Telephone and online support programs and assistive technologies that support informal carers of people living with young-onset dementia: A systematic review

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Telephone and online support programs and assistive technologies that support informal carers of people living with young-onset dementia: A systematic review

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Abstract

Objective: Carers of people with young-onset dementia can be challenged by the care they provide. Little is known about the types of telephone and online support programs and assistive technologies that may help to assist them with caregiving. This review aimed to identify telephone and online support programs and assistive technologies that informal carers find useful for caring for people with young-onset dementia. **Design:** A systematic review followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. An electronic search of the following five English databases was conducted: PubMed, PsycINFO, CINAHL, Web of Science, and Embase. In addition, the reference lists of eligible studies were manually searched to identify further studies. Databases were searched using synonyms and derivates for "dementia," "Alzheimer's disease," "young onset", "early onset", "caregiver", "online" and "technology". **Results:** We found 12 manuscripts that meet the study inclusion criteria. The dominant technologies were telephone and online support programs. Other assistive technologies included safety and monitoring support, telehealth, and a simple TV remote control. While carers reported positive effects of the telephone and online support programs, and technologies, such as improved self-efficacy, satisfaction, knowledge, well-being, and reduced burden, stress, depression, and anxiety, the studies were scarce, and a limited number of assistive technologies were explored. **Conclusion:** Given the increasing number of telephone and online programs and assistive technologies, it is disappointing to find a paucity of available manuscripts and the limited number of technologies explored for this population. Technologies to assist this population need to be developed and evaluated.

Keywords

technology, young-onset dementia, early-onset dementia, informal carers, online support, telephone support, assistive technology

Introduction

There are currently around 55 million people living with dementia globally (WHO, 2023). In most cases, people are diagnosed with dementia in advanced age, i.e., 65 years and older (Sokolovič et al., 2023). Young-onset dementia refers to dementia symptom onset before age 65 (Bruinsma et al., 2020). Young-onset dementia accounts for around 5% of all cases of dementia (Loi et al., 2023). However, this number may be underestimated. A recent systematic review drawing from 95 studies estimated the global prevalence of young-onset dementia to be 119.00 per 100,000 population (Henricks et al., 2021). Informal carers of persons with young-onset dementia are usually spouses or family members (Binford et al., 2023). A dementia diagnosis at a younger age can bring several challenges compared to a diagnosis at an older age for both the person with young-onset dementia and the carer. Carers and people with young-onset dementia may encounter inverse ageism; they may be raising a family, are often employed, could be looking after ageing parents, have financial responsibilities such as a mortgage, are generally physically fitter, may spend a drawn out time in the community post-diagnosis, and the person with potential young-onset dementia can face lengthy diagnosis outlets (Draper & Withall, 2016; Giebel, 2022; Holdsworth & McCabe, 2018; Lai et al., 2023). Furthermore, available support services might not be appropriate for this younger population, and therefore, carers and people with young-onset dementia might not willingly access the available services (O'Shea et al., 2019). In addition, there appear to be limited support services available specifically for carers of people with young-onset dementia (Holdsworth & McCabe, 2018). However, although the carers of this population are likely to be younger and more adept at using

technologies and the internet, it is unclear whether they find specific telephone or online support programs or assistive technologies to assist their caregiving. Furthermore, although there are benefits to using technology, there are also mixed findings. One of the key concerns is the high cost of technology, and there are worries that not all technology is suitable for everyone to use (Xiong et al., 2020). This review aimed to identify the telephone and online support programs and assistive technologies that informal carers of people with young-onset dementia found useful.

Telephone and online support programs provide information and support to family carers (Parkinson et al., 2016). Assistive technologies are "any item, piece of equipment, or product, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Myck-Wayne & Ramirez, 2014, p. 97). Assistive technology is categorised as low technology that is low-cost and relatively easy to use. Medium technology can be battery-operated or simple electronic items. Whereas high technology includes computers and sophisticated electronics. This type of technology can also include communication technology (Hasan & Linger, 2016).

There is growing evidence that technologies may help carers of older people with dementia manage care (Heintz & Vahia, 2020; Moyle, 2019). For example, digital technologies such as tablets may assist people with mild dementia with Instrumental Activities of Daily Living (IADL), and as a result, this may also support carers by reducing their burden (Kerkhof et al., 2016, 2021; Øksnebjerg et al., 2020). Digital technologies such as iPads and smart phones also helped people with dementia and their carers during the COVID-19 pandemic connect and engage with health professionals, friends, and family (Chirico et al., 2022). Assistive technologies such as electronic calendars may also help carers with time management (Persson et al., 2023). Furthermore, carers may opt to receive support from telephone or online support programs to manage the care burden. Technologies such as fall alarms and home monitoring have been used to monitor the safety of people living with dementia (Riikonen et al., 2010; Fange et al., 2020). While regarded positively, ethical issues have also been raised when monitoring people at home (Fange et al., 2020). Even though technologies seem to be gaining momentum in dementia care generally (Moyle, 2019), it is unclear whether telephone and online support programs or assistive technologies will benefit carers of people with young-onset dementia or if this population has specific technology needs that are not being addressed.

To the best of our knowledge, this is the first systematic review that identifies telephone and online support programs and assistive technologies that informal carers assessed to assist them with caring for people with young-onset dementia. The main research question is:

- What telephone and online support programs and assistive technologies do carers of people with young-onset dementia find helpful in supporting caregiving?

Design

A systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (Moher et al., 2009).

