**Exploring the views and the use of information and communication technologies to access post-diagnostic support by people living with dementia and unpaid carers: A systematic review**

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# **Abstract**

**Objectives:** This systematic review examined how information communication technologies (ICT) has been used to access remote post-diagnostic support that address the needs people with dementia, or those of dyad, and explored care recipients’ views on accessing support remotely.

**Method:** Concepts relating to dementia and ICT were searched across six databases (PsychInfo, PubMed, Cochrane Library, CINAHL, Social Care Online, and Web of Science) in March 2021 and updated in March 2022. Studies published from 1990 and written in English, German or French were considered for inclusion. Methodological quality was appraised using the Hawker quality assessment tool and reporting structured according to PRISMA guidelines.

**Results:** The search yielded 8,485 citations. Following the removal of duplicates and screening processes, 18 papers reporting on 17 studies were included. Studies described a range of post-diagnostic support, including medical follow-ups and therapeutic sessions, and were often delivered on a one-to-one basis via videoconferencing software. Whilst often relying on assistance from unpaid carers, people with dementia directly engaged with ICT to access post-diagnostic support in 13 studies. Accessing post-diagnostic support remotely appears feasible, nevertheless, care recipients’ views were mixed. Access was frequently facilitated by supplying devices and providing ongoing technological support.

**Conclusions:** Accessing post-diagnostic support remotely is likely to benefit some care recipients, however, to prevent widening inequalities in access, services within the current hybrid landscape need to accommodate to people who are digitally excluded. Future research should capture the support provided by unpaid carers to facilitate the engagement of people with dementia to remote post-diagnostic support.

**Keywords:** dementia; post-diagnostic support; ICT; remote service delivery

# **Background**

Globally, an estimated 55 million people are currently living with dementia and projections suggest this will increase to 139 million by 2050 (WHO, 2021). Accessing support is paramount to living well with dementia, nevertheless, challenged with increasing demand and coupled with finite resources, the ability of strained health and care systems to sustainably provide equitable, responsive, and timely post-diagnostic support, is of mounting concern.

Following a dementia diagnosis, post-diagnostic support can be defined as services delivered to cater the changing care and support needs experienced by people with dementia and unpaid carers throughout the disease trajectory (Prince et al., 2016). The prompt identification and the holistic management of needs are key components to good post-diagnostic support (Bamford et al., 2021). Dementia care pathways differ across regions and countries. In the UK, the provision of post-diagnostic support services often involves a mixture of providers (private, public and voluntary) operating within three sectors (primary and secondary healthcare, social care and third sector), across various care settings. Sectors differ in funding streams and priorities. Post-diagnostic support within the healthcare sector may encompass services such as dementia medical reviews and psychological support, the social care sector may provide day care centres, respite care and carer’s assessments, and the third sector may include centres, befriending services, and peer support groups (Frost et al., 2021).

Post-diagnostic support offers many potential benefits which extend from facilitating the initial adjustment phase, to dying well with dementia. Benefits include encouraging independence and positively impacting the social health of people with dementia (Giebel et al., 2020a; Kelly & Innes, 2016; Willis et al., 2018). Post-diagnostic support may alleviate the caregiving burden and help to address feelings of depression and anxiety within unpaid carers (Carter et al., 2020; Vandepitte et al., 2016). The usage of post-diagnostic support services should align with individual preferences whilst reflecting care recipients’ evolving needs. Nevertheless, the service provision landscape is fragmented and access remains inequitably laden with potential hurdles. Factors contributing to the unmet needs include poor signposting of services, rural residency, and financial and or time constraints (Bayly et al., 2020; Bieber et al., 2019; Giebel et al., 2021a; Watson et al., 2021). Whilst some barriers to accessing post-diagnostic support may span different contexts (Giebel et al., 2022a; Ketchum et al., 2022), many are likely to require setting-specific approaches.

The use of information communication technology (ICT) as a medium to feasibly deliver low-cost, sustainable and person-centred post-diagnostic support has received considerable political traction over the last decade (Wright, 2020). The potential role of ICT in achieving universal health coverage is recognised, and may, for example, increase care recipients’ access to services by overcoming barriers associated with rural residency (Bayly et al., 2020; Sekhon et al., 2021). Nevertheless, the adoption of ICT in practice has remained somewhat limited until the COVID-19 pandemic provoked, at least temporarily, a shift to remote service delivery.

Overall, research has largely focused on accessing remote services involved in forming a dementia diagnosis (Barth et al., 2018; Haralambous et al., 2019), assistive technology (Pappada et al., 2021), and post-diagnostic support which solely addresses the needs of unpaid carers (Etxeberria et al., 2020; Leng et al, 2020). Prior to the pandemic, some studies reported on remote post-diagnostic support that addressed the needs of people with dementia or those of the dyad. These included medical follow-ups (Azad et al., 2012), and non-pharmacological services such as exercise health (Alonso et al., 2020; Dekker-van Weering et al., 2019) and information provision (Hattink et al., 2016; Howe et al., 2020). Whilst the support accessed was valued by both members of the dyad, unpaid carers often became the primary users and navigated the technology (Hattink et al., 2016; Howe et al., 2020). The impact following the curtailment of post-diagnostic support provision during the pandemic is concerning (Giebel et al., 2020b; Giebel et al., 2022b; Giebel et al., 2020c) and is likely to entail long-term implications. As some services shifted to remote service provision, studies reported on post-diagnostic support accessed through innovative mediums, including remote memory clinics (Benaque et al., 2020), exercise health interventions (Di Lorito et al., 2021) and singing groups (Lee et al., 2021). Although many care recipients valued accessing post-diagnostic support remotely during the pandemic, the support was sometimes delivered at inconvenient times, and was perceived as being unable to replicate the benefits offered by face-to-face contact.

Despite a growing evidence base exploring the feasibility and acceptability of accessing post-diagnostic support remotely, both prior to and during the ongoing pandemic, these studies have yet to be systematically reviewed. Thus, this systematic review sought to explore the use of ICT to access post-diagnostic support services that address the needs of people with dementia or those of the dyad and their accompanying views on accessing dementia-related post-diagnostic support services remotely. Specifically, this systematic review addressed the following interlinked review questions; “*How has ICT been used to access post-diagnostic support that address the needs of people with dementia and unpaid carers? What are the views of people with dementia and unpaid carers on accessing dementia-related post-diagnostic support services remotely*?” Findings may provide insights and assist policymakers or service providers when planning and designing prospective remote dementia-related post-diagnostic support services.

# **Methods**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed when conducting and reporting this systematic review (Liberati et al., 2009). The review protocol was registered on PROSPERO International prospective register of systematic reviews (ID = CRD42021233776).

## **Search strategy**

A total of six databases were searched (APA Psych Info, PubMed, Cochrane Library, CINHAL Plus, Social Care Online and Web of Science) in March 2021 and updated in March 2022. Whilst not all ICT are internet-based, the majority are likely to require connectivity. As the internet was not widely available in commercial and public settings prior to 1990, a search restriction was applied to exclude studies published prior to 1990. Owing to the international make-up of the team, the search was extended to includes studies written in German, French and English. Input from a University of Liverpool specialist librarian was sought when devising the search strategy. The principle of Setting, Population, Intervention, Control and Evaluation (SPICE) was applied when selecting the search terms (Booth, 2006). Using a combination of Boolean operators and truncations, the same terms were searched within the titles and abstracts of studies across the databases (Population: “mild cognitive impairment”, Dement\*, Alzheimer\*, MCI; Intervention: “e health”, “information technology”, “technology based”, “web based”, eHealth, internet, online, telehealth, telemedicine). A controlled search was conducted where available, and subject headings were adjusted according to the different databases. Additional hand searches were conducted, and included screening the reference list and tracking the citations, using Google Scholar, of all included studies.

## **Eligibility**

Post-diagnostic support was defined as ‘*all services delivered following a dementia diagnosis to cater for the changing care and support needs of people with dementia and unpaid carers and informal carers during the disease trajectory, until end of life*’ (Prince et al., 2016). Eligible studies reported on the use of ICT access dementia-related remote post-diagnostic support that addressed the needs of people with dementia and or the dyad. Studies focusing on community dwelling people with dementia and or unpaid carers and satisfying the inclusion criteria outlined in Table 1 were included. Studies reporting on individuals not living with dementia or people with dementia not residing in community were excluded. Studies frequently report, notably during the pandemic, on participants who identify or self-report as living or caring for someone with dementia, without confirming the diagnosis (e.g., Giebel et al., 2020b; Giebel et al., 2021c; Talbot and Briggs, 2022). Thus, to draw conclusions from a wider pool of evidence, confirming the dementia diagnosis of the participants did not form a requirement to be considered for inclusion in our review.

