Participatory methods in designing digital health interventions for informal caregivers of people with dementia. A systematic review

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ABSTRACT

Aims: The growing use of technology in healthcare has contributed to the development of digital interventions for informal caregivers of people living with dementia. However, the marked heterogeneity of interventions poses challenges in evaluating their effectiveness. We conducted a review to delineate the distinctive features and development of the interventions, with focus on participatory methods.

Methods: We searched the following databases: Cochrane; Cinahl; Pubmed; Psychinfo; Scopus; Web of Knowledge, and IEEE, and screened and selected studies based on titles, abstracts and full texts. We used standardized procedure to abstract and synthetize relevant data of primary studies, and the Mixed Methods Appraisal Tool to assess their quality.

Results: Of 3136 records, 20 studies met the inclusion criteria. Most of the studies were web-based interventions, with multiple components and interactive features. The design and development of eight interventions employed participatory methods with large variations in the underlying framework and application.

Conclusions: This review sheds light on the design and development of digital interventions for dementia caregivers. The limited and heterogeneous use of participatory methods, along with inadequate reporting, hinders a clear understanding of intervention efficacy and implementation. Formal standardization of participatory action research methods is necessary to improve the design, development, and evaluation of digital interventions for caregivers of people with dementia.

1. Introduction

The World Health Organization (WHO) estimated that two-thirds of the sixty million people living with dementia (PLWD) (GBD 2019 Dementia Forecasting Collaborators., 2022) receive care at home from family members or friends (Alzheimer Disease International, 2018), referred to as informal caregivers (Schulz and Tompkins, 2010). Caring for a PLWD is often burdensome and challenging, especially for informal caregivers who may lack dementia education and knowledge (Morgan et al., 2022; Robinson et al., 2014). The 2022 World Alzheimer Report ({(World Alzheimer Report, 2022)}) revealed that up to 85 % of individuals with dementia and their caregivers may lack access to post-diagnostic support, including education, guidance, or resources that are crucial for managing the disease effectively.

The provision of educational and training support to informal caregivers is a key area of the Global Action Plan of the Public Health

Response to Dementia (World Health Organization, 2017), and ample evidence supports interventions for informal caregivers. In recent years, the growing use of internet and mobile technology facilitated the transition to digital interventions (Rathnayake et al., 2019), which are typically behaviourally based and delivered via the internet (Ritterband et al., 2006).

Both traditional and digital interventions for informal caregivers can contribute to reduce psychological distress and improve quality of care (Adler and Mehta, 2014; Cheng et al., 2019; de- Moraes-Ribeiro et al., 2024; Sztramko et al., 2021)However, evidence remains erratic due to the heterogeneity of interventions' characteristics and of methodologies employed to design and evaluate them (L. M. M. Boots et al., 2014; Parra-Vidales et al., 2017). We do not know how and why interventions work, which hampers their adaptability, implementability, and tailoring to the evolving needs of PLWD and their caregivers. A shift in focus from efficacy to the unpacking of the interventions inner mechanisms is

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needed.

Informal caregivers, can contribute significantly not only to co-design, develop, and improve digital interventions, but also to evaluate them. However, the involvement of informal caregivers is rare, underreported, and heterogeneous. Participatory research (PR) is a viable option to enable, engage, and involve relevant stakeholders and target groups in the design, conduction of studies, and the dissemination of results (Vaughn and Jacquez, 2020). Existing PR approaches (Frank et al., 2014; Mao et al., 2005; Wallerstein, 2020) hold the promise that the interventions are aligned with the needs of the relevant population, may increase their successful uptake and implementation (Camerini et al., 2013; Lentelink et al., 2018; Minkler et al., 2008), and can contribute to close the gap between evidence and practice (Wallerstein and Duran, 2010). However, evidence on the application of PR in the design and development of interventions for informal caregivers is sparse and lacks consolidation (Bowness et al., 2024; Liabo et al., 2020).

We conducted a systematic review to clarify and shed light on the methods and strategies used in the development of digital health interventions for informal caregivers, with a specific focus on PR methods. We aimed to 1) describe the characteristics, design, and development of digital health interventions for informal caregivers of people living with dementia and to 2) critically appraise and explore the use of PR methods from development to feasibility of interventions.

2. Methods

2.1. Search strategy

We systematically searched the literature in March 2023 according to the PRESS Peer Review of electronic search strategies guideline (McGowan et al., 2016). We developed the search strategy in consultation with an experienced librarian. We chose and combined keywords and search terms according to our main research question (how are digital health interventions for caregivers of PLWD designed?), specifying synonyms and alternative wording for digital, intervention(s), and caregivers, respectively. We adapted to and used our search syntax in the following databases: Cochrane; CINAHL; Pubmed; PsychInfo; Scopus; Web of Knowledge, and IEEE also combining Medical Subject Headings (MeSH), and/or APA Thesaurus of Psychological Index Terms as appropriate (see Annex 1).

2.2. Study selection process

Studies were included if: i) they reported the process of designing or testing a digital intervention; ii) the intervention was primarily dedicated to informal caregivers of people living with dementia; and iii) they were published in English. We excluded study protocols, secondary studies (including narrative and systematic reviews, and meta-analyses), dissertations, conferences' abstracts, editorials, and commentaries. We also excluded studies on interventions exclusively delivered face to face, and primarily targeting PLWD, or caregivers of people with other medical conditions. The study selection process included several phases (see Fig. 1). First, we imported the records retrieved (with titles and abstracts) from the databases into a dedicated electronic repository on Microsoft Teams and removed duplicates. In the second phase, two independent reviewers (AMA; GF) screened the titles and abstracts according to the inclusion and exclusion criteria, which were subsequently applied to the full texts. Disagreement between reviewers was resolved through discussion with a senior author (MF).

2.3. Data abstraction and study quality appraisal

The analysis of the selected studies followed a two-step approach. Initially, we conducted a descriptive examination of the studies included and of the interventions described according to our research questions. One of the researchers (AM) carefully read the full texts and identified
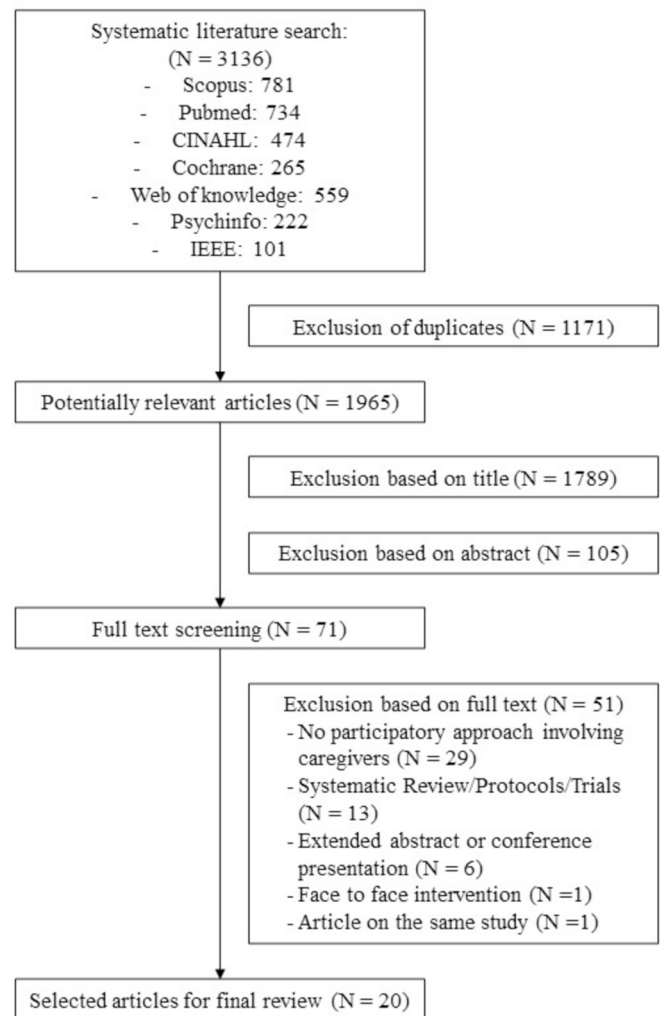

Fig. 1. Flowchart.

relevant studies characteristics that included author, publication year, country, name, content and features of the intervention described, target population and framework of the intervention).