Search strategy

In consultation with a health librarian, we developed the database searches. Five English databases were searched, including PubMed, CINAHL, EMBASE, PsycINFO, and Web of Science, in October 2023. Additionally, the reference lists of eligible studies and reviews were manually screened to identify further studies. Search terms used were synonyms and derivates of the following

keywords: "dementia," "Alzheimer," "young onset", "early onset", "caregiver", "technology". Full details of the search strategy used in PsychInfo are provided in Table 1.

The keywords and MeSH terms (combined using Boolean operators) were searched in the title and abstract to avoid missing relevant literature. To include as many papers as possible, the literature search covered from the inception of relevant research to October 2023.

Inclusion and exclusion criteria

Studies were included if they met the following inclusion criteria:

Population: The focus was on carers of people with young-onset dementia (i.e., the population of interest), and research was undertaken in all settings, such as community (home), care facilities, or hospitals.

Intervention: The intervention evaluated the outcomes of digital technologies (single or multi-component interventions, e.g., digital component/s only or combined with face-to-face sessions).

Outcome: Reported peer-reviewed research results based on quantitative, qualitative, or mixed methods studies.

Timeframe for follow-up: There was no timeframe for follow-up.

Publication language: The research was published in English in a peer-reviewed publication.

Studies were excluded if:

Population: The main focus was on populations other than carers of people with young-onset dementia.

Intervention: The intervention did not include telephone or online support programs or assistive technologies.

Outcome: The paper did not report empirical findings.

Publication language: The research was published in a language other than English, including reviews, protocols, reports, commentaries, editorials, conference abstracts, dissertations, book chapters, and textbooks.

Selection of publications

All retrieved articles were transferred into EndNote X8 as separate files, identified by their database names. All identified duplicates were removed automatically using the Find Duplicates function in EndNote X8, followed by additional manual removal. One reviewer (MS) screened all records for relevance to the topic and excluded articles based on title or abstract that did not meet the inclusion criteria. The selection was imported into Covidence, and two independent reviewers (MS, MQ) assessed full-text articles for eligibility. Because of the scarcity of studies in this area, all studies that met the inclusion criteria were included, including those where people with dementia included various diagnoses, and the results did not specify the findings specifically for carers of people with young onset dementia.

The review followed PRISMA guidelines (Moher et al., 2009) (see Figure 1). The systematic review protocol was registered with PROSPERO (International database of prospectively registered systematic reviews in health and social care, CRD42023478014.

Data extraction and analysis

All authors were involved in data extraction using a table with subheadings (Table 2). The information extracted from the eligible articles for data synthesis included the title, authors, year of publication, country, study aims, study design, setting, timeframe, participants, digital technology,

Table 1. Example of search strategy PsychINFO via OVID

PsycINFO via OVID
- Ensure "Map Term to Subject Heading" box is ticked
- Use Auto Explode function for search terms
- Search keywords in Title/abstract - ti,ab
- Limiter: English language only

APA Thesaurus of Psychological Index Terms	Keywords (brackets)
exp Dementia OR exp Alzheimer's Disease OR exp Semantic Dementia OR exp Vascular Dementia	dementia OR Alzheimer* OR "frontotemporal dementia" OR "vascular dementia" OR "mixed dementia" AND "young* onset" OR "earl* onset" OR presenile OR "under 65"
exp Caregivers	caregiv* OR care-giver* OR carer* OR caretaker OR caring OR family OR families OR "informal carer*" OR dependents OR support* OR "support person" OR caretaker* OR spous* OR husband* OR wife OR wives OR partner* OR couple OR couples OR "loved one*" OR mother* OR father* OR "adult child*" OR sibling OR son OR sons OR daughter* OR "next of kin" OR "significant other*" OR relative OR relatives OR parent OR parents OR kinship
exp Internet OR exp Digital Technology OR exp Information Technology OR exp "Information and Communication Technology" OR exp Assistive Technology OR exp Microcomputers OR exp "Virtual Reality Exposure Therapy" OR exp Artificial Intelligence OR exp Mobile Phones OR exp Smartphones OR exp Mobile Applications OR exp "Computer Assisted Therapy" OR exp Telemedicine	digital OR 'digital tech*' OR technology OR technologies OR ICT OR 'information and communication technolog*' OR online OR on-line OR website OR web OR internet OR computer OR platform OR wireless OR electronic OR multimedia OR e-learning OR email OR e-mail OR 'text messaging' OR smartphone* OR 'smart phone*' OR 'cell phone' OR iPhone* OR mobile OR 'mobile phone' OR 'mobile device' OR tablet OR 'software app*' OR 'software-app*' OR 'electronic-app*' OR app OR apps OR 'mobile app*' OR 'mobile application*' OR iPad* OR handheld-device* OR 'hand-held device*' OR handheld-computer* OR 'hand-held computer*' OR computer* OR palmtop* OR laptop* OR 'personal digital assist*' OR PDA OR 'telephone application*' OR touch-screen* OR touchscreen* OR interactive OR chatbot* OR 'conversation agent*' OR robot* OR 'dialog system*' OR 'dialogue system*' OR 'relational agent*' OR wearable* OR telemedicine* OR telehome* OR telehealth* OR telecare* OR telemonitor* OR mhealth OR m-health OR ehealth OR e-health OR 'assistive technolog*' OR virtual OR 'augmented realit*' OR exergam* OR 'artificial intelligence'