TABLE 1

## **Selection procedure**

The searches were conducted by TC. The PRISMA guidelines (Liberati et al., 2009) were followed when reporting this systematic review. All titles were screened and abstracts of relevant titles were read by TC and studies were excluded if they did not satisfy the inclusion criteria. For studies that appeared to satisfy the inclusion criteria, the study was read in full. If there was any uncertainty relating to the suitability of a study for inclusion, it was discussed amongst the review team members and included if in unanimous agreement.

**Quality appraisal**

The methodological quality of all included studies was appraised by quality assessment tool developed by Hawker and colleagues (Hawker et al., 2002), which accommodates for the methodological review of studies with disparate research paradigms. The tool consists of nine components to appraise the methodology of studies by examining the introduction and aims; methodology; sampling; data analysis; ethics and bias; results; transferability and generalisability of findings; and the implications and usefulness of findings to policy and practice. Each component is rated according to a four-point Likert scale (good, fair, poor and very poor) and numerical value are attributed to each scale (overall score range: 9-36), with an overall score of 36 indicating studies with rigorous methodologies. TC appraised the methodological quality of all included studies and no study was excluded based on their methodological quality.

## **Data extraction and analysis**

A bespoke form extracted relevant data from included studies, including the country of origin, year of publication, study objectives, design, sample, data collection, type of ICT used, characteristics of the post-diagnostic support accessed and / or the views of accessing remote dementia-related post-diagnostic support. TC extracted the data of the included studies. A meta-analysis was not feasible due to the heterogeneity of the included studies in terms of study designs employed and types of post-diagnostic support described. Therefore, following the guidance developed by the Economic and Social Research Council (ESRC) (Popay et al., 2006), the results were narratively synthesised and presented in a tabular format.

# **Results**

FIGURE 1

The initial search yielded 8,485 citations. Following the removal of duplicates and screening the titles and abstracts (Stage 1), a total of 56 studies were retrieved. Subsequent to full-text screening (Stage 2), a total of 18 papers reporting on 17 studies were included (Figure 1).

## **Study characteristics**

Nine studies employed a quantitative study design (Capozzo et al., 2020; Chodosh et al., 2015; Dial et al., 2019; Kim et al., 2017; Laver et al., 2020; Moo et al., 2020; Panerai et al., 2021; Possin et al., 2019; Ptomey et al., 2019), five employed a qualitative study design (Cousins et al., 2022; Giebel et al., 2021b; Killin et al., 2018; Masoud et al., 2021; O'Rourke et al., 2021) and four employed a mixed-methods approach (Dal Bello-Haas, M. E. O'Connell, et al., 2014; Gately et al., 2020a; Rogalski et al., 2016) (Table 2). Research emerged from six countries, including the USA, UK and Italy, and six studies included a comparative or control element (Chodosh et al., 2015; Kim et al., 2017; Laver et al., 2020; Moo et al., 2020; Panerai et al., 2021; Possin et al., 2019). Accessing remote post-diagnostic support during the COVID-19 pandemic was explored in six studies (Capozzo et al., 2020; Cousins et al., 2022; Giebel et al., 2021b; Masoud et al., 2021; O'Rourke et al., 2021; Panerai et al., 2021) and one study explored accessing remote post-diagnostic support in people from marginalised groups (Chodosh et al., 2015).

A dementia diagnosis formed a requirement in twelve studies (Capozzo et al., 2020; Chodosh et al., 2015; Cousins et al., 2022; Dal Bello-Haas, M. E. O’Connell, et al., 2014; Dial et al., 2019; Killin et al., 2018; Moo et al., 2020; O'Rourke et al., 2021; Panerai et al., 2021; Possin et al., 2019; Ptomey et al., 2019; Rogalski et al., 2016). Participants with a dementia diagnoses, a probable diagnosis or a Mini-Mental State Examination score below 24 was eligible to participate in Laver et al., 2019’s study. The participation or presence of unpaid carers, alongside the person with dementia, formed a requirement in four studies (Killin et al., 2018; Laver et al., 2020; Possin et al., 2019; Ptomey et al., 2019) and encouraged in two (O'Rourke et al., 2021; Rogalski et al., 2016). Access to wireless internet was a requirement in one study (Ptomey et al., 2019) and basic computer skills was a prerequisite in another (Gately et al., 2020a). Whilst not explicitly part of the inclusion criteria, Rogalski et al (Rogalski et al., 2016) briefly screened participants’ technology skills. People visual and or hearing impairments were excluded from Dial et al (Dial et al., 2019)’s study.

TABLE 2

All included studies were of good methodological quality, with scores ranging between 33-36 points, from a possible maximum of 36 points (Appendix, Table 1).

## **Types of remote post-diagnostic support accessed**

Studies described a range of remote post-diagnostic support which addressed the needs of people with dementia or of the dyad. People with dementia or both members of the dyad directly engaged with the ICT to access remote post-diagnostic support in thirteen studies (Capozzo et al., 2020; Cousins et al., 2022; Dal Bello-Haas, M. E. O’Connell, et al., 2014; Dial et al., 2019; Giebel et al., 2021b; Killin et al., 2018; Kim et al., 2017; Masoud et al., 2021; Moo et al., 2020; O'Rourke et al., 2021; Panerai et al., 2021; Ptomey et al., 2019; Rogalski et al., 2016) and four studies reported on support accessed by the unpaid carer (Chodosh et al., 2015; Gately et al., 2020a; Laver et al., 2020; Possin et al., 2019) (Table 3).

TABLE 3

### ***Post-diagnostic support accessed by people with dementia or both members of the dyad***

Studies described exercise classes (Dal Bello-Haas, M. E. O’Connell, et al., 2014; Giebel et al., 2021b; Ptomey et al., 2019), therapeutic interventions, including speech and language (Dial et al., 2019; Rogalski et al., 2016) and reality orientation (Panerai et al., 2021) therapy, supportive interventions, including support groups and memory cafés, (Cousins et al., 2022; Giebel et al., 2021b; Masoud et al., 2021), medical follow-ups (Capozzo et al., 2020; Kim et al., 2017; Moo et al., 2020), ‘check-up’ calls (Giebel., Hanna, Callaghan, et al., 2021; O'Rourke et al., 2021) and information provision (Killin et al., 2018). Some people with dementia had previously accessed support groups and memory cafes (Cousins et al., 2022; Masoud et al., 2021), reality orientation therapy (Panerai et al., 2021) and medical follow-ups (Capozzo et al., 2020; Moo et al., 2020) when delivered in in-person formats. Some unpaid carers provided support to facilitate the engagement of the person with dementia when exercising (Dal Bello-Haas, M. E. O’Connell, et al., 2014), and their presence was beneficial during speech and language therapy sessions (Rogalski et al., 2016). Most remote post-diagnostic support was mainly accessed on a one-to-one basis (Capozzo et al., 2020; Dial et al., 2019; Giebel et al., 2021b; Killin et al., 2018; Moo et al., 2020; O'Rourke et al., 2021; Panerai et al., 2021; Rogalski et al., 2016) and accessible from participants’ home. Support accessed ranged from a single medical follow-up visits (Capozzo et al., 2020) to a long-term medical management spanning five years (Kim et al., 2017). Two studies reported on follow-up with time frames of six (Rogalski et al., 2016) and 12 (Dial et al., 2019) months, and three studies reported on ongoing support accessed throughout the COVID-19 pandemic (Cousins et al., 2022; Masoud et al., 2021; O'Rourke et al., 2021).

#### Outcomes

Overall, adherence to remote post-diagnostic support was high (Dal Bello-Haas, M. E. O’Connell, et al., 2014; Ptomey et al., 2019; Rogalski et al., 2016). Moderate physical activity levels increased in care recipients participating in Ptomey et al. (Ptomey et al., 2019)’s exercise classes, and people with dementia improved in speech and language outcomes (Dial et al., 2019; Rogalski et al., 2016). Increased gains and confidence were maintained six months following the interventions (Rogalski et al., 2016) and long-term improvements were comparable to benefits received from accessing speech and language treatment in-person (Dial et al., 2019). Compared to the control group, increased Mini–Mental State Examination (MMSE) scores, decreased behavioural and psychological symptoms, notably depression, was found in people living with dementia who had accessed telephone orientation therapy, and outcomes positively impacted unpaid carers’ levels of distress (Panerai et al., 2021). The MMSE scores of people with dementia who attended long-term medical management through telemedicine and in-person were comparable. The MMSE score of people with dementia with less severe initial impairments decreased less in the telemedicine group than the in-person group (Kim et al., 2017). Following the implementation of social distancing, people with dementia were found to have a lower quality of life, worsening symptoms and language abilities (Capozzo et al., 2020).