Subsequently, AM analyzed and compared the methodologies used and participants involved according to the different stages of research process. More specifically, for each study we identified the phase of the intervention described; the research methods adopted; the main characteristics of populations involved and the use and type of participatory methods and strategies.

We developed a research protocol for this review but did not formally register it, as time constraints and limited resources posed challenges to completing the registration process. Nevertheless, we ensured the rigor and transparency of our methodology to maintain the quality and reproducibility of the review. Specifically, we assessed the methodological quality of the included studies using the Mixed Methods Appraisal Tool (MMAT), a tool that is specifically designed for the appraisal stage of systematic reviews that include qualitative, quantitative and mixed methods studies (Hong et al., 2018), and adhered to PRISMA guidelines (Moher et al., 2009) to format, standardize, and structure this manuscript (see Annex 2) . During the data abstraction and synthesis process, Microsoft Excel was the sole tool used to organize and manage the extracted information.

2.4. Theoretical frameworks

For data analysis, we referred to two theoretical frameworks: the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Skivington et al., 2021) and the framework from Vaughn and colleagues (Vaughn and Jacquez, 2020).

The MRC framework for complex interventions provides structured guidance for developing, evaluating, and implementing interventions that have multiple interacting components. It emphasizes a systematic and iterative approach through four key phases: 1) development of the intervention (designing the intervention components or adapting a pre-existing intervention); 2) feasibility (testing the intervention's acceptability and usability); 3) evaluation (assessing the intervention's effectiveness and mechanisms of action); 4) implementation (examining the scalability and sustainability in real world settings). This framework allowed us to identify and report the different phases of intervention implementation described in the studies even when these were not explicitly stated by the authors.

Additionally, we referred to the framework from Vaughn and colleagues (Vaughn and Jacquez, 2020) to identify the participatory research methods (PM) employed in the studies. In their work the authors provide a comprehensive overview of PM across various disciplines and approaches, as well as a detailed model outlining the desired level of participation at each stage of the research process. Their classification served as a reference to identify and analyse the types of participatory frameworks, tools, and methods implemented in the studies.

3. Results

The flowchart in Fig. 1 illustrates the study selection process, which led to the inclusion of 20 studies after screening of the 3136 records initially retrieved. We organized the results in three sections. The first section provides a summary of the risk assessment results obtained using the MMAT (Hong et al., 2018). The second section focuses on the general characteristics of the included studies, detailing the types and content of the interventions. The third section examines the digital components and methodological features of the studies. Specifically, we described the reported phases of intervention development, the key characteristics of the participants involved, and the types of participatory methodologies employed. Additional information about the study characteristics and methodologies are summarized in Table 1 and Table 2, respectively.

3.1. Risk assessment and quality appraisal

The studies were categorized into qualitative and mixed methods, depending on the study design, and were evaluated accordingly using the MMAT by two co-authors (AM and AMA), with experience in qualitative and quantitative methods respectively A senior researcher (MF) contributed to the evaluation in case of disagreement. Overall, all studies positively responded to the screening items (S1: are there clear research? S2: do the collected data allow to address the research questions?), thereby demonstrating their suitability for the assessment. All details about the screening questions and results are presented in annex 3. Qualitative studies, such as those by Baruah et al. (2020) and Davies et al. (2019), achieved the highest scores of 1.00 across all qualitative criteria, indicating robust methodologies and coherent data interpretation. Conversely, studies like Rathnayake et al. (2021) and Monteiro et al. (2023) scored lower, particularly in areas such as coherence between data sources and substantiation of results. Mixed methods studies also displayed a range of scores. High-scoring studies, including those by Boots et al. (2016), Boyd et al. (2021), and Gaugler et al. (2016), effectively integrated qualitative and quantitative components, achieving scores above 0.87. However, studies like Lewis et al. (2010) and Rathnayake et al. (2021) scored lower, reflecting challenges in integrating study components and appropriate statistical analysis.

Notably, Lewis et al. (2010) provided detailed information on co-design despite their lower MMAT scores, highlighting their effort to involve stakeholders in the design process. Baruah et al. (2021), despite having lower MMAT scores, explained these aspects in detail elsewhere (e.g., Baruah et al., 2020). In terms of MMAT criteria, the studies generally performed well in areas related to the appropriateness of the qualitative approach and the adequacy of data collection methods. These areas were consistently strong across high-scoring studies. However, weaker areas included the coherence between data sources, collection, analysis, and interpretation, as well as the substantiation of results by data. These aspects were particularly challenging for lower-scoring studies.

3.2. General characteristics

3.2.1. Types and contents of interventions

The selected articles were published between 2010 and 2023, and reported results of a large variety of studies conducted across diverse geographic regions, eight were developed and/or tested in Europe (L. M. Boots et al., 2016; Boyd et al., 2021; Dam et al., 2017; Davies et al., 2019; Kagwa et al., 2022; Masterson-Algar et al., 2023; Teles, Napolskij, et al., 2021; Teles et al., 2021a, b); seven in America (Gaugler et al., 2016; Goodridge et al., 2021; Lewis et al., 2010; McCarron et al., 2019; Mishra et al., 2023; Monteiro et al., 2023; Perales-Puchalt et al., 2022); three in Oceania (Loi et al., 2022; Rathnayake et al., 2021; Xiao et al., 2021) and two in Asia (India) (Baruah et al., 2020, 2021).

Half of the included studies were about web-based interventions (N = 11). Four interventions were delivered only via a mobile application (Goodridge et al., 2021; Kagwa et al., 2022; Mishra et al., 2023; Rathnayake et al., 2021), one had both a web-based and a mobile version (Boyd et al., 2021); and one was based on cell-phone text messaging (Perales-Puchalt et al., 2022).

Four programs addressed specific subgroups of caregivers such as caregivers of people living with dementia at early stages (L. M. Boots et al., 2016) or end of life (Davies et al., 2019); young caregivers (Masterson-Algar et al., 2023), and Latinx caregivers (Perales-Puchalt et al., 2022). One intervention was dedicated to both caregivers and PLWD (Boyd et al., 2021).

In almost all studies (N = 17 out of 20) the authors specified the theoretical frameworks used for developing the interventions. The interventions' structure and contents varied but most recurrent contents included: psychoeducation; problem solving exercises and coping strategies; care coordination; care planning; social support; and self-care. One intervention included contents related to end of life and death planning (Davies et al., 2019); one included Mindfulness based self-compassion techniques (Perez-Blasco et al., 2016), and one included reminiscence activities (Butler, 1963) (see Table 1 for details).