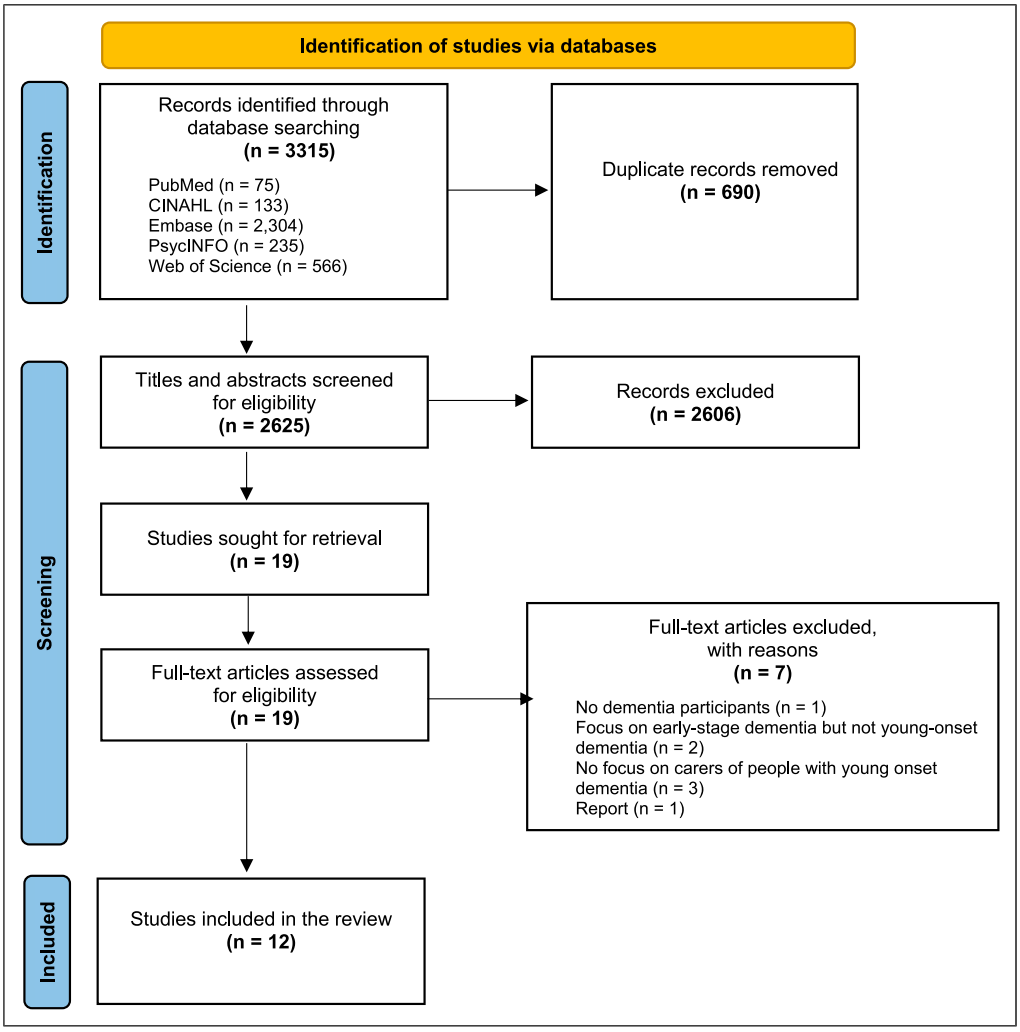

Figure 1. Prisma flow diagram.

intervention focus, data collection and key findings. Data were extracted by four reviewers (MS, MQ, LP, NL), and a consensus review was undertaken until agreement was reached for an article's final inclusion. Any discrepancies between researchers regarding inclusion were resolved through discussion between all authors (MS, MQ, LP, NL, WM).

Quality appraisal

The Mixed Methods Appraisal Tool (MMAT) version 2018 was used to assess the included studies' quality and risk of bias (Hong et al., 2018). This tool is a well-established tool for reviewing the quality of study designs. We assessed for randomization, group comparability at baseline, availability of complete outcome data, the outcome of assessors' blinding, and participants' adherence to the intervention when assessing the quality of randomized control

Table 2. Demographics and characteristics of the included articles (*N* = 12).

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Perin S.; Iai, R.; Diehl-Schmid, J.; You, E.; Kurz, A., Tensil, M.; Wenz, M.; Foertsch, B.; Lautenschlager, NT. (2023). **Germany** To assess the acceptability and feasibility of combining RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young; a web-based information and skill-building programme for carers of people with Young-Onset Dementia) with individually tailored support sessions with health professionals (asocial worker and a clinical psychologist) provided via online videoconferencing.	Non-randomised experimental study; quantitative and qualitative data.	Community Convenience sample of 20 informal carers. Mean age: 57 Range: 40–77 years. Age of person with dementia Mean: 56 Range: 41–68.	4-weeks plus 2 support sessions	Spouse; child; sibling	A web-based information and skill-building program for carers of people with Young-Onset Dementia: RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) combined with individually tailored support sessions with health professionals (a social worker and a clinical psychologist) provided via online videoconferencing.	Carer/s and healthcare professionals	Surveys, questionnaires, telephone interviews, face-to-face feedback.	Effects: Most carers (over 85%) rated the RHAPSODY-Plus program as good to very good, demonstrating high acceptability. Experiences and perceptions: Positive feedback about the program included receiving personal advice and the information provided in RHAPSODY. Some limitations in the feasibility of videoconferencing included network and technical issues and the loss of non-verbal communication.

