raising questions and discussing actions.	Caregivers reported that they no longer felt lonely in this role, because they were given basic information about the disease, as well as existing resources and equipment. They felt recognized and heard, they were able to express their uncertainties, stories and suggestions, increasing their commitment to the caregiving. They searched the Internet.	Involving ICs as part of the multiprofessional team increases the perception and understanding of the caregiver role and trust in their ability to perform this role. Contributes to caregiver empowerment.
A mixed approach was used: - Ten-minute multi-sector consultation from 15/06/2020 to 30/09/2020. - Online questionnaire on social media.	Ninety-six percent of informal caregivers use digital technology. The hybrid approach (both in person and online) can work for caregivers. The experience of ICs in collaborating with universities to work via multiple communication channels should be valued. Deep knowledge of needs and existing gaps allows to contribute to technological innovation, in order to overcome existing technological barriers and learn what are the facilitating mechanisms. The ICs mentioned the need for improved financial, emotional, psychological, training and educational support.	A technological approach in the following areas is required for the health and well-being of ICs: information, monitoring technology, and communication with other ICs and professionals. The experience of ICs in collaborating with universities to identify priorities and actions that speed up searches and future political decisions about significant and innovative solutions should be valued.
Sequential method, focus group and online questionnaire. Ten focus groups with 25 family caregivers. Intervention took place from 05/2017 to 08/2018. <u>1<sup>st</sup> part</u> : Discussion of targets and technological solutions. In what they think technology can help them. <u>2<sup>nd</sup> part</u> : online questionnaire about seven fields: physical health, mental health, well-being, social connection, education, employment, finances.	Technology maintains the ability to care and allows ICs to develop coping strategies and to guide themselves and socialize. Technology is an intermediary that connects ICs to information supports and other caregivers. Key targets for ICs are to reinforce and preserve their ability to provide care.	Technology is well positioned to find the best self-care, to facilitate the connections needed for a social life. Technological targets and suggestions should imply that the understanding of care as a source of overload was transformed into a more resilient, sustainable caregiving model. Technology can help promote such resilience but can be limited to the role of an intermediary that connects family caregivers to information supports and peers.
Participants completed a skill evaluation questionnaire and downloaded an app to their smartphones or computers that was used for a month. Then, participants completed two questionnaires that evaluated app features and aesthetic, and their	Study results showed normal levels of digital competence for the elderly and high levels for the informal caregivers. Elderly people use their smartphones to make calls (75%) and read e-mails (58.3%). They access the Internet (33.3%) but on their computers. ICs use their smartphones for calls, SMS, e-	Technologically experienced caregivers play an essential role in showing the benefits of technology for supporting care provision to elderly people. There were high levels of use of technology among the elderly and caregivers, but there was only an

relationship with the app. App features: user profile, family health history, health information, to receive studies based on their health profile, to establish a relationship with their caregivers.	mails and internet equally (91.7%). They access the Internet via their phones. This study concluded that 50% of ICs want to use the app to manage the appointments and clinical information of the person cared for and to access specific information that allows them to share and discuss to commit to the caregiving; they believe the app's aesthetic dimension is important.	average use of the mobile app. Additional training is recommended for the elderly and caregivers, including behaviours directed to keeping digital health records.
Five community listening sessions were made with one urban and one rural community. Each session took two hours. A questionnaire about demographics and access to technology was applied. Where they searched for information about self-care in relation to the SCD and which was their satisfaction level with the search for and support about management and resources. Seven aspects were evaluated: self-management information, such as receiving information, which information they wish to receive, changes in disease management, support types, barriers to and facilitators for the use of apps, mobile app preferences.	Participants are receptive as to using the app to self-manage the disease. Mobile app reduces the information access barrier. In rural communities, the app increases ICs' access to resources. The Internet is the reported source to learn about self-management techniques and receive information, reinforcing the importance of reliable websites. ICs want emotional support, information support from the family, and follow-up from healthcare professionals. Positive feedback about the app included easy configuration and good interface. Barriers: participants were not comfortable to use the Internet because they struggled to identify relevant, reliable information. The notification system, information trackers, and the fact that they can communicate with their healthcare professionals and caregivers were aspects valued by patients.	Results can be used to develop a patient-centred health app that is easy to use to facilitate disease self-management, therefore increasing access to resources by relatives that live in rural communities.
A pre-development survey was made about the following issues: care, support provided, what they would like in a caregiving mobile app. Identifying the needs of ICs and the gaps in web community networks. Demographics about the health of the person cared for and about the ICs' physical and mental health. What is the level of use of digital means when searching for information and support. Thirty-two caregivers completed an online questionnaire and in-person interviews followed by a usability test.	ICs said they liked using the app. They said it was useful, easy to use and helpful to improve quality of life, because they included multiple resources: a public forum for discussions with the community and other ICs in the same region without ever leaving home; and a market to purchase and sell material and equipment required for caregiving. Including many resources that caregivers need daily in an easy-to-use app allowed to save time and help browsing without any issue. The use of smartphones created an opportunity for the caregiving community to use technology in a useful way. The app included caregivers' ideas, which created an app that facilitated caregiving. As to concerns about safety and security, trust would increase if the app were supported by a renowned	Caregivers enjoyed the "Caregivers' Circle" and were confident that this app could help them improve their quality of life. Including many resources that caregivers need daily in one app allowed can save their time and help them live without problems.