3.2.2. Digital features and components

Also, the digital features and components of the interventions varied markedly. Based on human-computer interaction standards and previous studies (Donevant et al., 2018; Stephani et al., 2016), we differentiated features between passive and interactive components. While passive features usually do not require any responses or action from the user, interactive features require users to provide a response or modify contents in real time (Coyle and Thorson, 2001; Donevant et al., 2018).

Almost all interventions included passive features such as educational contents; videoclips, and hyperlinks to external resources. Two programs included audiotapes such as podcasts (Goodridge et al., 2021) or music tracks (Mishra et al., 2023). Interactive features varied across studies. Five interventions incorporated real-time chats to interact with a health care professional (L. M. Boots et al., 2016; Davies et al., 2019; Kagwa et al., 2022); a coach (Perales-Puchalt et al., 2022) or other users (Dam et al., 2017). Other interventions also included personal calendars or diaries and schedule reminders (Dam et al., 2017; Kagwa et al., 2022; Mishra et al., 2023; Perales-Puchalt et al., 2022; Rathnayake et al., 2021). Additional recurrent interactive features were training exercises

Table 1

Descriptive characteristics of the studies included (N = 20).

Author(s) and year	Country	Intervention name	Target population	Content	Features	Framework of the intervention	Medium
Baruah et al., 2020, 2021	India	iSupport	Caregivers of PLWD*	Psycho-education,self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person's centred care (Kitwood, 1997)	Website
Boots et al., 2016	Netherlands	Partner in balance	Caregivers of PLWD* at early stage	Self-management, problem solving techniques, psychoeducation, social support.	Video-clips; exercises; discussion forum; communication with a hcp; individualized feedback.	Stress and Coping theory(Lazarus and Folkman, 1884), Self-efficacy theory (Bandura, 1997)	Website
Boyd et al., 2021	UK	InspireD	PLWD* and caregivers	Reminiscence activities	Storage and selection of personal images; videos; audios with notes.	Reminiscence therapy (Butler, 1963)	Mobile application and website
Dam et al., 2017	Netherlands	Inlife	Caregivers of PLWD*	Social support; care planning.	Invitation of significant network members in the platform; chat network members; notifications; shared calendar; care book; educational video-clips; information; hypelinks to local resources.	Social support and buffering hypothesis (Cohen and Wills, 1985)	Website
Davies et al., 2019	UK	NA	Caregivers of PLWD* at the end of life	Coping strategies; problem solving techniques; relaxation exercises; psycho-education; care planning; end of life; death planning.	Video clips with caregivers; talk with a health care professional; chat with carers; hypelinks to local resources; find support in your local area.	Caregiver support theory (Parkinson et al., 2016)	Website
Gaugler et al., 2016; McCarron et al., 2019	USA	Care to Plan (CtP)	Caregivers of PLWD*	Care planning; care coordination; social support.	Generate tailored local support options based on a 20-item assessment and caregiver scenario; guidance to facilitate a recommended support option.	Ottawa Decision Support Framework (ODSF); Stress Process Model (Pearlin et al., 1990)	Website
Goodridge et al., 2021	Canada	NA	Caregivers of PLWD*	Mindfulness based self compassion (MBSC) techniques; psycho-education; self-care; coping strategies.	Podcasts; meditations; body-based practices; hyperlinks to existing resources (Youtube videos); Daily ecological momentary assessments (EMAs).	Mindfulness based Self Compassion (MBSC) (Perez-Blasco et al., 2016)	Mobile application
Kagwa et al., 2022	Sweden	STAV	Caregivers of PLWD*	Psycho-education; social support; self-care; problem solving strategies.	Tailored self-assessment tool, interactive chat with health care professionals, personal diary, mindfulness sessions, forum, hyperlinks with useful resources.	NS**	Mobile application
Lewis et al., 2010	USA	Internet-Based Savvy Caregiver (IBSC)	Caregivers of PLWD*	Psycho-education; decision-making techniques; self-care; care planning; coping strategies	Video clips with family carers	Stress and coping model (Lazarus and Folkman, 1884)	Website
Loi et al., 2022	Australia	START-online	Caregivers of PLWD*	Psychoeducation; Care planning; self-care; coping strategies.	Eight 1-h weekly sessions delivered by trained psychologist graduates; START-online manual; audio tracks; hypelinks to local resources.		Website
Masterson-Algar et al., 2023	UK	iSupport	Young caregivers of PLWD*	Psycho-education,self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person's centred care (Kitwood, 1997))	Website
Mishra et al., 2023	USA	Care4AD	Caregivers of PLWD*	Care Coordination; care monitoring; self-care.	Schedule reminders; wireless sensor tags; eBooks; video calling; music tracks.	NS**	Mobile application
Monteiro et al., 2023	Brazil	iSupport	Caregivers of PLWD*	Psycho-education, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions.	Person's centred care (Kitwood, 1997)	Website
Perales-Puchalt et al., 2022	USA	CuidaTEXT	Latinx caregivers of PLWD*	Care coordination; psycho-education; self-care; social support; end of life; problem solving strategies.	Daily automatic messages; keyword-driven messages; live chat interaction with a coach; booklet; video links; shared resources.	Social cognitive theory(Bandura, 1986); Stress process framework (Pearlin et al., 1990); Seven principles of communication (Cutlip, 1952)	Text messaging cell phone

Table 1 (*continued*)

Author(s) and year	Country	Intervention name	Target population	Content	Features	Framework of the intervention	Medium
Rathnayake et al., 2021	Australia	Dementia support for carers	Caregivers of PLWD*	Care coordination; psychoeducation; social support; problem solving techniques; care planning; self-care.	Calendar; task reminder function; video clips.	Adult learning theory (Knowles and A c. Di)., 1984)	Mobile application
Teles et al., 2021a, 2021b	Portugal	iSupport	Caregivers of PLWD*	Psycho-education, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions; mood status rating; personalization of names; hyperlinks to local resources.	Person's centred care (Kitwood, 1997)	Website
Xiao et al., 2021	Australia	iSupport	Caregivers of PLWD*	Psycho-education, skills training, self-care, problem solving strategies.	Multiple choice training questions with automatic feedback; open-ended questions; hyperlinks to local resources.	Person's centred care	Website

* people living with dementia.
** not specified.

and questions with immediate or automatic feedback from the program (Baruah et al., 2021; L. M. Boots et al., 2016; Masterson-Algar et al., 2023; Teles et al., 2021a, b; Xiao et al., 2021). Additional features allowed the users to tailor and personalize contents of the program, such as tailored local support options and keyword-driven automatic messages (Perales-Puchalt et al., 2022). One intervention (Boyd et al., 2021) was specifically designed to allow users to store and select personal images, videos or notes to enhance reminiscence activities.