(continued)

Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Climans R.; Berall, A.; Santiago, A.T.; Gardner, S.; Margles, D.; Shnall, A. (2022). Experiences and perceptions: Carers reported that being able to share experiences with other carers in similar circumstances helped them feel supported and less alone. Adult children were observed to have a reduction in both the negative impact of caregiving and depression scores. **Canada** To understand the impact of virtual support groups on Young-Onset Dementia family caregivers' psychosocial wellbeing, coping abilities, and knowledge about caring for the care recipient.	Pre-post mixed methods pilot study	Community Convenience sample of 31 informal carers. Spouses mean: 61.1. Adult child mean: 34.3. Age of person with Young-Onset Dementia N/S.	8–10 weeks	Spouse or adult children.	Virtual psychotherapeutic support group – psychotherapeutic support groups convened weekly for one hour for 8–10 weeks and were facilitated by one of two social workers trained in group psychotherapy.	Carers only	Pre- and post-surveys/ questionnaires and end of intervention focus groups.	Effectiveness: The evaluation of the virtual groups demonstrated high carer satisfaction and improved knowledge, wellness, and abilities. All spouses and 92.9% of adult children reported an increased ability to manage care for a person with dementia. Most spouses (75%) and adult children (92.9%) felt more compassion toward someone with dementia. The psychosocial measures revealed that carer wellbeing was maintained or improved during the intervention for both the adult children and the spousal groups. There was an increase in the number of coping strategies rated as helpful among spousal and adult children's groups.

(continued)

Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
De Stefano, M.; Esposito, S.; Iavarone, A.; Mazzi, M.C.; Siciliano, M.; Buonanno, D.; Artipaldi, D.; Trojsi, F.; Tedeschi, G. (2022). **Italy** To explore the effect of a telephone-based psychological intervention (phone-I) on the burden, mood disorders, needs and post-traumatic symptoms of caregivers of patients with early-onset Alzheimer's disease: A six-month study during the COVID-19 emergency.	Randomised controlled trial	Community 20 consecutive caregivers of patients with early onset Alzheimer's disease were recruited. Control group age mean: 57. Treatment group age mean: 49. Age of a person with dementia Control group: 61. Treatment group: 57.6.	1-month	Spouse, child, sibling.	Telephone-based psychological intervention (once a week for 4-weeks, 60 mins emphatic listening/ counselling) followed by a short-term assessment.	Carers only	Surveys/ questionnaires were assessed in week 5 and 6 months.	Effectiveness: (1) After the 4-week phone-I, the treated caregivers showed a relatively positive response in terms of reduction in perceived burden and post-traumatic stress symptoms and a modest benefit on depression compared to the caregivers. (2) The benefit of treated caregivers, and the second infection wave, disappeared six months later.

(continued)

Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Daeman, M.; Bruinsma, J.; Bakker, C.; Zwaaftink, RG.; Koopmans, R., Oostijen, A., Loose, B., Verhey, F., de Vugt, M.; Peetoom, K. (2022). **The Netherlands** To evaluate the Dutch RHAPSODY program in terms of user acceptability, usability, user satisfaction, and user behavior.	Cross-sectional study: quantitative and qualitative.	Setting N/S 55 carers were recruited via social media, newsletters, and mailing lists. 26 – pop-up survey. 19 – extensive survey. 10 – in-depth interviews. 53.8% carers and 46.2% health professionals. Carers mean: 64.5. Range: 52–81. Age of Young-Onset Dementia N/S.	N/S	Spouse; child; relative/s; health professionals.	Web-based/online information and support program.	Carer/s and health professional.	Surveys/ questionnaires; semi-structured interviews; online surveys. All participants who completed the extensive survey were invited for an in-depth interview that was conducted by telephone.	Effect: User acceptability: The majority strongly agreed the program was useful and easy to use and indicated they would use it again. User satisfaction: 94.7% rated the quality as good to excellent. Participants indicated they would use the program again and recommend it to others. User useability: Participants felt the program contained comprehensive information and was relevant for Young-Onset Dementia caregivers and also for persons not directly involved with Young-Onset Dementia. User behaviour: The most viewed page (360 unique page views) explained what Young-Onset Dementia entails. Most time was spent on the page about the diagnostic process (6.5 min).

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Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Bruinsma, J.; Peetoom, K.; Bakker, C.; Boots, L.; Millenaar, J.; Verhey, F.; de Vugt, M. (2021). **The Netherlands** To evaluate how spouses perceive the tailored intervention content on Young-Onset Dementia.	Pre-post feasibility study - qualitative and quantitative.	Community 40 carers were recruited via social media and newsletter. Age range: 52–81 years (Mean 64.5). People with Young-Onset Dementia, F, semantic dementia and primary progressive aphasia. Age 54–72.	8–10 weeks (flexible).	Spouse; family members.	Web-based - self-management intervention. Online coaching and tailored modules containing videos, personal stories, and psychoeducation for spouses of persons with Young-Onset Dementia.	Carers	Surveys/ questionnaires; semi-structured interviews; post-intervention phone questionnaire	Effect: The intervention matched the expectations of carers. Time restraints were a potential barrier before participation, but afterwards, carers positively evaluated the flexibility of the web-based approach. Effectiveness: Explorative quantitative findings reported carer's self-efficacy, anxiety, and depression. xperiences and perceptions: Caregiving spouses positively evaluated the intervention regarding usability, feasibility, and acceptability. Post-intervention, carers felt more at ease and confident about the caregiving role. Significantly improved post-intervention.
Metcalfe, A.; Jones, B.; Mayer, J.; Gage, H.; Oyebode, J.; Boucault, S.; et al. (2019). **England, France, Germany** To explore the acceptability of the RHAPSODY project (Research to Assess Policies and Strategies for Dementia in the Young) to caregivers and the potential for a larger trial of effectiveness.	Randomised controlled trial.	Community 61 Carers recruited from memory clinics. Carers immediate access group mean age: 57.6. Waitlist control mean age: 57.2. People with Young-Onset Dementia Immediate access group mean age: 61.6. Waitlist control mean age: 61.9	12-weeks	N/S	A web-based multimedia, information, and skill-building programme.	Carers/s and people with Young-Onset Dementia.	Surveys/ questionnaires; semi-structured interviews assessed baseline, weeks 6 and 12.	Effectiveness: (1) Seventy percent of carers described the program as useful and easy to use. (2) Eighty-five percent expressed intent to use the resource in the future. (3) Reductions in reported stress levels and carers' negative reactions to memory symptoms were observed following the use of the programme.