### ***Post-diagnostic support accessed by unpaid carers***

Studies described care management interventions (Chodosh et al., 2015; Possin et al., 2019), a home safety evaluation (Gately et al., 2020a) and a supportive intervention (Laver et al., 2020), which were delivered on a one-to-one basis and accessible from participants’ home. Support accessed ranged from a single home safety evaluation (Gately et al., 2020a) to a care management intervention lasting a year (Possin et al., 2019). Two studies reported on follow-ups with time frames of six months (Chodosh et al., 2015; Possin et al., 2019).

#### Outcomes

The care management intervention decreased the caregiving burden, behavioural problems and health care utilisation, regardless if unpaid carers accessed the support remotely or in-person (Chodosh et al., 2015). Compared to unpaid carers who had accessed care management remotely, a greater decline in the quality of life of people with dementia and more visits to the emergency department were found in the control group from baseline to 12 months (Possin et al., 2019). The depression scores of unpaid carers who accessed the care management declined more than the control group at 23 months (Possin et al., 2019). The supportive intervention, when accessed remotely or in-person, increased caregiving mastery and perceptions of caregiving. People with dementia in the remote group experienced greater a functional decline, but experienced greater improvements in behavioural problems compared to the in-person group (Laver et al., 2020). Delivering a care management and supportive intervention in an in-person format required greater expenditures (Chodosh et al., 2015) and travelling (Laver et al., 2020).

## **ICT formats employed, issues encountered and technological support**

Video-conferencing software was the most employed ICT format (Cousins et al., 2022; Dal Bello-Haas, M. E. O’Connell, et al., 2014; Dial et al., 2019; Gately et al., 2020a; Giebel et al., 2021b; Kim et al., 2017; Laver et al., 2020; Masoud et al., 2021; Moo et al., 2020; Ptomey et al., 2019; Rogalski et al., 2016), followed by the telephone (Capozzo et al., 2020; Chodosh et al., 2015; Giebel et al., 2021b; O'Rourke et al., 2021; Panerai et al., 2021; Possin et al., 2019). In Capozzo et al (Capozzo et al., 2020)’s study, people with dementia chose to access medical follow-ups through telephone calls, rather than via videoconferencing software. Six studies reported on ICT issues experienced. This included difficulties connecting devices to access exercise classes (Ptomey et al., 2019), accessing and using the information portal (Killin et al., 2018) and poor audio and visual quality during speech and language therapy sessions (Rogalski et al., 2016) and home safety evaluations (Gately et al., 2020a). Insufficient minutes on unpaid carers’ personal phone plans formed a barrier to engaging with a care management intervention (Chodosh et al., 2015) and two people with dementia ceased attending speech and language therapy sessions due to dementia severity or limited ICT literacy (Rogalski et al., 2016).

If required, devices were provided in seven studies (Chodosh et al., 2015; Dial et al., 2019; Gately et al., 2020a; Killin et al., 2018; Laver et al., 2020; Moo et al., 2020; Ptomey et al., 2019). These included tablets and or mobile phones, often pre-installed with the required software, or mobile phones with unlimited call minutes (Chodosh et al., 2015). Two studies (Killin et al., 2018; Moo et al., 2020) contacted participants beforehand to identify devices participants owned or engaged with. Sessions explaining the technology was delivered in-person (Killin et al., 2018; Laver et al., 2020; Ptomey et al., 2019) and remotely (Dial et al., 2019; Gately et al., 2020a; Killin et al., 2018; Moo et al., 2020). Two studies (Gately et al., 2020a; Moo et al., 2020) conducted a test-run with the participants beforehand. Some unpaid carers assisted people with dementia by setting up the technology (Giebel., Hanna, Callaghan, et al., 2021; Ptomey et al., 2019) and liaising with the study team regarding the technology setup (Moo et al., 2020).

## **Views on accessing post-diagnostic support remotely**

Thirteen studies explored the views of people with dementia and unpaid carers when accessing post-diagnostic support remotely (Table 3). Care recipients’ views were largely obtained via individual or dyadic interviews (Cousins et al., 2022; Dal Bello-Haas, M. E. O’Connell, et al., 2014; Giebel et al., 2021b; Killin et al., 2018; Masoud et al., 2021; O'Rourke et al., 2021) or quantitative surveys (Capozzo et al., 2020; Dal Bello-Haas, M. E. O’Connell, et al., 2014; Gately et al., 2020b; Laver et al., 2020; Possin et al., 2019; Ptomey et al., 2019). Ptomey et al (Ptomey et al., 2019) devised a simplified questionnaire, which was administered verbally and accessible to people with dementia. Dal Bello-Haas et al (Dal Bello-Haas, M. E. O’Connell, et al., 2014) observed the engagement of the dyad during the exercise class. Four studies (Cousins et al., 2022; Giebel et al., 2021b; Killin et al., 2018; Moo et al., 2020) studies included views of people with dementia reported by proxy.

Overall, views were mixed. People with dementia and unpaid carers enjoyed participating in exercise classes (Dal Bello-Haas et al., 2014; Ptomey et al., 2019), willing to continue accessing the intervention, and unpaid carers reporting an increase in exercising independently (Ptomey et al., 2019). During the exercise class, care recipients were able to focus without distraction, privacy was respected and able to engage with the facilitator (Dal Bello-Haas, M. E. O’Connell, et al., 2014). People with dementia enjoyed accessing speech language treatment remotely, would have liked to received more sessions, and found the pre-recorded videos helpful (Rogalski et al., 2016). Care recipients chose to access medical follow-ups remotely due to convenience, increased contact with service providers and to maintain the routine of the person with dementia (Moo et al., 2020). Accessing remote medical follow-ups yielded high satisfaction (Capozzo et al., 2020; Moo et al., 2020), care recipients were at least as satisfied when remotely accessing medical follow-ups as when attending visits in-person (Moo et al., 2020), and many would like to continue access appointments remotely (Capozzo et al., 2020). During the medical follow-ups, care recipients felt able to talk as when during in-person follow-ups, comfortable accessing care remotely (Capozzo et al., 2020) and staff answered their questions satisfactorily (Moo et al., 2020). Unpaid carers were satisfied with remotely accessing home safety evaluations (Gately et al., 2020b), supportive (Laver et al., 2020) and care management interventions (Possin et al., 2019). The remote safety evaluation was perceived as being time efficient and unpaid carers felt comfortable using the technology (Gately et al., 2020b). Nevertheless, when comparing in-person to remote service delivery, unpaid carers were slightly more favourable towards accessing home safety evaluations (Gately et al., 2020b) and supportive interventions (Laver et al., 2020) in an in-person format. Whilst some people with dementia and unpaid carers valued the information provided on the information portal (Killin et al., 2018), it did not align with their perceived present needs and many experienced difficulties whilst navigating the technology, which contributed to the underuse of the service.

During the COVID-19 pandemic, check-up calls (Giebel., Hanna, Callaghan, et al., 2021; O'Rourke et al., 2021), memory cafes (Masoud et al., 2021) and peer support group (Cousins et al., 2022; Giebel et al., 2021b) provided valuable support, an opportunity to engage in activities and to connect with others. Whilst some people with dementia recognised their friends remotely, some were unable to (Giebel., Hanna, Callaghan, et al., 2021; Masoud et al., 2021). Some unpaid carers reported that due to behavioural problems and general disinterest in technology, remote memory cafes were unsuitable for people with dementia (Masoud et al., 2021). Remote memory cafes rendered it difficult to meaningfully connect with others (Masoud et al., 2021) and remote memory cafes and support groups were ‘not the same’ as when meeting people in-person (Giebel., Hanna, Callaghan, et al., 2021; Masoud et al., 2021). Furthermore, these were perceived to provide fewer benefits (Masoud et al., 2021), and may be unsuitable for people with visual impairments (Giebel, Hanna, Callaghan, et al., 2021) or dementia-related behavioural problems (Masoud et al., 2021).