3.3. Methodological characteristics

3.3.1. Phases of the interventions

We used the MRC framework for developing and evaluating Complex Interventions to discern the phases of interventions from development to implementation, through feasibility testing and evaluation (Skivington et al., 2021). Eleven studies, out of the twenty studies included in our review, specifically focused on the development phase of the interventions. Ten studies referred to both development and feasibility stages (Baruah et al., 2020, 2021; L. M. Boots et al., 2016; Boyd et al., 2021; Dam et al., 2017; Davies et al., 2019; Gaugler et al., 2016; Goodridge et al., 2021; Lewis et al., 2010; Masterson-Algar et al., 2023; McCarron et al., 2019; Monteiro et al., 2023; Perales-Puchalt et al., 2022; Rathnayake et al., 2021; Teles, Napolskij, et al., 2021; Xiao et al., 2021). Three studies focused on interventions' feasibility (Kagwa et al., 2022; Mishra et al., 2023; Teles et al., 2021a, b), and one included feasibility and preliminary evaluation (Loi et al., 2022).

3.3.2. Participants' characteristics

All studies involved informal caregivers during one or more research steps. Eleven studies involved caregivers in designing and developing the interventions (Baruah et al., 2021; L. M. Boots et al., 2016; Boyd et al., 2021; Dam et al., 2017; Davies et al., 2019; Lewis et al., 2010; Loi et al., 2022; Masterson-Algar et al., 2023; McCarron et al., 2019; Rathnayake et al., 2021; Xiao et al., 2021). The number of caregivers included ranged from 5 to 11, and caregivers were mainly female except for one study (Baruah et al., 2020), and spouses or children of the person living with dementia. The mean age of caregivers ranged between 47 and 74 years old, with a caring experience of at least two years. Young caregivers' age ranged from 12 to 16 years old (Masterson-Algar et al., 2023). Only one study directly involved PLWD in designing the intervention (Boyd et al., 2021). Within studies that included feasibility assessments caregivers were always involved (Baruah et al., 2021; L. M. Boots et al., 2016; Dam et al., 2017; Gaugler et al., 2016; Goodridge et al., 2021; Kagwa et al., 2022; Lewis et al., 2010; McCarron et al., 2019; Mishra et al., 2023; Perales-Puchalt et al., 2022; Skivington et al., 2021; Teles et al., 2021a, b). The number of caregivers included in this

phase ranged from 4 to 47. In only one study (L. M. Boots et al., 2016), the authors specified that the caregivers involved in designing or developing the intervention were also involved in further stages of usability and acceptability assessments. Inclusion criteria of caregivers were quite homogenous across studies and included: being over 18 years old (except for iSupport study for young carers) (Masterson-Algar et al., 2023); being a primary carer of a community dwelling person with a diagnosis of dementia or Mild Cognitive Impairment (MCI); having a caregiver experience of at least from 1 to 6 years; providing care for a minimum of 8 h per week.

In addition to informal caregivers' engagement, all studies involved additional stakeholders in one or more of the research phases. Most of the studies (Baruah et al., 2020; L. M. Boots et al., 2016; Dam et al., 2017; Davies et al., 2019; Gaugler et al., 2016; Goodridge et al., 2021; Kagwa et al., 2022; Lewis et al., 2010; Loi et al., 2022; McCarron et al., 2019; Mishra et al., 2023; Monteiro et al., 2023; Perales-Puchalt et al., 2022; Rathnayake et al., 2021; Teles, Napolskij, et al., 2021; Teles et al., 2021a, b; Xiao et al., 2021) mentioned the involvement of health-care professionals or dementia care experts during the initial development of the intervention. Common experts' professional backgrounds were psychiatry, psychology, geriatrics, nursing, and social working. The number of experts involved ranged from 2 to 30. Other stakeholders were web-designers or computer scientists (Baruah et al., 2021; Boyd et al., 2021; Dam et al., 2017; Goodridge et al., 2021; Perales-Puchalt et al., 2022; Rathnayake et al., 2021); experts in digital health and health communication (Davies et al., 2019; Teles, Napolskij, et al., 2021); members of charity organizations or Alzheimer associations (Baruah et al., 2021; Davies et al., 2019; Goodridge et al., 2021; Monteiro et al., 2023; Teles, Napolskij, et al., 2021) and care administrators or dementia care managers (McCarron et al., 2019; Xiao et al., 2021).

3.3.3. Participatory methods

We referred to the framework from Vaughn and colleagues (Vaughn and Jacquez, 2020) to identify the participatory research methods adopted in the studies. We found eight studies that explicitly referred to participatory methods or frameworks. More specifically, authors mentioned co-production methods for intervention development (Davies et al., 2019) (Davies et al., 2016; Greenhalgh et al., 2016; Ward et al., 2018); stakeholders' engagement (McCarron et al., 2019) (Esposito et al., 2015); user-centred design or customer-centric approach (Kagwa et al., 2022; Perales-Puchalt et al., 2022); and co-design or iterative co-design (Boyd et al., 2021; Broderick and Devine, 2014; Goodridge et al., 2021; Masterson-Algar et al., 2023; Rathnayake et al., 2021; Ward et al., 2018).

The methods, stages and tools used to engage the different stakeholders varied significantly across studies. The stakeholders involved in

Table 2
Methodological details of the studies included ($N = 20$).

Author(s) and year	Study design	Phase of the intervention	Research steps	Caregivers' or PLWD* ic** and characteristics	Stakeholders' characteristics	Participatory frameworks and strategies
Baruah et al., 2020	Focus group study	Development	Information gathering	Ic: formal education till 15 years old; speaking english; mean years of experience in caring = 6 months; regular computer/internet users; resident locally; having an email address. $N = 13$. Mean age: 47.4; 61.5 % males; 85 % children; mean years of experience in caring: 2–2,5. Mean hours per week of care: 12.	Ic: professional caregiving experience in dementia ≥6 months. Hcps***$N = 10$: $n = 3$ psychologists; $n = 4$ social workers; $n = 1$ psychiatrist; $n = 1$ geriatrician; $n = 1$ nurse. Mean age: 34.9; 60 % females. Mean professional caregiving experience: 6.4 years.	NS****
Baruah et al., 2021	Mixed methods study	Development, feasibility	1. Preliminary adaptation design		Members of the research team.	NS****
			2. Preliminary adaptation test onsite	Ic: ≥ 18 years old; speaking english; regular computer user. $N = 4$. mean age: 35.75; n = 3 sons; n = 1 daughter. Mean experience in caring = 30 months.		
			3. Preliminary adaptation test online	$N = 11$. Mean age: 40.64; $n = 5$ sons; $n = 5$ daughters; n = 1 spouse. Mean experience in caring: 13 months.		
			4. Final refinement		Members of the research team, IT developers.	
Boots et al., 2016	Exploratory mixed-method study	Development, feasibility	1. Preliminary views exploration	$N = 28$: $n = 21$ females; $n = 7$ males; $n = 22$ spouses; n = 2 children; n = 1 child-in law; n = 1 sibling. Mean age = 63.3.		NS****
			2. Development and validation of contents and structure		Dementia care experts $N = 11$: $n = 1$ psychiatrist; $n = 3$ clinical neuropsychologists; $n = 4$ health psychologists; $n = 1$ occupational therapist; $n = 1$ social psychiatric nurse; $n = 1$ nurse practitioner. Mean Years of professional experience = 13.64 (SD = 7.43).	
			3. Usability testing	$N = 4$ (random sample from phase 1).	$N = 4$ (random sample from phase 2).	
			4. Pilot/Feasibility study (pre-post uncontrolled intervention)	Ic: spousal caregiver of PLWD or Mild Cognitive Impairment; access to Internet. N = 10: n = 3 females n = 7 males. Mean age = 68.10 (SD = 6.54); mean hours of care per week = 44.20 (SD = 56.85).		
Boyd et al., 2021	Mixed methods pilot study	Development; feasibility	1. User needs analysis and feedbacks	N = 5 PLWD. Mean age: 69.75. Mean time since diagnosis: 2.7 years.	$N = 5$: $n = 1$ volunteer and dementia empowerment officer; n = 3 IT developers; n = 1 research member.	Co.design: Workshop 1. Co-design the app; explore engagement and use
			2. Demonstration of the prototype and feedbacks	N = 6 PLWD. Mean age: 56.83. Mean time since diagnosis: 3.08 years.	Same participants	Workshop 2. Show the prototype and receive feedback
			3. Usability test	N = 5 dyads (caregiver and PLWD): n = 4 females; n = 6 males. $n = 6$ spouses; N = 1 daughter; n = 1 friend. Mean PLWD age: 66.2. Mean time since diagnosis: 8.8 years.		Workshop 3: Individual usability session
Dam et al., 2017	Exploratory pilot study	Development, feasibility	1. Users view exploration	N = 10: n = 7 females; n = 3 males; all spouses. Mean age = 73.7. Mean hours of care per week = 37.6. Mean years of experience in caring = 3.		NS****
			2. Modeling (development and validation of content and structure)	N = 2; all spouses.	N = 6: n = 2 researchers; n = 2 clinicians; n = 2 web designers.	
			3. Pilot/Feasibility	Ic: primary caregiver of PLWD living in the community; access to Internet. $N = 25$: $n = 12$ females; $n = 13$ males; $n = 8$ spouses; $n = 16$		

