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Protocol for a scoping review of older informal carers and digital health service use

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ABSTRACT

Introduction The ageing population and increasing demands for healthcare pose challenges for national health services, which are increasingly looking to digital health services (DHS) as a potential solution. However, older informal carers, who provide unpaid care, often lack the digital skills necessary to access and use DHS, placing them at risk of social exclusion. This scoping review aims to systematically map and explore the existing literature on this topic, with the goal of identifying and addressing gaps in the research.

Methods and analysis This scoping review follows Arksey and O'Malley's methodological framework. A systematic search will be conducted across seven databases: AgeLine, PubMed, ScienceDirect, Scopus, Social Sciences Abstracts, SocINDEX and Web of Science, focusing on studies published in English from 2010 onwards. The research team will collectively work on all stages of the review, ensuring consistency and collaboration throughout. Data extraction will capture key information on study topics, participant demographics, types of DHS and study design. The findings will be analysed using descriptive statistics.

Ethics and dissemination Ethical approval is not required for this scoping review as it will rely solely on previously published data. The findings will be disseminated through peer-reviewed publications, conference presentations and engagements with non-academic stakeholders through seminars and workshops to maximise societal impact.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review is based on a systematic search of seven selected online databases, providing a comprehensive and fine-grained mapping and exploration of the literature and evidence on this topic.
- ⇒ The scoping review adopts a mixed-methods approach for collating, summarising and reporting the results.
- ⇒ One team member will be appointed as responsible for the consultation process, contributing to maximise the societal impact of the scoping review.
- ⇒ The scoping review excludes research evidence that is not published in English.

INTRODUCTION

Western societies are undergoing two major structural changes, that is, demographic ageing and society digitalisation. In 2019, the share of people aged 65 or over in Europe was 20.3%. In the coming decades, the older European population will increase significantly. Specifically, between 2019 and 2050, the share of people aged 65–74 years is expected to expand by 16.6%, whereas the share of people aged 75–84 years is projected to increase by 56.1%. More importantly, the share of people aged 85+ is expected to more than double, up to 113.9%[1] (p. 17). Demographic ageing has a clear gender dimension, whereby older women currently outnumber older men. In 2019 there were, on average, 1.33 women aged 65 years or more for every man of the same age[1] (p. 19). An ageing population is accompanied by increasing care needs, posing new challenges to the sustainability of national health services.

Under strict financial constraints, the digitalisation of health services (ie, e-health) may represent an effective way to meet older people's increasing demands for care. In 2021, the European Union (EU) has identified the digitalisation of public services as one of the 'four cardinal points' of the so-called European Digital Decade,[2] accelerating a structural process that was brought about by the COVID-19 pandemic. Focussing on e-health, the EU has set important targets: for example, by 2030, 100% of European citizens are expected to have access to online medical records.[3] However, this push towards the digitalisation of health services may pose a serious threat for older people's social inclusion: many older people (especially many older women) may lack the digital skills that enable them to access and use digital health services (DHS), whether they be public or private. Indeed, the EU has recently stated that '46% of Europeans, in particular among older people, do not currently have the basic digital skills, hampering the use of digital technologies for everyday tasks and access to services offered online. While the digital skills gap between men and women has decreased in recent years, it is still significant for people who are older, have received less formal education or live in a rural area or an outermost region' (p. 24).[3]

In increasingly digitalised societies, older informal carers, that is, older adults who provide 'unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework'[4] (p. 7) are among the frailest groups of individuals, many of whom may lack the digital skills needed to access and use the DHS. Although informal older carers are a minority of the European population, the percentage of older informal carers is estimated to vary between 13% in Portugal and Spain, and more than 22% in Luxembourg, Belgium and Denmark; also, the percentage of older carers declines in older age groups and is lower in men than in women.[5] Given the current trend in demographic ageing (and the increasing financial constraints, limiting the state provision of health services), it is reasonable to think that the percentage of older informal carers will further increase in the coming years. Thus, a non-negligible share of the current and future old age population may be at high risk of social exclusion.

Despite the undisputed relevance of this topic, our preliminary search has revealed a shortage of research that focuses on older informal carers and DHS, here defined as 'covering all types of technology solutions used for delivering healthcare services digitally'[6] (p. 2). Although a few studies have analysed the barriers and facilitators to the use of e-health by older adults,[7] the studies on older informal carers and DHS have mainly focused on the design, development and implementation of digital devices, adopting a technical perspective,[8] the education and training of formal carers,[9] and the investigation of machine–human interactions.[10] Against this background, our scoping review contributes to fill in an important knowledge gap: the aim of this review is to systematically map and explore the literature and evidence on older informal carers and DHS use. Specifically, we address the following research questions:

1. RQ1: What are the issues explored in the literature on older informal carers and DHS use?
2. RQ2: What are older carers' characteristics and DHS types that research on older informal carers' use of DHS has focused on?
3. RQ3: What is the research evidence on the consequences of DHS use on older informal carers?
4. RQ4: What are the study characteristics of research carried out on older informal carers' use of DHS?