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Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Holthe, T.; Jentoft, R.; Arntzen, C.; & Thorsen, K. (2018) **Norway** To examine the family carers' roles and experiences with assistive technology as a means of supporting people with young onset-dementia (Young-Onset Dementia).	Qualitative research	Community 13 Carers aged 19–89 12 people with Young-Onset Dementia age 52–65 were recruited from four memory clinics.	3-weeks to 18-months	Spouse; child; parent (mother)	16 different AT, altogether 35 items categorised into 4 groups: Safety and security (sensors, timers & tracking devices, alarms & timers, GPS) Simple user interface (user interfaces to avoid being lost, simple TV remote control, calendar, electronic door lock, item locator, simple mobile phone), visual reminder/ strategies (white board, calendar, colour coding), and auditive reminder/ strategies (speaking wrist watch, message box, memory clock, medicine dispenser)	Carers/s and people with Young-Onset Dementia	Semi-structured interviews; observations of the use of the AT, the role of the FC, and the interaction in the dyads	Experiences and perceptions: (1) Six main themes emerged: timely information about AT; waiting times; AT incorporated into the structure of everyday living; AT experienced as a relief and burden; appraisal of the AT qualities and the committed carer. (2) With support from professionals, OTs (occupational therapists) or others, early and timely access to AT may empower the person with Young-Onset Dementia and the carers to cope with daily challenges and relieve both. (3) There are several limitations and barriers to the successful use of AT, with difficulties increasing over time. (4) Interventions implementing AT must be based on analysis of the needs of the person with Young-Onset Dementia and the carers: their capabilities, preferences, embodied habits, and coping strategies.

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Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Boots, LMM.; de Vugt, M.; Kempen, IJM.; Verhey, FRJ. (2018) **The Netherlands** To evaluate the effectiveness of the blended care self-management program, Partner in Balance, compared to a control group.	Single-blind randomised controlled trial.	Community and clinic 81 carers were recruited from memory clinics, mental health clinics and caregiver support services. Age intervention group: 67.8 Control group: 70.2. Age of people with Young-Onset Dementia N/S.	8-weeks	Spouse; child	Partner in Balance: the blended care self-management program PiB combines face-to-face coaching with tailored online thematic modules, including psychoeducation, behavioral modeling, reflective assignments, change plans, and email feedback from the coach over 8 weeks; and (3) a face-to-face evaluation session with the coach evaluating previously set goals.	Carer/s only	Surveys/ questionnaires assessed baseline and after 8-weeks.	Effectiveness: A significant increase in favor of the intervention group was demonstrated for self-efficacy (care management), mastery, and quality of life. Effect sizes were medium for quality of life (d = 0.58) and high for self-efficacy care management and service use (d = 0.85 and d = 0.93, respectively) and mastery (d = 0.94). No significant differences between the groups were found in depressive symptoms, anxiety, and perceived stress.

(continued)

Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Arntzen, C.; Holthe, T.; Jentoft, R. (2016) **Norway** To explore the trajectory of AT from introduction, when it is acted upon, explored, and evaluated by the person with Young-Onset Dementia and family carers.	Qualitative research; Phenomenological study	Community 14 carers were recruited. Aged 19–89 12 Young-Onset Dementia participants aged 52–65 (diagnosed with dementia in the last 12 months) were recruited from four memory clinics.	Up to 12-months	Spouse; child; parent	Assistive Technology (AT). 39 technical devices for safety and security, time aids, and GPS tracking device, e.g. sensor & location devices, automated timers, automatic calendars, talking wristwatch, medicine dispenser, simple TV remote control, item locator, white board, electronic doorlock, GPS, message box	Carers/s and people with Young-Onset Dementia.	In-depth interviews and observations at baseline and repeated every 3rd month up to 12 months.	Experiences and perceptions: Carers suggested the AT had to: (1) be valuable by addressing practical, emotional, and relational challenges; (2) fit well into, or be a better solution than, habitual practice and established strategies; (3) generate positive emotions and become a reliable and trustworthy tool; (4) be user-friendly, adaptable, and manageable; (5) Interest and engage the family carers.