Table 2 (*continued*)

Author(s) and year	Study design	Phase of the intervention	Research steps	Caregivers' or PLWD* ic** and characteristics	Stakeholders' characteristics	Participatory frameworks and strategies
				daughters/sons; n = 1 granddaughter. Mean hours of care per week = 24.7. Mean years of experience in caring = 2.1.		
Davies et al., 2019	Mixed method study	Development and feasibility	1. Synthesis of data	Ic: caregiver of a community dwelling PLWD towards the end of life; having a caregiving experience ≥3 years; ≥ 65 years old. *N* = 23: 77 % females; 59 % spouses.		Co-production method for intervention development (Davies et al., 2016; Greenhalgh et al., 2016; Ward et al., 2018):
						• Individual interviews: decide upon subject areas and topics
			2. Identifying intervention targets and components	N = 1 caregiver (part of the research development group).	Research development group *N* = 12: n = 3 experts in dementia and digital health; n = 6 hcps***; n = 2 members of charity organizations; *n* = 1 caregiver.	• Nominal group processes: help to set the focus of evidence synthesis and identify key targets
			3. Developing the intervention prototype 4. User testing	N = 1 caregiver (part of the research development group). Ic: caregiver of a community dwelling PLWD towards the end of life. N = 11; mean age:74; 73 % females; 55 % spouses /daughters/sons.	Research development group; research team.	
Gaugler et al., 2016	Parallel convergent mixed methods design	Development, feasibility	1. Development and design		Community Advisory Board *N* = 30: clinical professionals, scientific experts and social workers.	Iterative development process
			2. Feasibility and usability testing	Ic: primary caregiver of dwelling PLWD; hours of care per week ≥8. N = 21.		
Goodridge et al., 2021	Participatory Feasibility study	Development, feasibility	1. Co-design of the intervention		Interdisciplinary team: researchers; computer scientists; community advisors: member of the Alzheimer Association; family advisors; consultants.	Co-design
			2. Pre and post test	Ic: primary caregiver of a community dwelling PLWD; ≥ 18 years old; access to smartphone. *N* = 29: 91 % females; 76 % spouse/daughter/son of PLWD. Mean age = 59.6. *n* = 13 caregiving experience <2 years.		
Kagwa et al., 2022	Qualitative explorative design	Feasibility	1. Qualitative interviews post use	Ic: speak Swedish; ≥ 18 years old; experience in caring ≥6 months; access to a tablet or smartphone and Internet. *N* = 12: *n* = 7 females; *n* = 5 males; *n* = 11 spouses; n = 1 daughter.	N = 2 nurses (Members of the research team).	Customer-centric approach and value co-creation (Hardyman et al., 2015; McColl-Kennedy et al., 2012)
Lewis et al., 2010	NS****	Development, feasibility	1. Design and development	Ic: primary caregiver of a community dwelling PLWD.	Advisory Board: experts in dementia, web designers.	Iterative and instructional design:
						• storyboards and Videotapes of interactions with the PLWD
			2. Feasibility and acceptability	*N* = 47: 85 % females. Mean age: 55. Mean caregiving experience = 3.8 years (range: 1–21).		
Loi et al., 2022	Mixed methods unblinded before and after study	Feasibility and preliminary evaluation	1. Development		Project Advisory Group: caregivers, clinicians, dementia experts.	4 meetings in a year. Aim: collect advice about content, recruitment, and data collection.
			2. Feasibility and preliminary effectiveness	Ic: caregiver ≥18 years old; caregiving experience ≥3 years. *N* = 18: 60 % females; 75 % spouses. Mean years of experience in caring = 3 years (range: 0–10). Mean age: 67.5;		.

Table 2 (*continued*)

Author(s) and year	Study design	Phase of the intervention	Research steps	Caregivers' or PLWD* ic** and characteristics	Stakeholders' characteristics	Participatory frameworks and strategies
Masterson-Algar et al., 2023	Adaptation study	Development	1. Consultation and feedback	Ic: young caregiver between 11 and 17 years old; community-dwelling PLWD; experience in caring ≤6 months. N = 6: n = 5 females; n = 1 male; n = 3 son/daughters; n = 3 nephews. Age range: 12–16.	Ic: regular contact with young people and young caregivers. N = 4: n = 2 charity workers; N = n dementia researchers.	Co-design: • Online co-design parallel workshops. Aim: collect experiential information and Individual feedbacks
			2. Refinement and final adaptation	Same participants	Same participants	Online co-design parallel workshops. Aim: finalize adaptations.
McCarron et al., 2019* following Gaugler et al., 2016	Instrumental case study	Development, feasibility	1. Translational phase	N = 14 (included Community Advisory Board): n = 4 spouses; n = 9 daughters/sons; 77 % females. Mean age = 58.	Community Advisory Board N = 29: n = 14 caregivers; n = 8 long-term care administrators; dementia researchers, hcps***.	Stakeholders engagement (Esposito et al., 2015; Patient-Centered Outcomes Research Institute, 2015): • 7 meetings in-person or by phone. Aim: collect in-depth key perspectives to improve the program
			2. Feasibility and usability of the beta version	Ic: primary cg dwelling PLWD; PLWD diagnosed with dementia; > 8 h of care per week. N = 21.		
Mishra et al., 2023	Feasibility and acceptability study	Feasibility	1. Individual interviews	Ic PLWD: ≥ 55 years old; mild-to-moderately severe dementia; living in a residential facility and having an informal caregiver involved ≤8 h of care per week. N pwld = 10: n = 4 females; n = 6 males. Mean age = 73.4. N caregivers = 14: n = 12 females; n = 2 males. Mean age = 68.	N = 11: psychiatrists; clinical social worker; psychologists. mean age = 53.3.	NS****
Monteiro et al., 2023	Multicenter study	Development	1. Linguistic translation		N = 3; n = 1 professional translator; n = 1 research team member; n = 1 representative of the local Alzheimer Association.	NS****
			2. Contents assessment	Ic: ≥ 18 years old; speak portoguese; live in one of the three data collection regions. N = 24, all females. Years of experience in caring = 7 years. Mean age = 54.6	Ic: ≥ 18 years old; speak portoguese; live in one of the three data collection regions; professional caregiving experience ≥1 year. Hcps*** N = 24: 8 % nurses; 70 % females; mean age = 34.1.	
			3. Fidelity check		WHO authors	
Perales-Puchalt et al., 2022	Development and Usability study-mixed-methods	Development, feasability	1. Selection of design principles		Research team	User-centered design
			2. Vendor collaboration for text messaging design and delivery		Vendors	
			3. Evidence-Based foundation		Research team	
			4. Advisory Board guidance	N = 6 (included in the Advisory Board).	Advisory Board N = 27: n = 6 caregivers; n = 16 clinicians, n = 5 hcps***/researcher.	5 online meetings. Aim: collect feedback and inform the prototype.