Two studies reported reasons for declining remote post-diagnostic support. These included being unable to access or being unacquainted with the technology (Masoud et al., 2021; Moo et al., 2020), difficulties in engaging with the remote format and being unable to form meaningful connections with others remotely (Masoud et al., 2021).

# **Discussion**

Findings from our systematic review suggest that, whilst remote post-diagnostic support may help to address some of the needs presented by people with dementia, or the dyad, care recipients’ views on accessing services remotely remained mixed. The increased reliance on remote service delivery during the COVID-19 pandemic has shed light on the duality of the use of ICT in service delivery (Wheatley et al., 2022), and lessons learnt are invaluable to construct future resilient services. As some elements of remote service delivery are likely to endure as part of routine delivery, the use of ICT in service provision needs to be carefully considered, as to avoid further widening inequalities in access.

Remote post-diagnostic support may offer several benefits, nevertheless, these are likely to be limited to people with dementia and unpaid carers who can access and engage with ICT. Benefits include positively impacting on care recipients’ quality of life, behavioural problems, caregiving burden, speech and language abilities and level of physical activity (Panerai et al., 2021; Ptomey et al., 2019; Rogalski et al., 2016). Some studies found benefits to be comparable to those offered through in-person service delivery (Chodosh et al., 2015; Dial et al., 2019; Kim et al., 2017; Laver et al., 2020; Possin et al., 2019). However, remote formats may be unable to replicate some benefits relating to social health, such as meaningfully engaging with others (Giebel et al., 2021b; Lee et al., 2021; Masoud et al., 2021), which is important to living well with dementia (Reilly et al., 2020). Accessing remote post-diagnostic support may not be suitable for people with advanced dementia (Rogalski et al., 2016) or sensory impairments (Giebel et al., 2021b), conditions which often form part of the exclusion criteria of studies exploring remote interventions (Yi et al., 2021). This highlights the importance of identifying when along the disease trajectory remote post-diagnostic support is suitable, and that the presence of comorbidities may hinder the ability to optimally engage with remote services.

A person-centred approach is integral to the delivery of dementia care pathways (NICE, 2018). People with dementia and unpaid carers should be offered a range of tailored post-diagnostic support services that cater to their changing needs, and be presented with choices on how to access them. Prior to the COVID-19 pandemic, some care recipients preferred to access post-diagnostic support remotely, and the shift to remote service delivery during the pandemic was welcomed by some. Remote services may offer practical benefits such as reduced travel and associated costs, preservation of the person with dementia’s routine, and help to circumvent mobility and caring constraints (Lee et al., 2021; Masoud et al., 2021; Sekhon et al., 2021). People with dementia and unpaid carers were satisfied with accessing some forms of post-diagnostic support remotely (Dal Bello-Haas, M. E. O’Connell, et al., 2014; Ptomey et al., 2019; Rogalski et al., 2016), which aligns with findings of previous research (Hattink et al., 2016; Howe et al., 2020b; Sekhon et al., 2021). During the COVID-19 pandemic, remote post-diagnostic support was greatly valued, helped to scaffold much needed routines and to reduce loneliness (Capozzo et al., 2020; Cousins et al., 2022; Masoud et al., 2021; O'Rourke et al., 2021). Nevertheless, when comparing remote to in-person service delivery, care recipients’ views were mixed (Gately et al., 2020b; Laver et al., 2020; Moo et al., 2020) and unpaid carers felt that remote memory cafes were overall less beneficial, and unsuitable to people with dementia with behavioural problems (Masoud et al., 2021). When interpreting the views on accessing post-diagnostic support remotely during the COVID-19 pandemic, it is important to acknowledge that in-person service delivery was either unavailable or undesirable at that time. Thus, the hybrid delivery landscape needs to accommodate to presenting needs whilst empowering care recipients to access post-diagnostic support in their preferred format.

Many people with dementia and unpaid carers received ICT devices and ongoing technology support from the study team, which aligns with the findings of previous reviews (Gately et al., 2019; Sekhon et al., 2021). Nevertheless, after receiving the device and in-person orientation session, some care recipients continued to experience difficulties whilst engaging with ICT to access post-diagnostic support remotely (Killin et al., 2018). This queries the capacity of the current health and social care system to sustainably adopt similar delivery models without increasing the digital divide. Accessing services remotely is likely to require a suitable device, adequate digital literacy, which are likely to be intrinsically related to socio-demographic factors (Hargittai et al., 2019). People with dementia often relied on assistance from unpaid carers to access remote post-diagnostic support by installing the technology or facilitating their engagement with the service (Giebel et al., 2021b; Ptomey et al., 2019; Rogalski et al., 2016). Whilst the participation or presence of unpaid carers, alongside the person with dementia, formed a requirement to satisfy the inclusion criteria of several studies included in this review, the support provided by unpaid carers was not systematically captured. Understanding the degree of reliance on unpaid carers, and characterising the support provided is important, as some people with dementia live alone, and the ability of unpaid carers to provide technological support, is likely to be related to socio-demographic factors, notably the age (Arighi et al., 2021). Additionally, unpaid carers may benefit from respite when people with dementia attend or engage with post-diagnostic support (Giebel et al., 2021c). Thus, if unpaid carers are required to provide support to facilitate the access or engagement of people with dementia with remote post-diagnostic support, this may limit the downtime they receive. Although beyond the scope of this systematic review, the assistance provided by service providers to promote meaningful engagement with people with dementia remotely is likewise fundamental (Di Lorito et al., 2021; Yi et al., 2021), and ensuring service providers are adequately supported is key to the sustainable delivery of quality of support.

# **Strengths and limitations**

To our knowledge, this systematic review is the first to synthesis evidence relating to accessing remote post-diagnostic support that address the needs of people with dementia or those of the dyad, and the explore care recipients’ on accessing services remotely. Searches were conducted across six databases and studies written in English, German and French were considered for inclusion. Whilst included studies were of good methodological quality, some limitations ought to be acknowledged when interpreting our results. Firstly, due to a lack of resources, only one study team member screened the citations, appraised the methodological quality of studies and extracted the relevant data. Although any uncertainties were discussed and agreed upon with all study team members, the lack of a second reviewer independently screening the citations may have led to some citations being missed. Grey literature was not searched, and studies that did not confirm the self-reported dementia diagnosis of participants were included in our review. Evidence synthesised came from six countries (mainly the US and UK) and only one study explored the access to remote post-diagnostic support with people from minority groups (Chodosh et al. 2015). Cognisant that digital access and literacy is likely to be influenced by several socio-economic factors, our findings may not be representative nor generalisable to settings which are less economically developed, or populations coming from minority groups. Furthermore, several included studies lacked long follow-up time frames, control groups and the support provided by unpaid carers was not systematically captured. The study designs and tools employed in future studies would benefit from including longer follow-up time frames, control groups, capturing the support provided by unpaid carers, as well as investigating the feasibility and acceptability of remotely accessing different types of post-diagnostic support, notably those relating to social health, to reflect the diverse range of post-diagnostic important to living well with dementia.

# **Conclusion**

This systematic review suggests that accessing post-diagnostic support remotely is likely to benefit some care recipients, nevertheless, views towards accessing services remotely remained mixed. Access to remote post-diagnostic support was frequently facilitated by providing ICT devices and ongoing technological support. These are important factors to consider whilst employing ICT within service delivery, and to avoid widening inequalities in access, it is important that services operating within the current hybrid service delivery landscape remain accessible to care recipients who are digitally excluded or who prefer to access services in-person.

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# **Competing interests**

The authors report there are no competing interests to declare.

# **Ethics approval**

Not applicable.

# **Data availability statement**

Not applicable.

# **Author contributions**

TC: Conception, generated the search strategy, screening of the citations (stage 1 and 2), extracted the data and appraised the methodological quality of included studies, interpretation of results, drafting and writing the manuscript. CG and SR: Conception, interpretation of results, editing and reviewing the manuscript, supervision of TC. SM: interpretation of results, editing and reviewing the manuscript, supervision of TC. HT: interpretation of results, editing and reviewing the manuscript. All authors reviewed and agreed to submit this version of the manuscript.