Findings from our scoping review will contribute to set a future research agenda that will ultimately enhance older informal carers inclusion in digitalised societies.

METHODS

In this scoping review, we draw on Arksey and O'Malley's scoping study methodological framework,[11] which consists of six stages: identifying the research questions (stage 1) and the relevant studies (stage 2), selecting the studies (stage 3), data extracting and charting (stage 4), collating, summarising and reporting the results (stage 5) and (6) consultation. We will treat these stages in an iterative way to make sure that the literature is comprehensively covered.

Identification of relevant studies (stage 2)

To define our search strategy, we drew on established guidelines.[12] First, starting from the aim and the RQs of the scoping review, we began by defining the inclusion and exclusion criteria, along with the core concepts of the scoping review, namely informal care provision and DHS (see table 1). We then conducted a pilot search on Google Scholar to identify relevant keywords, which served as a starting point for developing the search query. The basic search string that we have developed is the following:

'(Elder* OR Old*) (Care* OR Care provi* OR Provi* of care)' AND ['(Electronic OR E- OR Digital OR Online OR Web OR Information and communication technolog* OR ICT* OR Information technolog* OR IT* OR Communication technolog* OR CT*) AND (Health OR Care OR Medical OR Patient) AND (Communication OR Consultation OR Information OR Help OR Monitoring OR Support) AND (App* OR Blog* OR Device OR Group OR Forum OR Platform OR Program OR Record OR Resource OR Service OR Sensor OR Wearable*)']

We will start from the basic search string which will be adapted to suit the database's different features. We will perform the search on seven selected online databases, that is, AgeLine, PubMed, ScienceDirect, Scopus, Social Sciences Abstracts, socINDEX, Web of Science to make sure that the literature is relevant to the research questions addressed in our scoping review (for the complete search strategy, please refer to online supplemental table S1). We will import all the records into EndNote Web 20, a reference manager tool. Although this software is able to identify and discard duplicates, we anticipate a manual search for duplicates.

We will limit our search to studies (including the grey literature) that were published in English starting from 2010 onwards (see table 1 for the inclusion criteria); 2010 is an important milestone, coinciding with the publication of the Digital Agenda for Europe.[13] Indeed, the 2010 Digital Agenda for Europe identified for the first time the information and communication technologies as a load-bearing pillar for the EU playing a relevant role in the public service modernisation (including in the health sector). The focus on English-language publications is due to the predominance of English in academic research and practical reasons, that is, the authors' language capabilities and financial constraints. Whenever possible, the team will discuss whether to add filters, for example, research area, to refine the search.

The search strategy will be developed jointly by all team members, with the support of an experienced librarian

Table 1 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population: Older carers	Studies on older adults (whose age or average age is 65 years or over) who take care of someone else	Studies on older adults (whose age or average age is 65 years or over) who do not take care of someone else Studies on younger adults (whose age or average is 64 years or less), regardless of care duties and responsibilities
Concept: Informal care provision Digital health services (DHS)	Studies on informal care provision (non-professional, unpaid and continuous care) to someone, of any age, who cannot manage fundamental self-care and instrumental activities of daily living due to a chronic condition, a disability or an impairment, and with whom there is a family or a social relationship (grandchildren, spouse, acquaintance, adult children, colleague, friend or neighbour) Studies on DHS, whether they be public or private, provided or supported by digital platforms to help monitoring (sensors tracking vital signs), by mobile applications (electronic health records), by websites for health information searching (online support group or web-based health information and consultation), or by other tools (robotics)	Studies on formal care provision (professional, paid and more or less continuous care) to someone who is in a clinical or community settings (including a home setting) with whom there is a professional relationship Studies on any type of offline health service
Context	Worldwide	
Search strategy	English Publications from 2010 Books, book chapters or book reviews, conference abstracts, meeting abstracts or early access articles, dissertations or theses, proceeding papers, research articles (experiments or observational studies, longitudinal or cross-sectional studies, quantitative, qualitative or mixed studies), reports, reviews or descriptions of study protocols	Any language other than English Publications before 2010 Editorials

from the University of Milano-Bicocca. Although one team member will be in charge of performing the search (in addition to the management of the identified records), all team members will regularly meet up to discuss issues. We anticipate recruiting one PhD student as part of the team.

Selection of studies (stage 3)

We will implement a two-step procedure to select relevant studies that meet the eligibility criteria. First, we will read the titles, abstracts and keywords of the studies identified at stage 2, organising our EndNote Web V.20 library in different categories (eg, excluded studies, included studies and studies with doubt eligibility) to improve the effectiveness of the screening process. Second, we will conduct a full-text reading of the selected studies, to establish final eligibility for the scoping review. We will document the screening process using a Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow diagram for the scoping review (PRISMA-ScR).[14]

One team member will be in charge of performing the screening, meeting regularly with the other team members to discuss ambiguities and challenges related to the eligibility assessment (eg, studies stored in the category ‘doubt eligibility’). The other team members will independently perform the screening of a sample of publications, to confirm the relevance to the scoping review. The research team will collectively work on the screening process, until agreement among the authors is reached. In case of disagreement, we will involve an expert in scoping review, who will act as external referee. Table 1 shows the inclusion and exclusion criteria, following the population, concept, context framework for scoping reviews.