	<p>organization.</p> <p>ICs have suggested that the app should include a resource that would help with mental health, namely relaxation techniques, motivational quotes and guides, which would remember them to take care of themselves.</p>	
<p>The study took place between July 2017 and April 2018.</p> <p>Previous contact was made with the AFMADO association and explanatory sessions were held (individual and group). Two groups were created, one with and one without Healthcare Professionals. Intervention: developing an app based on the CoP theory, with space for chatting and a member file with information about each member. The following aspects were evaluated before and after the VCoP intervention: quality of life, health literacy, and the Barthel scale associated to the Spanish population.</p>	<p>Quality of life was 66.6 and increased to 69.5.</p> <p>There was no discrepancy between sexes for the quality of life. Age was the only sociodemographic criterion that affected the quality of life: the elderly increased their QoL to 74.6. Young people went from 66.7 to 67.85. Spouses said that the app had a positive impact on the quality of life.</p> <p>As to HL, the average rate of 26.10 (in 40) increased to 30.68. Internet interventions can help caregivers meet their needs, which is a positive experience.</p> <p>Allowed to get to know their peers and to feel less lonely.</p>	<p>Caregivers can benefit from the VCoP, because it enables interaction and knowledge sharing between caregivers and helps them meeting their needs. VCoP's impact is governed by age and relationship with the person cared for. It was positive for the caregivers' quality of life, at a physical level, when the functional condition of the person with Alzheimer's Disease worsened.</p> <p>The VCoP was considered a useful tool.</p> <p>HL had a positive impact in the physical area of the QoL of caregivers.</p>
<p>First contact made by phone (data collection: demographics, health, "Deficit of quality-of-life technology" questionnaire, and CREATE – Centre for Research and Education in Aging and Technology Enhancement). Classified participants according to their health literacy level and portal use. This classification resulted in four groups (G1: high HL, yes portal; G2: high HL, no portal; G3: low HL, yes portal; G4: low HL, no portal).</p> <p>Second contact made with four focus groups (N=75) aimed to analyse participants' attitudes. Sessions took one hour, were recorded and used NVS.</p>	<p>Participants with the higher HL who use the portal struggle to solve issues without the digital support and feel more pressured to use these methods.</p> <p>Those who do not use the portal say they do not feel safe using it due to the risk of sharing of personal data and prefer to use the phone. People with low HL who do not use the portal do not have experience using computers, are not trained and do not have Internet access at their homes, but those who use the portal say they are more interested in learning and training with new technologies.</p> <p>People who are more familiar with accessing health information using the Internet might be more willing to participate in research related with digital technology. The study revealed that HL was a factor that contributed to trust when accessing digital health information. But it was not directly related to the motivation of getting involved in health care. If portal users understand the benefits, this would be a motivation to portal use. Specific technology training is required to gain trust. ICs play a potential role in improving access to portal use for the elderly who cannot access portals.</p>	<p>The study concluded that there should be more research focused on the attitudes and experiences of informal caregivers of elderly people as substitute users for the elderly.</p> <p>Health organizations should connect people to technology by adopting the following strategies: campaign to disclose the benefits of technology and how they meet people's needs; offer specific training so that they can use technological tools in a secure, trustful way; include informal caregivers in the campaign and training; create workflows where people can communicate to update data, exchange information and clarify any doubts that validate their knowledge. This would create a tool designed for support and commitment.</p>

## Discussion

According to the studies that were analysed, demographic changes are leading to an increasing need for long-term care, which results in people informally caring for their relatives. Being an informal or family caregiver brings uncertainties, isolation, and overload [21, 24]. Studies showed that the involvement of the caregiver in the care plan is essential. Active involvement of informal caregivers as a member of the interprofessional care team results in an improved experience, increased caregiver capacity and the appreciation of the caregiver role [25-26]. These results are in accordance with the literature where ICs are considered “one of the elements of the sustainability of social and health systems” [30]. This emphasizes how important it is for healthcare professionals to work with ICs in order to find the strategies that are most adequate for effective empowerment [30]. The empowerment of ICs should be “a priority in health care organizations and the nurse assumes a major, dynamic, empowering role when it comes to the most adequate response to meet those needs” [31].