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Table 1 Study inclusion and exclusion criteria

|  |  |  |
| --- | --- | --- |
|  | **Inclusion criteria** | **Exclusion criteria** |
| 1 | Empirical studies with either qualitative, quantitate or mixed-method study designs. | Service proposals, study protocols, guidelines, opinion pieces or case studies / reports that are based on anecdotal evidence |
| 2 | Studies written in English, German or French and published between 1990-2022. | Studies written in a language other than English, German or French. Published prior 1990.  |
| 3 | Studies describing at least one type of ICT used as a medium to access post-diagnostic support that either address the needs of people with dementia or those of the dyad, and reporting on one or both of the following, (1) characteristics of the post-diagnosis support service accessed; (2) the views of people with dementia (or those reported by a proxy) and unpaid carers on accessing dementia-related post-diagnostic support services remotely | Studies investigating the use of ICT as a medium to access non-dementia related post-diagnostic support, or post-diagnostic support that solely address the needs of the unpaid carers or studies that do not report on one of the following criteria: a) characteristics of the post-diagnosis support intervention accessed; b) the views of people with dementia (or those reported by a proxy) and unpaid carers on accessing dementia-related post-diagnostic support services remotely |
| 4 | Participant lives with dementia and resides in the community (includes supportive / assistive living accommodation). Study participants with a dementia diagnosis, probable diagnosis and those identifying as living with dementia will be included. Participant is an unpaid carer to someone living with dementia. Studies involving participants from one or both study population will be considered. Participants living with dementia and unpaid carers did not have to be living together.  | Participant does not live with dementia (e.g., mild cognitive impairment diagnosis/ subjective cognitive impairment) or does not reside in the community (e.g., nursing / care home).  |
| 6 | If a study has mixed study samples or is multicomponent, it will only be considered for inclusion if the findings relating to the information of interest are reported separately in the result section. | Studies which do not report on the information of interest separately in the result section |