Table 2 (*continued*)

Author(s) and year	Study design	Phase of the intervention	Research steps	Caregivers' or PLWD* ic** and characteristics	Stakeholders' characteristics	Participatory frameworks and strategies
			5. Sketching and protoyping		N = 7 research members	
			6. Usability testing	Ic: Spanish/English speakers; ≥ 18 years old; identified as Latinx; PLWD diagnosed with clinical dementia diagnosis and Ascertain Dementia Cognitive Scoring; having a cell-phone. N = 6: n = 4 females/daughters; n = 1 males/ sons; n = 1 grand-daughter. Mean age = 44.6 (SD = 6.8).		
Rathnayake et al., 2021	Mixed methods study	Development	1. Needs assessment	N = 10	Hcps***, IT experts	Co-design (Ward et al., 2018); Iterative co-design process (Broderick and Devine, 2014):
						• Online survey and individual interviews. Aims: collect needs and perceptions; feedback for contents
			2. Development of the application		Research team; nurse educator, geriatric nurse; physician, IT experts.	3 in presence meetings with authors. Aim: develop the contents.
Teles et al., 2021a, b	Exploratory study	Development	1. Needs assessment		Research team	NS****
			2. Content translation		Professional translator expert in health communication; mental health professional; nurses; gerontologists.	
			3. Cultural adaptation		Research team	
			4. Expert panel appraisal		n = 1 member of Alzheimer association; n = 1 professor in psychology and researcher in dementia; n = 1 expert in implementation.	
			5. Fidelity check		WHO authors	
Teles et al., 2021a, b	Mixed method usability study	Feasibility	1. User feedback	Ic: ≥ 18 years old; frequent internet users; having an email address. N = 7: n = 4 females; n = 3 males; n = 4 spouses; n = 3 children/grandchildren. Mean caregiving experience: 6 years. Mean age:59.3.	Ic: health and social support professional; experience in dementia. N = 8: all females. Mean age:35.2; mean professional caregiving experience: 6.5 years.	NS****
			2. Usability test	Ic (same for phase 1). N = 10; n = 7 females; n = 2 spouses; n = 8 children/grandchildren. Mean years of experience in caring: 4.1. Mean age: 50.8.	N = 5: n = 5 females. Mean age:38. Mean professional caregiving experience: 11.2.	
Xiao et al., 2021	Interpretative description study	Development	Stakeholders' perspectives	Ic: ≥ 18 years old; mean years of experience in caring ≥1. N = 16: 65 % females; 88 % spouses. Mean years of experience in caring: 5 years. Mean age: 74.5;	Ic: support group coordinators or case managers. N = 20: 88 % females; mean caregiving professional experience: 8 years.	NS****

* people living with dementia.
** inclusion criteria.
*** health care professionals.
**** Not specified.

the studies were grouped and labelled with several terms such as "advisory board" (Lewis et al., 2010; Perales-Puchalt et al., 2022); "community advisory board" (Gaugler et al., 2016; McCarron et al., 2019); "project advisory board" (Loi et al., 2022); "interdisciplinary team" (Goodridge et al., 2021) or "research development group" (Davies et al., 2019), and often included caregivers, experts in dementia, and other stakeholders (see Table 2). Engagement strategies included nominal group techniques (Davies et al., 2019), group meetings (Davies et al., 2019; Perales-Puchalt et al., 2022), individual recurrent meetings (Davies et al., 2019), and co-design workshops (Boyd et al., 2021; Masterson-Algar et al., 2023).

The members of these groups were usually involved both at initial, development stages to pin down the key components of the intervention, and in later stages. Davies and colleagues (Davies et al., 2019) for instance, involved a research development group that identified the future key targets components of the intervention, and refined the intervention prototype. Similarly, Perales-Puchault and colleagues (Perales-Puchalt et al., 2022) relied on the members of an advisory board in all phases of the research process, with the aim of refining the contents in accordance with the final users' needs and preferences. Furthermore, Boyd and colleagues (Boyd et al., 2021) organized three co-design workshops with caregivers and care recipients with the aim of co-designing the application. Finally, although the authors didn't make any explicit reference to a participatory approach, Xiao and colleagues' interpretative study (Xiao et al., 2021) relied on the involvement of different stakeholders to inform the future implementation of "iSupport for dementia" program in Australia. Indeed, sixteen caregivers and twenty between dementia care managers and care staff members were involved in separate focus group discussions to collect preliminary perspectives and attitudes towards the future intervention.

4. Discussion

The aim of this review was to describe the characteristics, design, and development of digital health interventions for informal caregivers of people living with dementia. We focused on the adoption of participatory research methods and found that only few studies applied them, and that methods and results were rarely reported with sufficient detail to allow replication. These findings are also reflected in the outcomes of the risk assessment procedure, which highlighted a broad spectrum of research quality, encompassing both the variability in study designs and the heterogeneity of the methods employed.

4.1. General features and digital components of the interventions

In exploring the general characteristics of the interventions, we aimed to provide a synthesis of the support currently available for caregivers, focusing on the components and content rather than the outcomes produced, which are the primary focus of most reviews. Summarizing the distinctive elements of each intervention allowed us to delve deeper into their components and underlying theoretical frameworks, highlighting recurring elements that are often not defined in a consistent or clear manner.

Compared to web-based interventions, mHealth interventions offer the advantages of being cost-effective, personal, and highly accessible (Fiordelli et al., 2013; Handel, 2011). Only four studies were about interventions delivered by a mobile application. Because interventions were often co-designed with caregivers older than 65 years, this finding suggests that the use of mobile technology may still represent a barrier for older people, who are more familiar with computers rather than mobile devices such as smartphones and tablets (O'Connor et al., 2016). Indeed, the use of mHealth applications in education and support for carers is still in its infancy, but may grow and accelerate as digital literacy improves (Rathnayake et al., 2019).

Most of the studies included multiple components, such as psychoeducational techniques, skills training, care coordination, reminiscence,

and relaxation techniques. This finding is consistent with the literature suggesting that multi-component interventions appear to be more effective in improving caregivers' well-being compared to other interventions (Elvish et al., 2013).