Extracting and charting (stage 4)

At this stage, we will formulate a data charting using STATA V.18,[15] to collect relevant information from the studies included in the scoping review. For RQ1, we will include the study topic(s), for example, motivations to and experiences on DHS use, barriers/facilitators to DHS use, such as individual and contextual factors, acceptance, easiness of use and usability of DHS, and so on. For RQ2, we will extract older informal carers demographics and socioeconomic characteristics, such as age, education, gender and the relationship with the care receiver.

In addition, we will gather data on the type of DHS, such as electronic health records, health information and technology, online support groups, wearable sensors, and so on. For RQ3, we will collect data on the consequences, in terms of health and well-being of DHS use, including burden and stress. For RQ4, we will collect data on the study design, such as the country in which the study was conducted, the population characteristics, the sample size, the type of study (eg, observational vs experimental, cross-sectional vs longitudinal), and so on. For each study included in the scoping review, we will also extract the following data: publication year, journal subject area, authors' name, publication title, DOI, and so on. We will assign each study a unique identifier.

Data extracting and charting is an iterative process. First, we will formulate the preliminary version of the data charting, on reading 10 articles (stage 1). Then, each team member will pilot it using (the same sample of) 20 articles (stage 2), before finalising the data charting to be used for data extraction, that is, a STATA data matrix (stage 3). We will modify the data charting, if needed, later during the process. The research team will collectively work on the development of the data charting (stage 1–3), until agreement among the authors is reached. In case of disagreement, we will involve an expert in scoping review, who will act as external referee. Once intersubjective agreement on data extracting and charting is reached, one team member will perform the data extraction for the studies included in the scoping review (stage 4). The research team will meet regularly to discuss doubtful cases.

Collating, summarising and reporting the results (stage 5)

We will provide a summary overview of the included studies, including publication year, journal subject area, type of study (eg, research article, conference proceedings, etc). For RQ1, we will use thematic analysis and code extracted qualitative data into a number of overarching categories.[16] Depending on the number of studies included in the scoping review, we will consider performing thematic coding using specialised qualitative software (eg, NVivo). We will use descriptive statistics to provide a description of the extracted data. Specifically, we will use measures of central tendency and/or measures of variability, and/or frequency distribution. Descriptive statistics will be reported in tables, charts and/or in narrative form. We will provide a narrative summary of the tabulated and/or charted results, clarifying how the statistics relate to the scoping review's aim and research questions. The authors will perform the univariate analysis, which will be discussed among the team. The authors will also write the narrative comment. We will report the results according to the PRISMA-ScR.[14]

Consultation with stakeholders (stage 6)

The consultation with the stakeholders entails the identification of key stakeholders (stage 1), the definition of the consultation process (stage 2), and its implementation (stage 3). As a preliminary step, we have organised a meeting with colleagues from our research network and members of the Italian non-profit organisation AUSER—active in the field of active ageing—to identify key stakeholders and fellow academics experts in ageing research (stage 1). We intend to organise a number of seminars and workshops, targeted to the academic audience, to get feedback and suggestions on the ongoing work (stage 2). Specifically, fellow academics will actively contribute to refining the scoping review protocol, offering insights into the development of the research questions, the identification of suitable search strategies and the data analysis techniques. Also, we will engage with the stakeholders, for example, charities and other non-profit organisations (eg, Age Platform Europe), to collaboratively plan effective dissemination and knowledge transfer initiatives, aimed to maximise the societal impact of the scoping review. Results from the scoping review will be presented both in academic and non-academic settings. We will appoint a team member in charge of the consultation process.

PATIENT AND PUBLIC INVOLVEMENT

As this is not a clinical study, patients will not be involved in the development of the scoping review protocol. With the support of the key project stakeholders, we will identify older informal carers, to be consulted when developing effective dissemination and knowledge transfer initiatives.

ETHICS AND DISSEMINATIONS

This scoping review protocol describes in detail the method we will adopt to systematically search, map, synthesise the literature on informal care provision and DHS use. Ethical approval is not required because the scoping review is based on published data and does not entail any data collection on humans and animals.

Findings from the scoping review will be disseminated through a publication in peer-reviewed scientific journals and participation in major professional conferences. As anticipated in stage 6, we will also engage in disseminating the study findings to the non-academic stakeholders, through the organisation of seminars, round table discussions and podcasts.

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Contributors ES conceptualised the study protocol. ES authored the sections: Introduction, Extracting and charting (Stage 4), Collating, summarising, and reporting the results (Stage 5), Patient and public involvement, Ethics and dissemination. ES and FC jointly developed the research questions. ES and FC jointly wrote sections Identification of relevant studies (Stage 2), Selection of studies (Stage 3) and Consultation with stakeholders (Stage 6). ES is the guarantor.

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