Table 2 Study characteristics

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Authors** | **Year** | **Country** | **Aims** | **Design** | **Participants** | **Method** | **Results** |
| Dal Bello-Haas et al., (Dal Bello-Haas et al., 2014) | 2014 | Canada  | To examine the demand, acceptability, practicality, and implementation of telehealth-delivered exercise for rural dwelling people living PLWD and informal carers.  | Mixed-methods exploratory approach  | - Phase 1: PLWD: n=42. UNPAID CARERS: n=35. - Phase 2: n=2 dyads. PLWD: n=1AD; n=1 FTD | - Phase 1: Semi-structured interviews, quantitative survey, Older Persons Attitudes Towards Physical Activity and Exercise.- Phase 2: Intervention: revised version Menorah Park Engagement Scale, attendance.- Post-intervention (4 weeks): dyadic interview and questionnaire. | - PLWD and unpaid carers interested in remote exercise. - High attendance rate, dyads enjoyed the intervention.  |
| Chodosh et al., (Chodosh et al., 2015) | 2015 | USA | To compare the effectiveness and costs of telephone only approach to in person plus telephone for delivering an evidence-based coordinated care management program for dementia | Quantitative | - n=144 dyads. - PLWD: Average of 73.1 years; 62.5% female. - UNPAID CARERS: Average of 50 years; 65.3% female. n=77 adult child; n=33 unrelated; n= 25 spouse.  | - Random allocation to in-person and telephone format, or only through telephone calls.- Baseline, 6 and 12-month follow-up: ZBI; PHQ-9; CG-QOL; HUI; Blessed Roth Dementia Scale; BAS. -Unpaid carer questionnaire: dementia care quality, PLWD health care utilization, hospitalisation, nursing home placement.  | - Improvement in care quality in both groups- Similar unpaid carer burden, PLWD problem behaviours, retention and health care utilization across both groups- Greater costs when delivering intervention in-person |
| Rogaliski et al., (Rogalski et al., 2016) | 2016 | USA | To determine if internet-based delivery of speech and language therapy was feasible for individuals with progressive aphasia symptoms. | Mixed-methods | - n=34 dyads enrolled, n=31 dyads completed. - PLWD: average of 67.2 years; 52.9% female. n=28 PPA; n=3 other dementia. - UNPAID CARERS: n= 27 spouses | - Baseline, 2- and 6-month follow-up: ASHS-FCM; CCRSA. - 2 and 6-month follow up: Evaluation of target words. 6-moths follow-up: treatment compliance. - Post-intervention: dyadic semi-structured interview | - Increase in functional gains and confidence in communication at 2-months follow-up, maintain at 6-month follow up.  |
| Kim et al., (Kim et al., 2017) | 2017 | South Korea | To assess the feasibility of telemedicine in the long-term management of patients with dementia based on cognitive function as the primary outcome | Qualitative  | - PLWD: n=188. - In-person: n=90; average of 78.0 years; 67% female. 88.9% AD; 8.9% VaD and 2.2% other dementia. -Remote: n=98; average of 78.2 years; 69% female. 91.9% AD; 8.1% VaD. | - CDR; Korean version of MMSE scale  | - No statistically significant difference in MMSE scores between PLWD accessing medical follow-ups remotely and in-person. - Telemedicine may be useful to care recipients to reside in rural areas.  |
| Killin et al., (Killin et al., 2018) | 2018 | UK, Scotland  | To determine the feasibility of improving the quality of life of PLWD and informal carers with the Digital Support Platform (DSP). | Qualitative  | - n=10 dyads. - PLWD: average of 74.5 years, 80% male. n=4 AD; n=6 mixed dementia. | - Dyadic semi-structured interviews  | - Valued post-diagnostic support, but less suitable during early stages of dementia.- Challenging to navigate DSP. |
| Dial et al., (Dial et al., 2019)  | 2019 | USA | To evaluate the feasibility and utility of treatment delivered through teletherapy compared to in-person treatment with people with PPA | Quantitative | - PLWD: n=31; n=17 in-person; n=14 teletherapy. - In person: n=5 nfvPPA; n=6 svPPA; n=6 1vPPA. LRT treatment: n= 12; 66.7% female; average of 68.9 years, MMSE: 23.8. VISTA treatment: n =5; 60% female; average of 67.6 years, MMSE 26.0. - Teletherapy: n=5 ngvPPA; n=4 svPPA; n=5 1vPPA. LRT treatment: n=9; 55.6% male; average of 61.0 years MMSE: 24.8. VISTA treatment: VISTA n=5; 60% female; average of 67.8 years, 27.6 MMSE.  | - 3, 6 and 12-month follow up. LRT treatment: pre-post change score on trained items, untrained items and changes score on the BNT and WAB AQ. VISTA treatment: change score of the percent of correct intelligible scripted words and NAT.  | - Both treatment types resulted in significant improvements which were maintained regardless if accessed in-person or remotely |
| Possin et al., (Possin et al., 2019) | 2019 | USA | To determine whether the Care Ecosystem is effective in improving outcomes important to PLWD, unpaid carers, and payers beyond those achieved with usual care | Quantitative, single group pragmatic randomised clinical trial | - n=780 dyads. - PLWD: Care Ecosystem: n=512; average of 78.7 years; 58.2% female;49.8% mild; 28.7 moderate †; 21.5% advanced. Control: n=268; average of 77.6 years; 52.6% female; 50.4% mild, 29.1% moderate; 2.6% advanced †- UNPAID CARERS: Care Ecosystem: n=512; average of 65.3 years; 69.9% female. Control: n=268; average of 64.0 years; 73.1% female | - Baseline, 6 months and post-intervention (12 months): QoL-AD, PHQ-9, ZBI, Caregiver Self Efficacy and hospitalisation / use of emergency services. - Post-intervention: questionnaire  | - Care management successfully delivered via centralised hubs. - Compared to usual care, the Eco System increased PLWD’s quality of life, reduced emergency department visits, reduced unpaid carers’ depression and caregiving burden.  |
| Ptomey et al., (Ptomey et al., 2019) | 2019 | USA | To evaluate the feasibility of a group video conference approach to increase moderate physical activity (MPA) in adults with AD and informal carers.  | Quantitative | - n=9 dyads enrolled, n=7 completed. - PLWD: n=AD. average of 74 years. 56% female. - UNPAID CARERS: average of 67 years. 67% female.  | - Baseline and post-intervention (12 weeks): QOL-AD, SF-36. - During the intervention: attendance, minutes of MPA. - Post-intervention: questionnaires for PLWD and unpaid carers | - Good attendance rate- Increase in weekly MPA in both members of the dyad |
| Capozzo et al., (Capozzo et al., 2020) | 2020 | Italy | To evaluate whether the assessment of people with FTD using telemedicine is feasible and acceptable during the COVID-19 pandemic | Quantitative | - PLWD: n=32; 56.3% male; average of 66.3 years. n=2 PPA; n=3 PPA-Parkinsonism; n=12 bvFTD; n=9 bvFTD-Parkinsonism; n=2 bvFTD-PSP; n=2 bvFTD-MSA; n=2 bvFTD-ALS.- UNPAID CARERS: n=15; 100% spouses | - Questionnaire (including changes in cognitive, behaviour, personality, language, sleep disturbances, nutritional status, swallowing capacity, respiratory function, access to rehab, SALT, pharma therapy); CDR-FTD; COVID-19 symptoms. Unpaid carer distress evaluated with 5-point Likert scale, question from Neuropsychiatric Inventory.- Post-intervention: questionnaire one week after  | - Most were satisfied with the remote neurological consultation. - Compared to the last in-person consultation, half of PLWD experienced worsening of clinical symptoms (behaviour and language functions) and quality of life.  |
| Gately et al., (Gately et al., 2020a) | 2020 | USA | To examine the feasibility of using videoconferencing software for an occupational therapy home safety evaluation  | Mixed-methods | - UNPAID CARERS: n=10; average of 62.8 years, 80% women. n=6 spouse; n=4 adult child | - Field notes (technical glitches, audio and video problems, number of unpaid carers present, difficulties logging on, device ownership, formal support requirement and use of a second device)  | - Remote home safety evaluations are feasible- Technical difficulties experienced during most evaluations. |
| Gately et al., (Gately et al., 2020b) | 2020 | USA | To examine caregiver satisfaction with the video telehealth home safety evaluation, through in-depth examination of caregiver satisfaction relative to person, environment, and occupation factors | Mixed-methods | - PLWD: n=10; average age of 82.5 years; 90% male; 60% in the mild-to-moderate stages (MMSE score > 12.2). - UNPAID CARERS: n=10; average of 62.8 years, 80% women. n=6 spouse; n=4 adult child | - Post-intervention: questionnaire (ability to see, hear, communicate, understand the provider, comfort of technology use, sufficient technical assistance, privacy, time, format preference). - Risky Behaviour Questionnaire; Confidence in Caregiving Scale. - Field notes | - Overall positive experience.- Lower satisfaction related to technological glitches and the presence of PLWD during the home safety evaluation.  |
| Laver et al., (Laver et al., 2020) | 2020 | Australia | To determine whether delivery of a dyadic intervention using telehealth was noninferior to delivery of the same program using in person delivery through home visits | Quantitative, Non-inferiority randomised control trial | - n=63 dyads. - PLWD: In person: n=32; average of 80.5 years; 72% male. Telehealth: n=31; average of 79.5 years; 52% female. - UNPAID CARERS: In person: n=32; n=25 spouse; 81% female; average of 70.7 years. Telehealth: n=31; n=23 spouse; 71% female; average of 69.5 years | - Baseline and post-intervention (4 months): CMI, PCI, CAFU, Caregiver Behavioural Occurrence and Upset Scale. - Post-intervention: unpaid carer questionnaire.- Therapists recorded time travelling and spent with participants.  | - Improvements in CMI and PCI in both intervention arms. - Same time to deliver the intervention, remote delivery significantly reduced therapists’ travel time. |
| Moo et al., (Moo et al., 2020)  | 2020 | USA | To evaluate efforts to recruit patients affiliated with an outpatient dementia management programme into Home Clinical Video Telemedicine | Quantitative, retrospective programme evaluation study | - n=222 dyads. - In person: n=184 dyads. PLWD: 96.7% male; 76.6% White; average of 84 years. -UNPAID CARERS: 91.8% female; 56% spouses; 33.2% adult child. - Telemedicine: n=38 dyads. PLWD: 97.4% male’ 73.7% White; average of 79 years. UNPAID CARERS: 78.9% female; 84.2% spouses; 13.2% adult child | - Post-intervention: five-point Likert scale questionnaire (miss work to attend and impact on PLWD’s daily routine). Open-ended questions on experience and logistics.- Ranked reasons for participating in telemedicine intervention | - Follow-up visits delivered as successfully through telemedicine as in in-person format. - Telemedicine may offer benefits (reduce travel distance and PLWD routine), but may not be suitable for all dyads.  |
| Masoud et al., (Masoud et al., 2021) | 2021 | USA | To provide insight into the experiences of PLWD and informal carers who regularly attend Memory Cafes. To explore how these gatherings, affect perceptions of social connectedness. | Qualitative exploratory study | - PLWD: n=5 self-identified as living with dementia. - UNPAID CARERS: n=12. n=8 spouses; n=4 adult children. | - Individual and dyadic semi-structured interviews  | - Highlights benefits offered by attending Memory Cafes.- Virtual Memory Cafes may offer similar benefits to some PLWD and informal carers.  |
| O’Rourke et al., (O'Rourke et al., 2021) | 2021 | UK, England | To explore the impact of the COVID-19 pandemic on PLWD and informal carers and how negative effects could be mitigated | Qualitative | - PLWD: n=11 interviewed, data provided for n=19. Average of 76.5 years; 52.6% female, 68.4% living with others, 89.4% White British. n=6 AD; n=4VaD; n=3 FTD; n=3 mixed; n=2 Lewy Body; n=1 addition PCA diagnosis. - UNPAID carers: n=10 interviewed, data provided for n=13. 84.6% female; 61.5% spouse | - Individual and dyadic semi-structured interviews | - Some PLWD were coping well, whereas some experiences negative impacts. - Value of personalised COVID-19 information and regular ‘checking in’ calls.  |
| Panerai et al., (Panerai et al., 2021) | 2021 | Italy, Sicily  | To determine whether telephone-based reality orientation therapy (T-ROT) can improve cognition, mood, and neuropsychiatric symptoms among patients with major neurocognitive disorders who are forced to isolate, and whether T-ROT can relieve the burden of distress among their informal carers. | Quantitative non-randomised interventional comparison  | - n=27 dyads. n=14 dyads experimental and n=13 dyads in control group. - PLWD: average of 65 years. n=3 AD; n=5 vascular dementia; n=1 FTD; n=1 mixed dementia; n=4 other. - UNPAID CARERS: Average 61 years. | - Baseline and post intervention (4 weeks): CIRS, Katz Index of Independence in Activities of Daily Living, Lawton Instrumental Activities of Daily Living Scale. HAM-D, CSDD, NPI-Q, CBI. | - Compared to non-treatment, T-ROT significantly improved PLWD depression, behaviour, cognition and burden on unpaid carers.  |
| Cousins et al., (Cousins et al., 2022) | 2022 | UK, England  | To gain an understanding of the experiences, impact and implications of the COVID-19 pandemic on PLWD and informal carers. | Qualitative  | - PLWD: n=5. n=1 YOD; n=2 FTD; n=1 vascular dementia with Lewy bodies; n=1 unknown. 100% male. - UNPAID CARERS: n=7. n=5 spouse; n=2 adult children. 100% female.  | - Individual and dyadic semi-structured interviews | - Both positive (opportunities for quality time) and negative experiences (feelings of loss and isolation) during the COVID-19 pandemic.  |
| Giebel et al., (Giebel, et al., 2021b) | 2022 | UK | To explore how community services and institutional care settings have adapted during the pandemic in the UK and are providing care to people living with dementia and carers | Qualitative  | - PLWD: n=8 AD; n=2 VD; n=3 YOD. - UNPAID CARERS: n=10 adult child; n=6 spouse; average of 55.3 ± 6.2 years; 93.8% female | - Semi-structured interviews with unpaid carers | - Lack of support available during the COVID-19 pandemic.- Whilst remote services were helpful to some, did not replace in-person services.  |

Acronyms: AD: Alzheimer’s Disease; ALS: Amyotrophic Lateral Sclerosis; ASHS-FCM: American Speech-Language-Hearing Association functional communication measures; BAS: Bi-Dimensional Acculturation Scale; BNT: Boston Naming Test; CAFU: Caregiver Assessment of Functional Upset; CBI: Caregiver Burden Inventory; CCRSA: Communication Confidence Rating Scale for Aphasia; CDR: Clinical Dementia Rating Scale; CIRS: Cumulative Illness Rating Scale, CG-QOL: Caregiver Quality of Life; CMI: Caregiver Mastery Index; CSDD: Cornell Scale for Depression in Dementia; FTD: Frontotemporal dementia; HAM-D: Hamilton Rating Scale for Depression; HUI: Health Utilities Index; LRT: Lexical Retrieval Treatment MMSE: Mini-Mental State Examination; MSA: Multiple System Atrophy; NAT: North Western Anagram Test; NPI-Q: Neuropsychiatric Inventory Questionnaire; PCA: Posterior Cortical Atrophy; PCS: Perceived Change Scale; PHQ-9; Patient Health Questionnaire-9 items; PLWD: People living with dementia; PPA: Primary Progressive Aphasia; PSP: Progressive Supranuclear Palsy; QOL-AD: Quality of Life for the adult with Alzheimer’s Disease; RMBPC: Revised Memory and Behaviour Problem Checklist; SF-36: Short Form Health Questionnaire; T-MMSE: Telephone Mini-Mental State Examination; VaD: Vascular Dementia; VISTA: Video-implemented script training for aphasia; WAB-AQ: Western Aphasia Battery Aphasia Quotient; YOD: Young Onset Dementia; ZBI: Zarit Burden Interview. †Baseline dementia severity data missing for 15 of the 780 dyads.