(continued)

Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
O'Connell, M.; Crossley, M.; Cammer, A.; Morgan, D. (2014). **Canada** To describe the development of a novel use of telehealth videoconferencing to deliver a specialized support group for spousal caregivers of rural individuals with atypical and early-onset dementias.	Qualitative research	Rural and remote memory clinic 11 carers were recruited from the memory clinic. Age N/S People with Frontotemporal Dementia and early-onset. A few months to 3 years since diagnosis. Age N/S.	18-months	Spouse	Telehealth videoconferencing. Group members travelled to a local hospital-based site using Telehealth Saskatchewan's videoconferencing equipment. Each group member saw a large screen upon which images of the six physical locations were displayed. Monthly meeting: 90 minutes. Group focus: Emotion processing. Carers received one training session.	Carer/s only	Focus groups; in-person workshop with discussion sessions.	Experiences and perceptions: Using telehealth, videoconferencing was accessible to rural carers who were geographically isolated and could only meet virtually to attend a specialized support group. Group interventions for carers must be specialized and only include family members caring for individuals with similar diagnoses to maximize effectiveness. It was important to have a group comprised mostly of spouses of similar ages. The similarity in day-to-day challenges was important to the quality of the support provided by this intervention.
Jentoft, R.; Holthe, T.; Arntzen, C. (2014). **Norway** To explore why the SRC (simple remote control) is significant and beneficial in the everyday lives of Young People with Dementia and their caregivers.	Qualitative research. Participatory design.	Community 8 carers were recruited from four memory clinics. Age N/S. Young People with Dementia participants aged 52–65	3–15 months	Spouse; child; parent (mother)	Simple remote control	Carers/s and people with early-onset Frontotemporal Dementia.	In-depth interviews, field observations	Experiences and perceptions: (1) The Simple remote control successfully solved the challenges faced by Young People with Dementia with operating TVs, thus reducing stress for Young People with Dementia and therefore reducing the burden for carers. (2) Carers recommended access to professional support and advice regarding assistive technology, which is vital for establishing a system for follow-up and continued collaboration to make future adaptations and adjustments.

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Table 2. (continued)

Author/s, publication year, country & study aim	Study design	Study setting & sample	Time Frame of Intervention	Carer/s	Description of technology	Intervention focus	Data Collection	Key findings
Shnall, A.; Agate, A.; Grinberg, A.; Huijbregts, M.; Nguyen, M.Q.; Chow, T.W. (2013) **Canada** Explores how the needs of families living with Frontotemporal Dementia resulted in three programme initiatives developed at Baycrest (an academic health sciences centre focused on ageing in Toronto, Canada) to meet the needs of this population.	Qualitative feasibility research	Healthcare Complex Number of carers N/S, People with Frontotemporal Dementia. Age N/S.	10-week intervention plus 10-week follow-up	Spouse; child (teenager)	An Internet-based videoconferencing support group for spouses, a website that provides support and counsel for children and their parents, and an adult day programme designed for patients with Frontotemporal Dementia.	Carers/s and people with young on-set dementia	Surveys/ questionnaires; focus groups; interviews.	Experiences and perceptions: The first program (Internet-based videoconferencing support group for carers): All carers were very positive about participation, given the competing demands of having to work, household responsibilities, responding to the needs of children, and dealing with the pressure of caring for a spouse with Frontotemporal Dementia; the third program (Website for children and well parents): children took on caregiving responsibilities as part of their lives, but they never described them as a burden. Children often feared overwhelming their parents with their own needs and pain, and the hesitation of children to express their needs and feelings openly and honestly with their parents made it more difficult for family members to find common ground.

N/S = not stated.

trials. In quantitative non-randomized studies, we assessed the sample representativeness of the target population, the use of measurements appropriate for both outcome and intervention, the availability of complete outcome data, accounting for confounders during design and analysis, and administration of the intervention as intended. One rater (MS) independently assessed the quality of the included studies. A second rater (MQ) then assessed a random sample of the articles to ensure agreement was reached. Where there was disagreement between the reviewers, a third reviewer (WM) appraised the paper, and a discussion took place to resolve any discrepancies (see Table 3).

Results

Study selection

A total of 3,315 studies were retrieved from five databases (PubMed, CINAHL, EMBASE, PsycINFO, and Web of Science), and after removing 690 duplicate records, a title and abstract screening excluded 2606 studies that did not meet the inclusion criteria. A full-text review of the remaining 19 studies was conducted against the inclusion and exclusion criteria. A further seven studies were removed for the following reasons: did not include people with dementia ($n = 1$), focus on early-stage dementia but not young age ($n = 2$), did not focus on carers of persons with young-onset dementia ($n = 3$), and one was a report ($n = 1$). In total, 12 articles met our inclusion criteria and were included in this review (Figure 1).

Study characteristics

The studies were conducted in a small number of countries, predominantly in Europe (The Netherlands ($n = 3$), Norway ($n = 3$), Germany ($n = 1$), Italy ($n = 1$)), and one study was conducted in three countries, i.e. England, Germany, and France. The remaining three studies were conducted in Canada. Most of the studies were conducted in the community ($n = 8$), followed by the memory clinic ($n = 1$) and healthcare complex ($n = 1$). Two did not report the setting. There were a variety of designs. The main design was qualitative research ($n = 5$) followed by randomized controlled trials (RCTs) ($n = 3$), pre-post mixed methods ($n = 3$), and non-randomized quantitative and qualitative research ($n = 1$). The studies undertaken in The Netherlands, Norway and Canada were undertaken in each country by the same team of authors.

Participant characteristics

Most of the studies invited only informal carers to participate. The study sample included informal carers of people living with young-onset dementia, predominantly spouses, children, siblings, or relatives. One study (Daeman et al., 2022) also included formal carers (health professionals), and another study (Metcalfe et al., 2019) did not report the carers' details (see Table 2).

Dementia type and severity

Although the focus was on carers of people with young-onset dementia, the most common type of dementia reported was Alzheimer's disease, followed by Frontotemporal Dementia.

Table 3. Quality assurance.