Moreover, most interventions adopted interactive features such as real-time chats, training sessions, task reminders, shared calendar or live feedback. However, only four studies out of twenty allowed users to personalize, and only to some extent, the contents of the program. Tailoring strategies can vary from simple actions such as incorporating the user's name in the contexts, to more complex methods such as adapting the contents, and its delivery to the caregivers' preferences and needs (Morrison, 2015). Compared to non-tailored, tailored health messages are more likely to be read, recalled, and elaborated (Lustria et al., 2013), but evidence on tailored approaches to health interventions is still limited (Beck et al., 2010). This discrepancy may be related to different challenges associated with developing personalized digital health interventions including the costs and resources associated with the technological infrastructure and development of customized contents. Additional issues pertain to data privacy and ethical considerations (Maeckelberghe et al., 2023; Sebri and Savioni, 2020).

Within the context of dementia, a potential alternative solution to the one-size-fits-all approach is the development of targeted interventions dedicated to subgroups of caregivers with common features including culture, stage of dementia, and type of relationship with the care recipient. We found that only four interventions were developed for specific subgroups of caregivers. In a previous systematic review, Van Mierlo and colleagues (Van Mierlo et al., 2012) explored the effectiveness of several interventions within subgroups of caregivers, and found that certain characteristics of the care recipient such as the type and severity of dementia or the type of relationship with the person with dementia were related to better outcomes in several interventions such as decreased caregiver burden and increased competence (Van Mierlo et al., 2012). These findings are aligned with the criticalness of user-centred contents for better usability, acceptability, and, ultimately, effectiveness (Kirvalidze et al., 2023). To this end, careful planning and design of digital health interventions can greatly benefit from the active and continuous collaboration between experts in the field and final users (Skivington et al., 2021).

4.2. Design of the interventions and participatory methods

Half of the studies included in this review described the development phase of the intervention, and all studies involved informal caregivers of PLWD in one or more stages of the intervention, but not much for the design of the intervention. Moreover, the sample size of carers involved in the intervention design phase was quite small, and smaller compared to the feasibility and evaluation phases. When other stakeholders (including healthcare workers and dementia experts) participated in the design, piloting, and testing of a new intervention, they often outnumbered informal caregivers. The difficulty in recruiting informal caregivers of PLWD is well-known (Brangman, 2022). In a very recent study, Joshi et al. (2023) reported the lessons learned from recruiting caregivers to participate to a randomized controlled trial. The identified barriers pertained to three different levels: individual (i.e., carers' time constraints and motivation); community (i.e., reaching underrepresented caregivers); institutional (i.e., obtaining informed consent and navigating research registries) (Joshi et al., 2023). The authors concluded that establishing meaningful relationships with participants and collaborating with support group leaders and organizations was crucial for motivating caregivers to enrol and engage in the study.

We also found little age, gender, and type of relationship diversity in caregivers' characteristics across studies. Only one study focused on the early stages of the disease, and one on end of life. All studies involved caregivers with three or more years of caregiving experience, who were already far along in the caregiver journey. This finding raises issues of limited representativeness and external validity of the effectiveness,

acceptability, and usability of interventions. Early-stage dementia caregivers are known to experience distress and depressive symptoms and have likely different needs compared to 'experienced' caregivers (Blieszner and Roberto, 2010). Boots et al. (2015) talked about a paradox between the need of support and the acceptance of help, whereby difficulty in acknowledging support is related to difficulties in accepting the disease and fear of stigma (L. M. M. Boots et al., 2015). A further comprehension of the experiences of early-stage caregivers is crucial to develop interventions better tailored to their specific needs.

We also aimed at investigating the use of participatory methods in primary studies, including the strategies and approaches used to engage participants in decision-making processes (Vaughn and Jacquez, 2020). As said, in addition to informal caregivers, all interventions were developed with different stakeholders, including health-care professionals, dementia care experts and web-designers. However, reporting of the inclusion of stakeholders and participatory methods was generally poor. Specific terminology exists, such as "community advisory board", which refers to a specific research paradigm and participatory approach, namely the community-based participatory research (CBPR) (Newman et al., 2011), but was seldomly used in primary studies. Indeed, only eight studies explicitly mentioned participatory methods or frameworks. But comparisons were not straightforward. Few authors specified in detail how and why adopting a participatory approach contributed to the development and finalization of the intervention. We argue that the harmonization of participatory research methods, frameworks and terminology is needed to facilitate a more comprehensive comparison between the existing approaches and methodologies used in designing digital health interventions.

A major finding of this review was that participatory methods and frameworks are still relatively underutilized in the development of digital health interventions for dementia caregivers. This may undermine both the research phase and the uptake of interventions of proved effectiveness (Ramanadhan and Viswanath, 2018), and impact on their implementation and scale up (Clemensen et al., 2017). When participants contribute to research since its early stages, barriers and facilitators to future uses and applications are timely anticipated and considered (Wallerstein and Duran, 2010), which can fill the know-do gap, and favour the translation of research findings into new and better practices.

4.3. Limitations

Some limitations are worth noting. First, the heterogeneity in how studies reported methodological details has hindered a systematic comparison between the interventions. However, this lack of consistency may represent an incentive itself for further research to report more about the development phase of the interventions, so to inform and guide future researchers in designing digital health programs. Second, we excluded interventions that did not target informal caregivers. Further research could specifically focus on the design of digital health interventions primarily dedicated to people living with dementia.

5. Conclusions

This review provides an insight into digital health interventions for caregivers of people living with dementia. Unlike other reviews, we focused on how interventions were designed rather than on their efficacy. We explored the use of participatory research methods, a promising yet still relatively underexplored approach. These approaches are rarely adopted during the development of digital health interventions, and when they are, they are often reported without clear practical implications or references to the underlying framework. Our study does not aim to resolve the issue of heterogeneity but rather to systematically shed light on it. This connects to the challenge of evaluating the efficacy of interventions: how can effectiveness be assessed when the frameworks, methods and terminologies are so diverse? Replications are difficult.

Future research may benefit from a clearer presentation and systematization of the existing participatory methods. Indeed, despite the challenges, participatory research seems crucial to enhance the use and acceptance of digital health interventions, especially when these are designed to address a range of complex and multifaceted requirements, such as those daily faced by informal caregivers of people living with dementia.

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author(s) used Chat GPT in order to occasionally rephrase and shorten the text. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Annex 1. Search strategy.