Table 3 Summary of post-diagnostic support accessed and ICT formats employed

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| --- | --- | --- | --- | --- |
| **Reference** | **ICT format (s) employed** | **ICT support provided** | **Post-diagnostic support accessed** | **Views on accessing remote post-diagnostic support**  |
| ***Post-diagnostic support accessed by people with dementia or both members of the dyad*** |
| Dal Bello-Haas et al., (Dal Bello-Haas et al., 2014) | -Video-conferencing software. - Accessed in a telehealth suite. | - One investigator attended the first two sessions and provided on-site training and evaluate participants’ ability to set-up equipment and exercise safely.  | - 40-45minutes sessions, twice a week for four weeks.- warm-up, aerobic exercise using an upper extremity cycle ergometer, and a cool down.- Led by a research assistant in a telehealth suite in the Saskatoon Regional Health Authority, another research assistant attended the sessions with the participants in the telehealth suite in the rural regional health authority. | - PLWD observed laughing and smiling during some sessions. - Overall intervention rated as good-to-excellent; good voice quality, good-to-excellent visual quality, the ability to engage with the facilitator and with the group was excellent.- Participants enjoyed the intervention, being able to exercise with people and easy to use ICT. - One participant mentioned the lack of variety between sessions. *-Everyone knows TV nowadays, it’s just like being there’* (Unpaid carer) |
| Rogalski et al., (Rogalski et al., 2016) | - Communication bridge web application. - Included ‘to do lists’, pre-recorded strategy videos and embedded video-conferencing software function.  | - In-person training on ICT use.- Account set up for each participant. | - Initial evaluation, eight one-hour video-conferencing treatment sessions and two evaluations (two- and six-months post-enrolment). - Treatment followed impairment-based approaches, activity and / or participation approaches. - Individualised home exercise program- Provided ongoing disease education, counselling and support.  | - 16/31 dyads reported that the intervention ‘exceeded’ their expectations.- Out of 30 dyads, several stated that the pre-recorded videos were helpful, 37% would not change anything and 20% would like more sessions.  |
| Kim et al., (Kim et al., 2017) | - Videoconferencing software (Tandberg 990 system), a personal computer and monitors.- Accessed remotely from rural health centre. | None reported. | - Medical follow-up with specialist in Kangwon National University Hospital.- Medications review, disease education, supportive psychotherapy. - Between April 2007 and December 2012. | None reported.  |
| Killin et al., (Killin et al., 2018) | - Digital Support Platform (DSP) consisted of three tools: living it up, jointly and click and go. | - Provided tablets, PCs, mobile with data depending on need and preference.- DSP pre-installed on devices.- In-person demonstration of DSP. | -Living it up: a wellbeing portal. Provides information, advice and community networks.- Jointly: a care coordination services that enables all unpaid carers to communicate and access shared tools.- Click and go: a support appointment scheduling interface for families with statutory package of care in place. - Participants had accessed the DSP for at least two months.  | - Lack of a perceived current need for the DSP. - Understood as suitable for people at latter stages of disease trajectory. - Carers were the primary users, and some carers and PLWD found the DSP too difficult to use. - ‘*But she’s not a teacher – she finds it very difficult… And it can be a bit upsetting as well. She’s much better than me but she’s not very happy trying to take me by the hand and leading me through the procedure and she gets very frustrated as well’* (PLWD)- ‘*As I say, if-if somebody had gone through it with me at the beginning, that would have been helpful. Just sat down and said now, you know, this is what you can do with it and that’s what you can do with it. I think that would have been helpful’* (Unpaid carer)*- ‘I’m not here feeling sorry for myself, I can get into (the tablet) and the day goes quicker… I dunno what to say to be honest. I love it. I love it.’* (PLWD) |
| Dial et al., (Dial et al., 2019) | - Videoconferencing software (Adobe connect or Fuze). - Telephone or Team Viewer for trouble shooting.  | - Document which included written instructions and screenshots to install the videoconferencing software.- Additional support provided by telephone or Team Viewer. - An iPad Air with pre-installed software was provided to participants who did not own a computer or webcam. | - LRT treatment: trained to use word finding strategies capitalizing on the retrieval of residual semantic, phonological, orthographic and autobiographical or episodic knowledge. Cueing hierarchy. - VISTA treatment: facilitate grammaticality, intelligibility and fluency of connected speech. Script training. | None reported.  |
| Ptomey et al., (Ptomey et al., 2019) | -Video conferencing software (Zoom). - iPad mini tablet and Fitbits.  | - Provided iPads, Fitbits and HDMI adaptor. - iPad pre-installed software and videos explaining how to use the ICT.- In-person raining on ICT use.  | - 30-minute exercise sessions via video-conferencing, three times per week, over 12 weeks. - Groups of 5-8 dyads, each in their own home. - A warm up, MPA and a cooldown. MPA included walking, sit to stand, dance movement and resistance exercises. - Context of sessions varied, led by a health coach- Each dyad attended a monthly 15 minutes education / support session with the health coach.  | - PLWD and unpaid carers enjoyed the program. - 28.6% of unpaid carers experienced difficulties when connecting the iPad to the internet and, 14.3% reported difficulties connecting the Fitbit to the iPad. - All unpaid carers reported it was easy to navigate the iPad and the Zoom app. |
| Capozzo et al., (Capozzo et al., 2020) | - Videoconferencing software option, but all participant chose telephone calls | None reported. | - Consultation with neurologist and lasted between 60-90 minutes. - Assessment based on a structured question to identify significant changes since last evaluation (behaviour, personality, language, sleep disturbances, nutritional status, swallowing capacity, respiratory function, access to rehab, SALT, pharma therapy) | - Satisfied with voice quality: 81% very satisfied; 19% fairly satisfied; not satisfied at all: 0%.- Satisfied with the neurologist's skills to understand problems: 88% very satisfied; 12% fairly satisfied; 0% not satisfied.- Satisfied with experience: 81% very satisfied; 19% fairly satisfied; 0% not satisfied. - Able to talk as during in person consultation: yes: 82% and No: 18%. |
| Moo et al., (Moo et al., 2020) | -Videoconferencing software (CISCO Jabber)- Telephone for trouble shooting | - Provided videoconferencing software access and, if required, a webcam. - Technician called unpaid carers to identify home computer and internet capabilities. - Provided support to download and install videoconferencing software over the telephone.- Conducted a test run before intervention. - Participants received an email with appointment time and log in details. | - Telemedicine visits complimented in-person follow-up visits. - Conducted by a behavioural neurologist and lasted 45 minutes. -Topics covered included: changes in cognition, behaviour, mood, sleep, appetite, continence, mobility issues, safety concerns, independent activities of daily living and activities of daily living. - Recommendations communicated with unpaid carers and medication changes or referrals inputted into the medical record. - Next visit scheduled depending on need (ranged from 2 weeks – 9 months). - Between March 2013 to October 2014. | - Convenience regarding travel and to maintain PLWD’s routine-Similar satisfaction regardless if accessed remotely and in-person or in-person only.- Decreased in travel distance when service accessed remotely- Participants reported being at least as satisfied with remote visits as when accessed in-person.  |
| Masoud et al., (Masoud et al., 2021) | - Video conferencing software (Two memory cafes used Zoom and one used Microsoft Teams)  | None reported | - Held at least once a month. - Included different activities (trivia, jam making, bingo) and invited guest facilitators.  | - Engaging with remote Memory Cafes was different and not the same as in person format, but was appreciated during the COVID-19 pandemic. - Some unpaid carers reported the convenience offered by remote service delivery. *- ‘I don't feel like I do about the support group, which I've been to for much longer and, also, in person and done some socializing with some of them. It'll take a while, I think, to feel that we're part of a group’* (Unpaid carer)*- ‘We've enjoyed the [virtual] memory cafe as is. I do know that mom and dad - it is more likely that will attend via zoom then if it was in person... because to get mom out of the house, it becomes an ordeal...’* (Unpaid carer) |
| O’Rourke et al., (O'Rourke et al., 2021) | - Telephone | None reported | - Check-up calls, weekly, fortnightly or monthly. - Calls mostly by voluntary organisations, sometimes by NHS staff. - Asked how the person / dyad were managing, engage in conversation (social or identifying support needs).  | - Valued during the COVID-19 pandemic. *- 'one of them will ring you, and say 'how's things going?' and all of the rest of it, you know, and then if you've got any problems that come up during the conversation, you'll find someone will follow it up, and then ring you back, which all makes you feel good*’ (Unpaid carer). - *'Age concern in (town), you know, we are... every... certainly every month we'll have a phone call from them saying, you know, are you okay, Mr (surname), is there anything we can do for you and whatever'* (PLWD) |
| Panerai et al., (Panerai et al., 2021) | - Telephone | None reported | - Ten sessions lasting 50-60 minutes over four weeks, three sessions a week. - Each session focused on a theme (me and the calendar, holidays and anniversaries, my story, my family, my home, my daily life, my character, my appearance, my preferred food and my leisure time).  | None reported. |
| Cousins et al., (Cousins et al., 2022) | - Video conferencing software | None reported | - Remote peer support groups. - Different activities (e.g., games and crafts).  | - Source of positivity during lockdown. Valued and helpful.- *'Yeah, and he's really enjoyed that... it was the other members that we've got to know since we've been on the Zoom. And we've made real friends with them, haven't we? Through Zoom.'* (Unpaid carer)*- ‘The thing is, that if we didn't have these (the groups) it would be a bit bleak. I think all the online things they do at least give you a feeling, you known, that you are still part of a community’* (PLWD) |
| Giebel et al., (Giebel et al., 2021b)  | - Video conferencing software (Zoom), telephone, Facetime | None reported | - Telephone calls from memory clinic and care navigators. - Facetime and videoconferencing software to access groups.  | - Limited provision of remote support, telephone calls were sometimes at inconvenient times. Did not replace in-person support- Hearing impairments impaired engagement with remote services. *- ‘…but it’s not quite the same as in person is it, and I know you can see somebody on a screen but it’s not quite the same as sitting down and having a cup of coffee and a good chat is it really’* (Unpaid carer)*- ‘he [PLWD] also struggles we’ve noticed with understanding using like a zoom, my brother will set up zoom and we can zoom and I’ve noticed he has certain faces he uses when he’s finding a way to answer a question he doesn’t understand’* (Unpaid carer) *- ‘there has been no outside support at all erm other than we did have 1 phone call from the Care Navigators… so maybe about 3 or 4 weeks ago just to see how my mother in law was getting on and whether she needed anything which was really lovely but possibly**a little late’* (Carer) |
| ***Post-diagnostic support accessed by unpaid carers*** |
| Chodosh et al., (Chodosh et al., 2015) | - Telephone  | - Some unpaid carers not engaging with care managers due to limited minutes included in phone plan. - Provided phones with unlimited minutes for eight unpaid carers.  | - 12 months intervention delivered by social workers. - Initial and 6-months assessment guided intervention and assessed unmet needs for assistance; lack of social support; educational needs; difficulty with managing dementia related behavioural issue and safety concerns; need for respite; depression of the PLWD and carer; management of other chronic medical issues; need for diagnostic information and assistance with acute medical issues.- Complimented with counselling, education and self-management skills, referrals for community services and medical care.- Minimum of seven contacts with participants, either in-person or telephone calls.  | None reported. |
| Possin et al., (Possin et al., 2019)  | - Telephone, email | None reported.  | - Delivered by care team from two hubs – University of California and University of Nebraska. - Care team navigators telephoned dyads on average 15 times during the 12-month intervention. Responded to unpaid carer’s initial needs, screened for problems and provided personalised support and standardised support.- Additional contact by email and mail. Care team navigators - Lighter version offered, included educational materials though the post, possibly to contact care team navigators if required.  | - 97% reported that they would recommend the care ecosystem to another unpaid carers- 45.4% were very satisfied; 32.9% were satisfied; 17.5% were neutral; 2.8% were unsatisfied and 1.2% were very unsatisfied with the intervention |
| Gately et al., (Gately et al., 2020a; 200b) | - Videoconferencing software. - Telephone used during two evaluations due to audio loss during videoconferencing call.  | - Remote assistance to download videoconferencing software for unpaid carers owned a laptop with a camera, microphone and access to broadband internet. -Tablets / laptop with pre-installed videoconferencing software was provided if needed. - 15-minute ‘test call’ - Remote support from technician during two home visits. -Research assistant often remotely assisted to log in and during the home visit.  | - A home safety evaluation (40-45 minutes) | - Scale 1 (strongly disagree) – 5 (strongly agree). Median scores: able to hear = 4.5; able to see = 4; easy to communicate = 4; understood providers = 5; comfort using tech =5; sufficient technical assistance = 4; time efficiency: = 5; Prefer video to in-person = 3. |
| Laver et al., (Laver et al., 2020) | - Videoconferencing software (Cisco Webex) | - Able to use own laptop, tablet or smartphone. - Opportunity to loan a tablet with pre-installed software. - In person videoconferencing demonstration.  | - Up to eight consultation (60 minutes) over 16 weeks. - Participants in telehealth group received two sessions in person, six over telehealth. - Theory-based intervention delivered by an occupational therapist, consisted of an assessment of PLWD, unpaid carer and environment. - Works with unpaid carer to solve, educate, build skills and stress management. Works with the dyad to promote activity engagement  | - Moderate-high levels of satisfaction with programme. - In-person intervention yielded more favourable satisfaction scores. |

