REVIEW ARTICLE



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A systematic review of digital access to post-diagnostic health and social care services for dementia

James Watson¹ | Kerry Hanna² | Catherine Talbot³ | Marcus Hansen⁴ |

Jacqueline Cannon⁵ | Thais Caprioli^{1,6} | Mark Gabbay^{1,6} | Aravind Komuravelli⁷ |

Ruth Eley⁸ | Hilary Tetlow^{6,8,9} | Clarissa Giebel^{1,6}

Correspondence

Clarissa Giebel, University of Liverpool, Waterhouse Building, Liverpool, UK. Email: clarissa.giebel@liverpool.ac.uk

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The Pandemic Institute; National Institute for Health and Care Research Applied Research Collaboration North West Coast

Abstract

Objectives: For many people with dementia and unpaid carers, using technology for care and support has become essential. Rapid proliferation of technology highlights the need to understand digital access to health and social care services for dementia. This mixed-methods systematic review aims to explore digital access to health and social care services for dementia, from the perspective of people with dementia and unpaid carers.

Methods: Nine electronic databases were searched in May 2023 for qualitative, quantitative, or mixed-method studies, published in English or German, focused on experiences of using technology-delivered health and social care services for people with dementia and unpaid carers. After removal of duplicates and screening, 44 empirical papers were included.

Results: From the 44 studies, findings were grouped into five categories, highlighting experiences for people with dementia and unpaid carers: (1) Adapting to technology, (2) Inequalities and variations in outcomes, (3) Impact on caring, (4) Impact on health, and (5) Impact on relationships. Proliferation of technology in care access emphasised the need for quick adaptation to technology and examination of its impact. The impact of such service delivery has evidenced mixed findings. There were improvements in the health and wellbeing of people with dementia and unpaid carers, and benefits for their dyadic relationship. However, using technology for health and social care access is not always possible and is often reliant on unpaid carers for support. Lower tech-literacy, lack of equipment or money to buy equipment and poor internet connection can impact the potential for positive outcomes. Conclusions: Technology can bring great benefits: social inclusion, improved service access and care. However, using technology in service delivery in dementia needs careful thought. Professionals and service providers need to be cognizant of the complex nature of dementia, and the benefits and challenges of hybrid service delivery.

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¹Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

²School of Health Sciences, University of Liverpool, Liverpool, UK

³Ageing and Dementia Research Centre, Bournemouth University, Bournemouth, UK

⁴Faculty of Business and Law, Liverpool John Moores University, Liverpool, UK

⁵The Lewy Body Society, Wigan, UK

⁶NIHR Applied Research Collaboration North West Coast, Liverpool, UK

⁷Mersey Care NHS Foundation Trust, National Health Service, Liverpool, UK

 $^{^{8}}$ Together in Dementia Everyday (TIDE), Liverpool, UK

⁹Service User Reference Forum (SURF), Liverpool, UK

KEYWORDS

care access, dementia, inequalities, systematic review, technology, unpaid carers

Key points

- Evidence emphasises benefits and challenges to the availability, implementation, use, of technology in health and social care access in dementia.
- Though there are issues, technology can help improve quality of life for people with dementia, can support carers to care, and facilitate positive relationships between unpaid carers and people with dementia.
- Proliferation of technology for care access was expedited during COVID-19, but has not been equally rolled out, making remote and disadvantaged groups less well-served.
- A hybrid delivery of services in which people are given choice of delivery method, and are supported in accessing and using technology, will better serve people with dementia and unpaid carers.

1 | INTRODUCTION

In the UK and globally, the number of people with dementia is increasing. In the UK as of 2024, there are an estimated 1 million people with dementia, with figures predicted to reach almost 1.7 million by 2040. The greatest proportional increase is expected among people with severe dementia, which is associated with more acute and heightened care and support needs. The increased need for health and social care will be reflected in service use, and it is predicted that the cost of providing care to people with dementia will reach £80.1 billion by 2040, compared to £23 billion in 2015.