The WHO has defined a long-term strategy for the expansion and use of digital health, emphasizing the positive impact that it can have on health care access and provision, as well as on the health and well-being of the population and caregivers [27]. According to the literature, health technology is “one of the strategies used by the health care professional to empower citizens to use it in a secure way” [32].

The studies revealed that low health literacy was a barrier to access to digital information and the correct use of technological tools. Lack of training makes browsing difficult and results in user insecurity [22, 29]. The initial findings of a European survey on population health literacy, carried out by the WHO Action Network on Measuring Population and Organizational Health Literacy (M-POHL), indicate that 22%-58% of the population find it challenging to access and interpret digital health information [33]. On the other hand, the European data report that in

2019 in European countries such as Finland, the Netherlands, the United Kingdom and Germany, 75% of the active population had basic digital skills [34].

Promoting health literacy improved safety in caregiving and decreases the risk associated to this activity [32].

Using digital technology in the health field can benefit the caregivers and the population [21-22, 24, 28-29].

Questions about privacy and security when using these digital tools are an important factor for users. Although there is an increasing concern about what is the best way to develop emerging online technologies (e.g., ethical data use), results show that a hybrid model with an online and in-person approach can work well for caregivers in rural areas [27]. The model that includes digital technology and an in-person approach is pointed out as a more reliable model for the ICs.

These results are in line with the American study that described that ICs use the internet (77.5%) to access health information for themselves (73%), for others (67.5%) and to communicate with the doctor [35].

Evidence indicates that ICs intend to use digital tools: establish communication relationships with person cared for, their family members, the peers and health professionals [21, 23, 24, 25, 27].

## Principal Results

The text highlights privacy concerns limiting technology use, underscoring the impact of low health literacy on users' digital engagement. ICs benefit from digital tools, finding empowerment, recognition, and improved quality of life. The integration of multiple resources in technology supports caregiving, saving time and facilitating daily tasks. Collaboration of ICs in technology development is crucial for innovation and overcoming barriers, emphasizing the need for user-driven solutions.



## Limitations

As to the analysis of included studies, it was not possible to use a tool to evaluate study quality. In the papers that were analysed, it was not possible to identify references about improvement opportunities arising from the research process. The fact that samples in presented studies are small does not allow to extrapolate data to the population.

Included papers were published in English, French, Spanish and Portuguese, and the inclusion of articles in other languages could have brought more relevant information to this review. However, searching in four databases allowed to expand search comprehensiveness.

## Comparison with previous work

In Portugal there are few scientific studies carried out by nurses that refer to the use of digital technologies as a resource to train people with dependence and informal caregivers.

## Conclusions

Evidence found in studies revealed that ITCs like digital platforms, portals, online community groups were preferentially used by informal caregivers via mobile apps and that computers were more used by the people cared for. Studies showed that ICs had access to and used digital technology to meet the needs of the person cared for, but also to meet their own needs. Studies showed that digital technology is an accessible tool for empowering ICs. However, there were concerns regarding privacy, security and the use of these tools, which should be taken into account by health care professionals and researchers. Highlights also go to the need to digitally train ICs and the people cared for.

ICs play a key role in the provision of quality care to dependent people to whom they commit. This way, it is important to learn how digital tools can be used in a useful, beneficial way that allows to empower ICs.

The participation of ICs is essential when it comes to developing digital tools (platforms, mobile

apps, portals), because they can contribute to developing tools that meet users' needs (ICs and the people cared for). The use of digital technologies can guarantee access to knowledge, therefore empowering caregivers when it comes to making a decision and sharing care provision with health care professionals. It is worth to mention the importance of digital empowerment for an improved digital health literacy of ICs and the people cared for. Digital technology allows for accessible, targeted, and effective communication. Health care professionals and researchers should guarantee information reliability, security and clarity and optimize existing resources.

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## **Conflicts of Interest**

The authors declare that there are no conflicts of interest.

## **Abbreviations**

CINAHL – Cumulative Index to Nursing and Allied Health Literature

EBSCO – Elton Bryson Stephens and Company

HL – Health literacy

IC – Informal caregiver

ICTs – Information and communication technologies

JBI – Joanna Briggs Institute

MEDLINE – Medical Literature Analysis and Retrieval System Online

PCC – Population, concept, context

PUBMED – Public/Publisher Medline

SCOPUS - bibliographic database containing abstracts and citations for academic journal articles

WHO – World Health Organization

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## Supplementary Files