Acronyms: PLWD: People living with dementia

Table 4 Methodological appraisal of included studies (Hawker et al., 2002)

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Reference** | **Abstract** | **Introduction and aims** | **Methods and data** | **Sampling** | **Data analysis** | **Ethics and bias** | **Results** | **Transferability and generalizability** | **Implications and usefulness** | **Overall Score** † |
| Dal Bello-Haas et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Chodosh et al., | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Rogalski et al.,  | Good | Good | Fair | Good | Fair | Fair | Good | Good | Good | 33 |
| Kim et al.,  | Fair | Good | Good | Good | Good | Fair | Good | Good | Good | 34 |
| Killin et al.,  | Fair | Good | Good | Good | Good | Fair | Good | Good | Good | 34 |
| Dial et al.,  | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Possin et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Ptomey et al.,  | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Capozzo et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Gately et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Gately et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Laver et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Moo et al.,  | Fair | Fair | Good | Good | Good | Good | Good | Good | Good | 34 |
| Masoud et al.  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| O’Rourke et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Panerai et al.,  | Good | Good | Good | Good | Good | Fair | Good | Good | Good | 35 |
| Cousins et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |
| Giebel et al.,  | Good | Good | Good | Good | Good | Good | Good | Good | Good | 36 |

†Very Poor =1; Poor =2; Fair=3; Good =4 points. Score range = 9-36 (minimum- maximum)

Figure 1 PRISMA flowchart

**n = 60**

**n = 14**

**n = 8,485**

APA Psych Info = 1,190

PubMed = 2,681

Cochrane Library = 622

CINHAL Plus = 1,413

Social Care Online = 255

Web of Science = 2,324

Additional hand searches

**n = 0**

**n = 4,722**

**n = 18 papers**

**n = 17 studies**

Duplicates;

**n = 3,763** removed

Title / abstract screening;

**n = 4,662** removed

Full text screening;

**n = 46** removed

Searches updated 2022;

**n = 4** added

Identification

Screening

Included

Eligibility

Out of scope = 3,461

Document type = 834

Study design = 345

Unavailable = 21

Language = 1

Out of scope = 28

Study design = 1

Unavailable = 2

Did not satisfy inclusion criteria = 15

*MCI / PLWD not disaggregated = 11*