Dementia has a profound impact on individuals living with the condition, and their unpaid carer(s), impacting their physical and mental health, ability to perform activities of daily life (ADL) and instrumental activities of daily life (IADL), social isolation and quality of life (QoL).5-7 People with dementia can struggle to access the services they need, from getting a diagnosis to additional and tailored support services and appropriate healthcare. Unpaid carers can feel stress, anxiety and suffer caregiver burden if not supported effectively by formal services and professionals.8 Furthermore, relationships with family and friends can be strained and dynamics can change, enhancing feelings of isolation for both the person living with dementia and any unpaid carers. 10 However, these impacts are often not felt equally. Some socio-demographic and geographic groups can be further disadvantaged and endure negative experiences and outcomes more acutely.7,11 This includes people from more socio-economically disadvantaged areas, regions or countries, secluded or remote geographic areas, or minority ethnic groups. 12

In recent years, with services encountering greater demand, there has been a shift towards developing access to services through remote means to alleviate pressure and create a better system for service users. ¹³ This includes the development of technology that can support people in their access and ongoing use of health and social care support services. ¹⁴ Such means of technology have been employed for people with dementia and their unpaid carer(s), whether that be through clinician-led telemedicine in the home, ¹⁵

online social and peer support groups, ¹⁶ or internet-based dementia education tools. ¹⁷

These means of service access and contact between professional staff and both people with dementia and unpaid carers, were essential during the COVID-19 pandemic, ¹⁸ and accelerated greatly due to greater demand and need for remote support. ¹⁹ However, large-scale, rapid transitions in service delivery for a population with varying levels of digital support, has emphasised and widened digital inequalities. ²⁰ Access to technology is not equal, neither is the ability to use technology to use services. ²¹ Many people require technology support which was not necessarily available during COVID-19, especially for those without unpaid carer(s), or carers who could facilitate technology use. ²² Since the curtailment of COVID-19 lockdowns, the dichotomy between the benefits of the ubiquitous use of technology in health and social care services, ^{19,23} and a return to in-person appointments and home visits has continued to illustrate the challenges faced by people with dementia and unpaid carers. ^{24–26}

Existing systematic reviews and meta-analyses highlight that technology-based interventions among people with dementia and unpaid carers can impact QoL, reduce burden and depression, and increase dementia and health-related knowledge. They also investigated the use of specific communication technologies in facilitating social networks and reducing social isolation. Martin et al.²⁷ and Lins et al.²⁸ for example, explored smart home technologies for health and social care support, and telephone counselling for unpaid carers respectively. Though telephone counselling demonstrated positive results for unpaid carers, both reviews noted the paucity of evidence which met their inclusion criteria. Many reviews highlight the dearth of evidence available to include in systematic reviews, due to a focus on a very specific technology (e.g. virtual reality),²⁹ intervention (e.g. counselling unpaid carers),30 or outcome measure (e.g. social isolation).31 There is increasing evidence of the benefits of technology as a means to increase health and social care engagement, use and quality, and improve health and social outcomes among people with dementia and unpaid carers.31 This is a process that has further accelerated since the COVID-19 pandemic.³² However, there is a

definitive lack of synthesis and evaluation of such evidence. As such, there is a need to identify and examine the evidence of how people with dementia and their unpaid carers use technology to access health and social care, and the impacts it has on health and social outcomes.

With overarching issues in accessing and receiving good quality and appropriate care and support for people with dementia, and such stark inequalities across different geographic areas and sociodemographic groups, it is critical to identify and understand how people with dementia and unpaid carers are accessing support, and how they can be supported. This review aims to explore the experiences surrounding digital access to health and social care services for dementia, from the perspective of people with dementia and their unpaid carers. These findings will provide better understanding on optimum usage of/possible barriers to accessing online/remote services for post diagnostic dementia care.

METHODOLOGY

This systematic review was registered with the PROSPERO interprospective register of systematic CRD42023414359) prior to commencing the review.