Authors	Screening Questions		Qualitative Studies				
	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	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?
Perin et al., (2023)	Yes	Yes					
Climans et al., (2022)	Yes	Yes					
De Stefano et al., (2022)	Yes	Yes					
Daeman et al. (2022)	Yes	Yes					
Bruinsma et al., (2021)	Yes	Yes					
Metcalfe et al., (2019)	Yes	Yes					
Holthe et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Boots et al., (2018)	Yes	Yes					
Arntzen et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
O'Connell et al., (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jentoft et al., (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shnall et al., (2013)	Yes	Yes	Yes	Yes	Yes	Yes	No

Authors	Randomized Controlled Studies				
	2.1. Is randomization appropriately performed?	2.2. Are the groups comparable at baseline?	2.3. Are there complete outcome data?	2.4. Are outcome assessors blinded to the intervention provided?	2.5. Did the participants adhere to the assigned intervention?

(continued)

Table 3. (continued)

Authors	Randomized Controlled Studies				
De Stefano et al., (2022)	Cannot tell	No	Yes	Cannot tell	Cannot tell
Metcalfe et al., (2019)	Yes	Yes	Yes	No	Cannot tell
Boots et al., (2018)	Yes	Yes	No	Yes	No

Authors	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 there confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
Perin et al., (2023)	Yes	Yes	Yes	Yes	Yes

Authors	Mixed Methods Studies				
	5.1. Is there an adequate rational 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?
Climans et al., (2022)	Yes	Yes	Yes	Yes	Yes
Daeman et al. (2022)	Yes	Yes	Yes	Yes	Yes
Bruinsma et al., (2021)	Yes	Yes	Yes	Yes	Yes

Technology type

The most frequent technologies were online support interventions that provided information and skill-building programs that were often accompanied by counselling sessions with health professionals (Boots et al., 2018; Bruinsma et al., 2021; Daeman et al., 2022; Metcalfe et al., 2019; Perin et al., 2023; Shnall et al., 2013), virtual psychotherapy (Climans et al., 2022), telephone-based psychological intervention (De Stefano et al., 2022), various assistive technologies such as sensor and location devices, automated timers, mobile phone, automatic calendar, talking wrist watch, and medicine dispenser (Arntzen et al., 2016; Holthe et al., 2018), a simple TV remote control (Holthe et al., 2018; Jentoft et al., 2014), and telehealth (O'Connell et al., 2014). Three of the studies assessed the same RHAPSODY program (Daeman et al., 2022; Metcalfe et al., 2019; Perin et al., 2023).

Number and duration of technology sessions

The number and duration of the technology sessions varied between the publications. The length of the intervention ranged from 4 weeks to 10 weeks for 60 minutes of listening/counselling to a monthly 90-min meeting. Arntzen et al. (2016) did not report the length of the technology duration.

Carers training

The training of carers to use the technologies was reported in only one paper (O'Connell et al., 2014). However, it is assumed that some form of training must have taken place to teach carers how to use the technologies.

Effect and effectiveness of technologies

All studies reported improved carer management following participation in the reported interventions. Positive outcomes included carer higher self-efficacy (Boots et al., 2018; Bruinsma et al., 2021), carer satisfaction and improved knowledge (Bruinsma et al., 2021), improved well-being and reduction in perceived carer burden and stress (Boots et al., 2018; De Stefano et al., 2022; Jentoft et al., 2014; Metcalfe et al., 2019), and reduced carer depression (Bruinsma et al., 2021; Climans et al., 2022; De Stefano et al., 2022) and anxiety (Bruinsma et al., 2021). There was also an increase in carer coping strategies related to online programs. However, Boots et al. (2018) did not find any significant differences between the intervention and control groups in depressive symptoms, anxiety, and perceived stress. In addition, carers rated the programs from good to very good, demonstrating high acceptability, satisfaction, and useability.

Quality assurance

All qualitative studies were reported to be of a high standard except for Shnall et al. (2013), who failed to provide quotation support for their analysis and interpretation. None of the RCTs were of a high standard. De Stefano et al. (2022) met only one criterion, and Metcalfe et al. (2019) and Boots et al. (2018) met three of the five quality assurance criteria. Perin et al. (2023) were of a high standard in the non-randomized controlled studies, and all mixed methods studies (Bruinsma et al., 2021; Climans et al., 2022; Daeman et al., 2022) were also ranked to be of a high standard (see Table 3).

Discussion

In this review, we aimed to understand the telephone and online support programs as well as assistive technologies that informal carers assessed as helpful when caring for people with young-onset dementia. However, this review is limited by the small number of studies from predominately Europe. This finding may be influenced by Europe being in the top five countries in the development of all 64 technologies and their substantial R&D investment (Australian Strategic Policy Institute, 2024 https://www.aspi.org.au/opinion/critical-technology-tracker-two-decades-data-show-rewards-long-term-research-investment). Furthermore, the small number of research teams suggest that such technologies and young-onset dementia are not topics of significant interest in the current dementia literature. Given the rarity of young-onset dementia; this topic might also not be attractive to research funders. This is disappointing, given the increasing number of people with young-onset dementia and the care burden for carers of this population. However, the apparent limited development of technologies for this population, and the difficulties in gaining a diagnosis, including long delays in receiving a diagnosis, may also have contributed to the low number of manuscripts regarding technology support. Furthermore, the lack of healthcare professional training in using these technologies and limited knowledge may also have exacerbated problems in encouraging carers to trial available technologies and creating new research opportunities (Isidori et al., 2022; Mengestie et al., 2020). In addition, caregivers are price-sensitive because of caregiving's financial demands, which may also have contributed to the low number of technologies available for evaluation (Xiong et al., 2020).