1	Scopus	TITLE-ABS-KEY (mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND TITLE-ABS-KEY (application OR app OR intervention) AND TITLE-ABS-KEY (dementia OR alzheimer) AND TITLE-ABS-KEY (caregiver OR family OR carer OR spouse)
2	Pubmed	("Mhealth"[Title/Abstract] OR "smartphone"[Title/Abstract] OR "mobile"[Title/Abstract] OR "online" [Title/Abstract] OR "internet"[Title/Abstract] OR "health technology"[Title/Abstract] OR "smartphone"[MeSH Terms]) AND ("Application"[Title/Abstract] OR "App"[Title/Abstract] OR "intervention"[Title/Abstract] OR "Psychosocial Intervention"[MeSH Terms] OR "mobile applications"[MeSH Terms]) AND ("dementia car*"[Title/Abstract] OR "alzheimer car*"[Title/Abstract] OR "dementia famil*"[Title/Abstract] OR "alzheimer famil*"[Title/Abstract] OR "caregivers"[MeSH Terms])
3	CINAHL	mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND (application OR app OR intervention OR) AND (dementia OR alzheimer) AND (caregiver OR family OR carer OR spouse)
4	Cochrane	(mhealth):ti,ab,kw OR (smartphone):ti,ab,kw OR (mobile):ti,ab,kw OR (online) OR (internet):ti,ab,kw OR ("health technology"):ti,ab,kw OR [mh smartphone] AND (application):ti,ab,kw OR (app):ti,ab,kw OR (intervention):ti,ab,kw OR [mh "Mobile Applications"] OR [mh "Psychosocial Intervention"] AND (alzheimer):ti,ab,kw OR (dementia):ti,ab,kw OR [mh "Alzheimer's disease"] OR [mh dementia] AND (caregiver):ti,ab,kw OR (family):ti,ab,kw OR (carer):ti,ab,kw OR (spouse):ti,ab,kw OR [mh Caregivers] AND #1-#4}
5	Web Of Knowledge	TS = (mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND TS = (application? OR app? OR intervention) AND TS = (dementia OR alzheimer) AND TS = (caregiver? famil* OR carer? OR spouse?)
6	Psychinfo	(Mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND (Application OR App OR intervention) AND ("Alzheimer car*" OR "dementia car*" OR "dementia famil*" OR "Alzheimer famil*")
7	IEEE	(((mhealth OR smartphone OR mobile OR online OR internet OR "health technology") AND (application OR app OR intervention) AND (dementia OR alzheimer) AND (caregiver OR family OR carer OR spouse)))

Annex 2. PRISMA checklist (Page et al., 2021).

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title page
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	–
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pages 1–2
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 2
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Study selection process (page 5)
Information sources	6	Specify all databases, registers, websites, organizations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Study selection process (page 5)
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Search strategy (page 5) and Search strategy (Annex 1)
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Study selection process (page 6) and Flowchart (Fig. 1)
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Study selection process (page 6) and Data abstraction (pages 6–7)
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Data abstraction and study quality appraisal (page 6) and Theroetical frameworks (pages 7,8)
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Data abstraction and study quality appraisal (page 6) and Theroetical frameworks (pages 7,8)
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Study selection process (page 6)
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1 and Table 2
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Theroetical frameworks (pages 7,8)
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Data abstraction and study quality appraisal (use of the Mixed Methods Appraisal tool pag. 7)
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Flowchart (Fig. 1)
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Flowchart (Fig. 1)
Study characteristics	17	Cite each included study and present its characteristics.	General characteristics (pages 9–10) and Methodological characteristics (pages 10–13) and Table 1 and Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A

(*continued*)

Section and Topic	Item #	Checklist item	Location where item is reported
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 1 and Table 2
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Risk assessments bias
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	General features and digital components of the interventions (pages 13–15) and Design of the interventions (pages 15–17)
	23b	Discuss any limitations of the evidence included in the review.	Limitations (page 17)
	23c	Discuss any limitations of the review processes used.	Limitations (page 17)
	23d	Discuss implications of the results for practice, policy, and future research.	Conclusions (page 17)
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Data abstraction and study quality appraisal (page 7)
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Data abstraction and study quality appraisal (page 7)
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	–
Competing interests	26	Declare any competing interests of review authors.	–
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	See Annexes

Annex 3. Risk assessment using the Mixed Methods-Assessment tool (MMAT).

Author(s) and year	S1	S2	1.1	1.2	1.3	1.4	1.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5	Mean score
Baruah et al., 2020	1	1	1	1	1	1	1																1
Baruah et al., 2021	1	0	1	0	0	0	0																0,29
Boots et al., 2016[a]	1	1	1	1	1	1	1	1	1	0	1	1						0	1	1	1	0,8	0,87
Boyd et al., 2021[a]	1	1	1	1	1	1	1	1	1	1	1	1						1	1	1	1	1	1
Dam et al., 2017[a]	1	1	1	1	1	1	1	1	1	1	1	1						1	0	1	1	1	0,94
Davies et al., 2019	1	1	1	1	1	1	1																1
Gaugler et al., 2016[a]	1	1	1	1	1	1	1	1	1	1	0	1						1	1	1	1	0,8	0,93
Goodridge et al., 2021[a]	1	1	1	1	1	1	1	1	1	1	0	1						1	1	1	1	0,8	0,93
Kagwa et al., 2022	1	1	1	1	1	1	1																1
Lewis et al., 2010[a]	1	0	1	1	1	0	0						1	0	0	1	0	0	1	1	1	0,4	0,55
Loi et al., 2022[a]	1	1	1	1	1	1	1	1	1	1	0	1						1	1	1	1	0,8	0,93
Masterson-Algar	1	1	1	1	1	1	1																1

(*continued*)

Author(s) and year	S1	S2	1.1	1.2	1.3	1.4	1.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5	Mean score
et al., 2023																							
McCarron et al., 2019	1	1	1	NA	1	0	1																0,71
Mishra et al., 2023[a]	1	1	1	1	1	1	1	1	1	1	1	1						1	0	1	1	1	0,94
Monteiro et al., 2023	1	1	1	0	1	1	0																0,71
Perales-Puchalt et al., 2022[a]	1	1	1	1	1	1	1						1	1	0	1	1	1	1	1	1	0,8	0,93
Rathnayake et al., 2021	1	1	1	1	0	0	0																0,57
Teles et al., 2021a, 2021b	1	1	1	1	1	1	1																1
Teles et al., 2021a, 2021b[a]	1	1	1	1	1	1	1						1	1	1	1	1	1	1	1	1	1	1
Xiao et al., 2021	1	1	1	1	1	1	1																1

Notes: The scores are represented as "1" (Yes), "0" (No), and "NA" (Can't tell).

Mixed-Methods Assessment Tool (Hong et al., 2018**) legenda:** Screening questions: S1: "Are there clear research questions?" S2: "Do the collected data allow to address the research questions?". For qualitative studies: 1.1: "Is the qualitative approach appropriate to answer the research question?" 1.2: "Are the qualitative data collection methods adequate to address the research question?" 1.3: "Are the findings adequately derived from the data?" 1.4: "Is the interpretation of results sufficiently substantiated by data?" 1.5: "Is there coherence between qualitative data sources, collection, analysis, and interpretation?". For quantitative non-randomized studies: 3.1: "Are the participants representative of the target population?" 3.2: "Are measurements appropriate regarding both the outcome and intervention (or exposure)?" 3.3: "Are there complete outcome data?" 3.4: "Are the confounders accounted for in the design and analysis?" 3.5: "During the study period, is the intervention administered (or exposure occurred) as intended?". For quantitative descriptive studies: 4.1: "Is the sampling strategy relevant to address the research question?" 4.2: "Is the sample representative of the target population?" 4.3: "Are the measurements appropriate?" 4.4: "Is the risk of nonresponse bias low?" 4.5: "Is the statistical analysis appropriate to answer the research question?". For mixed methods studies: 5.1: "Is there an adequate rationale for using a mixed methods design to address the research question?" 5.2: "Are the different components of the study effectively integrated to answer the research question?" 5.3: "Are the outputs of the integration of qualitative and quantitative components adequately interpreted?" 5.4: "Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?" 5.5: "Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?"

[a] = Mixed-methods studies. The category "2. Quantitative: Randomized Controlled Trials" is not included in the table as no studies in the review met the criteria for this category, due to exclusion criteria. The score for the item "5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?" is calculated, as suggested by the Mixed-Methods Assessment Tool (MMAT), as the lowest average score obtained between the qualitative and quantitative components.

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