2.1 Search strategy

KH performed searches of numerous electronic databases were searched for relevant research related to the topic of the review. The exhaustive list of databases encompasses: APA PyscINFO, The Cochrane Central register of Controlled Trials (CENTRAL), The Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus, MEDLINE, PubMed, Social Care Online and Web of Science. Qualitative, quantitative and mixed-methods studies were included in the searches using the following search terms:

'dementia' AND 'social care' OR 'social support' OR 'day care' OR 'respite care' OR 'domiciliary*' OR 'home care' AND 'digital*' OR 'remote*' OR 'online*' OR 'telehealth' OR 'virtual*' NOT 'pharmacolog*' OR 'medicat*' OR 'drug'

Inclusion criteria

Papers included in this systematic review were focused on specific populations, including people with dementia, or unpaid carers of people with dementia. For a paper to be included, the sample population needed to be one of the following: (1) people with dementia (any subtype or onset), (2) unpaid carer(s), or (3) dyads combining people with dementia and their unpaid carer(s). If the sample population included unpaid carers, they needed to be 18 years and over. For inclusion within the review, studies needed to focus on digital access to health and social care services among the population(s) identified for inclusion. Digital services refer to 'off-the-shelf' digital

technologies (e.g. Zoom videoconferencing software), or digital interventions designed for people with dementia and, or unpaid carers.

Studies written in English or German and published from 1 January 2010 until 26 May 2023 were considered for inclusion.

Exclusion criteria 2.3

Studies were excluded if participants had no dementia diagnosis or were non-community dwelling. Formal diagnosis refers to a: (1) clinical record of dementia diagnosis, (2) enrolment as a patient within a dementia clinic or from dementia-specific residential/nursing facilities, or (3) self-reported dementia (based on a professionals' clinical report). Papers were removed if participants were paid carers, or unpaid carers aged under 18 years. Non-English and non-German language, and papers pre-2010 were removed. Papers published prior to 2010 were removed as digital access for health and social care has developed greatly in recent years. Prior to 2010, there was extremely limited use of technologies used to access health and social care services in dementia, and generally, the technologies available were not as developed or accessible as those since 2010. The PRISMA flowchart demonstrates the papers included at each stage, and in the final systematic review findings (Figure 1).

Study selection

KH and JW screened titles and abstracts of included articles against the above criteria in stage 1. The selected records were then screened in full in stage 2, by three authors (KH, JW and CT). Any discrepancies were resolved in discussion with all authors and 10% validity checks for articles carried forward from Stage 2 were conducted.

Data extraction 2.5

JW extracted the data from the final 44 papers included within this systematic review. To do so, each article was read in full, with data relevant to the focus and topic of the review extracted. Additionally, basic descriptive information from each paper, including author, paper topic, methods, technology researched, and outcome measures (see Table A1) was included.

Assessment of quality

JW conducted the quality assessment, with a 10% validity check conducted by CG to ratify the quality of the papers. To assess the quality of research papers, the Standard Quality Assessment Criteria for Evaluating Primary Research Papers³³ was employed. This includes a 14-point checklist for quantitative studies, and a 10-point checklist for qualitative studies. This method of quality assessment allows a practical method of assessing and adjudging the merits,

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FIGURE 1 PRISMA flowchart of papers selected at each stage, and included in findings.

strength and validity of research employing a variety of methods. Some criteria in both qualitative and quantitative quality assessment checklists may not be applicable to some studies, and 'N/A' is stated, which lowers the overall potential score. The quality assessment scores did not impact the inclusion of studies but emphasise the strength of their findings and conclusions. Scores of 80% and over indicate a strong study, 70%–80% a good study, 50%–69% an adequate study, and under 50% a study of poor-quality.

2.7 | Data synthesis

A meta-analysis was unfeasible due to the heterogeneity in aims, explanatory variables and outcome measures. As such, data were synthesised using a narrative summary approach.³⁴ The synthesis helps to make sense of the variety of research and findings from the papers included in the review. As such, qualitative, quantitative and mixed-methods studies were examined to understand two key points:

(1) what technology is being used to enable digital health and social care access for people with dementia, or unpaid carers, and (2) what were the outcomes for participants using these technologies, and, to what extent did the use of technology impact care access. From the papers in this systematic review, several key themes were noted and discussed in turn in the main body of the results: (1) Adapting to technology, (2) Inequalities and variations in outcomes, (3) Impact on caring, (4) Impact on health and (5) Impact on relationships. Some papers included findings related to multiple themes, and are discussed within multiple themes in the findings.