As indicated in the results, all studies reported improved carer management following participation in the reported interventions. We found that the main types of technology used involved online information programs that provided strategies and support for informal carers. These are often run in combination with health professional support and counselling services. Such programs may require skilled health professionals to run them. Therefore, without skilled staff, these programs are not possible. However, such programs have the advantage of enabling a flexible support approach, which is important for a carer with time constraints. In particular, there was an increase in carer coping strategies related to the online programs. Although not tested, improved carer coping may reduce the likelihood of early entry of the person with young-onset dementia into nursing home care. This must be tested in future research as it may encourage more funding and research opportunities for technology development. In addition, these programs were rated good to very good by carers. However, online programs were at times limited by internet access and technical issues. Therefore, this must be taken into consideration, particularly where internet access can be challenged, such as in rural and remote communities where the internet signal might be weak. Furthermore, such programs limit health professionals' access to carers' non-verbal communication, sometimes making support difficult. However, these programs can be readily available in most communities and may be particularly useful when participants face similar challenges and are of similar ages (O'Connell et al., 2014).

Most of the interventions did not have a long follow-up period apart from De Stefano et al. (2022), who found that the benefits of a 4-week telephone-based psychological intervention had disappeared by six months. Future research must investigate the sustainability of the technology over a longer period so that effectiveness and dose requirements can be fully understood.

Young-onset dementia is known to have a significant impact on the marital relationship (Bruinsma et al., 2020). In a study of spousal carers, apathy was identified as hurting the marital relationship (de Vugt et al., 2006). It was concluded that interventions targeting apathy could

improve the marital relationship and delay the transition of the person with young-onset dementia to a nursing home. Unfortunately, none of the technology interventions targeted apathy in this review.

Several assistive technologies were involved in the review. The main message was that to be successful, the chosen assistive technology must be based on an analysis of the needs of the person with young-onset dementia and the carer. Technologies can fail when they are not targeted to the population or the condition.

It appears that technologies can support carers of people with young-onset dementia and should be introduced into care. However, as the number of studies and technologies were limited, further research is needed to determine the most effective technologies. Importantly, we must also understand the cost of technologies and their impact on care. While technologies may improve the quality of life for carers and people with young-onset dementia, this is likely not true for all technologies. None of the publications discussed the financial implications of the technologies, and yet the cost and availability of technologies are likely to impede their use. While some technologies are initially expensive, their overall effect may be cost-effective (Mervin et al., 2018). Incentives and regulations could assist carers in choosing cost-effective technologies.

Strengths and limitations

This review reports the technologies tested by informal carers of people with young-onset dementia to support care. It contributes to the body of knowledge regarding effective technologies to assist carers of young-onset dementia. Although only a few manuscripts were available, they allowed us to identify the technologies that can support carers of people with young-onset dementia. The review identified the main effective technologies as online information and skill-building programs.

There are some limitations to this review. The limited number of studies in this area resulted in us including various study designs with different levels of evidence. Although three RCTs were included, none of these studies were of a high standard. Furthermore, we may have missed some literature as we excluded literature in any language other than English and grey literature. This may have resulted in publication bias. Furthermore, as we only focused on informal carers of people with young-onset dementia, there may be other literature involving technologies that include other stakeholders, such as people with young-onset dementia and healthcare professionals. In addition, we have included papers where there are people with other forms of dementia in addition to young-onset dementia and where the population data was not specified in the analyses or results section of the paper. This may have skewed the findings about people with young-onset dementia.

Implications for future research and practice

Although many available technologies could assist informal carers, they may need help knowing where to find effective and reliable technologies (Moyle et al., 2022). Furthermore, the research on technologies, carers, and young-onset dementia is limited; therefore, it is impossible to know the available technologies' efficacy unless experts thoroughly examine them. Therefore, there is a need for more research in this area and further development of technologies specific to the needs of this population of carers. Furthermore, future research requires the development of technologies that are co-designed for carers' use. Once more technologies are available, they will need to be evaluated through robust study designs, such as RCTs, to assess the effectiveness of the technologies.

Another solution could be for a readily available list of available technologies, including their efficacy, cost and where they can be purchased. This may help carers avoid purchasing expensive or useless technologies. A dementia society could develop and maintain such a list. Helping carers of this population may help develop a more positive attitude, overcome the burden of care, and improve the quality of the carer-person with young-onset dementia relationship.

The manuscripts and data were from a few countries, and no data was from low-income countries, which we assume would differ from those found in these manuscripts as technologies tend to be more readily available in wealthier countries. It would be interesting to investigate if carers of people with young-onset dementia in low-income countries use technologies. If they are not being used, strategies to improve their use should be implemented.

Conclusions

Technologies can offer opportunities for carers to improve care for people with young-onset dementia. Researchers, dementia organizations and policymakers must assist carers by developing and evaluating technologies for this population and promoting evidence for their use.

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Author contributions

All authors designed the study. MS developed the search strategies and searched the databases. MS, LP, MQ, NL contributed to the article selection and data extraction. WM supervised the study and wrote the first draft of the manuscript. All authors provided comments on and edited drafts of the manuscript. All authors agreed on the submission of the final manuscript.

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Ethical statement

Ethical approval

This systematic review only involved library searches and did not involve human participants. Therefore, it did not require ethical approval.

Registration

This review was registered in PROSPERO International Prospective Register of Systematic Reviews (Registration number: CRD42023478014).

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