3 | RESULTS

Initial literature searches were applied, with 3854 articles returned (see Figure 1). Following removal of duplicates, 2487 articles remained, of which 192 were moved to full-text screening. Full-text screening resulted in 44 articles being included in this systematic review.

3.1 | Characteristics of included studies

Of the 44 studies included, 24 employed quantitative research methods, 18 qualitative and two mixed methods^{35,36} (see Table A1). Most of the papers were conducted in Western nations (35 in Europe or North America). Although they all explore the use of technology as a means for health and social care access among people with dementia or unpaid carers, there were differences in their approach and aims. For example, multiple studies investigated teleconferencing for peer support, looked at telemedicine for ongoing health observations, or eHealth literacy. There were also a variety of outcome measures used, including those related to the practicalities of accessing and using technology (e.g. health literacy), unpaid carer health and wellbeing (carer stress) or ability to care, or the health and wellbeing of people with dementia. The majority (38: 86.4%) of the 44 studies involved in this review included unpaid carers as participants, with only 18 (40.9%) including people living with dementia as participants. The mean populations ample size was 83, but across the studies the population sample size ranged from 3 to 580, with the qualitative studies tending to have small sample populations. Most of the evidence in this review was assessed as being of adequate, good, or strong quality (Tables A2 and A3), with 10% sample quality assessments validating these scores.

3.2 Study outcomes

From the 44 papers included in this review, findings were synthesised into five categories: (1) Adapting to technology, (2) Inequalities and variations in outcomes, (3) Impact on caring, (4) Impact on health and (5) Impact on relationships. Many papers contained findings related to multiple categories, and as such, some papers are mentioned across categories, with results and narrative related to the category.

3.3 Adapting to technology

Fifteen studies focused on adapting to technology. These studies highlighted numerous factors associated with the likelihood of initial uptake, use, and quality of interactions with technology for support. The success of technology-based services, including telemedicine, videoconferencing for peer support and clinical symptom observations, were often more likely if the person living with dementia had support from an unpaid carer, especially a younger carer, ³⁷ or they and their carer were given ongoing formal support in using the technology by the researchers or the technology developers. 38-40 The opposite was also evident, with technology-based services refused or met with a lack of uptake⁴¹ and poor experiences, due to a lack of equipment, 15,42 poor support in using the technology, or a perceived poorer quality of care resulting from teleconsultations. 38,40,43-45 A learning curve in adapting to technology was evident-sometimes expedited during COVID-19-with initial expertise and knowledge limiting use among people with dementia and unpaid carers. 18,36

Some studies noted issues in the time taken to get people to a stage of being able to use the device or technology appropriately following training and support.³⁸ Carers felt that the way systems worked-for instance telemedicine systems during COVID-19-were a hindrance and increased stress, as they were not able to get through for consultations due to busy telephone lines and lack of available staff. 44 There were also issues for both carers and people with dementia being able to have frank conversations with care providers or peers if the other person in their care dyad was present. 40,46 Furthermore, some studies identified that among some people with dementia and unpaid carers, there was a preference for in-person or hybrid delivery of services. 36,42 Not having the equipment or training to access or use technology, or feeling more comfortable with in-person contact, led to some feeling more isolated, that they were missing out on support and were less able to have their voice heard. 18,36,40,45,46 However, research also identified that technology-based services offer another avenue for support, 46 that can overcome geographic barriers in peer support. 36,45 Technology use also made carers feel more supported and able to be candid with professionals, 46,47 reduced preparation time for consultations,42,48 and negated symptom-associated and travel pressures. 18,45

3.4 Impact on caring

Nineteen studies focused on the impacts on caring. These come under two sub-themes: (1) impact on the carer's wellbeing, (2) carers' ability to provide care.

3.4.1 | Impact on carers' wellbeing

There are some studies identifying how technology can impact carers and caring. Few studies tried to identify changes in the social aspects of caring. However, videoconferencing for chair yoga, 40 and virtual cognitive stimulation therapy (vCST)⁴⁹ demonstrated improvements in carer socialisation, both during the activity with the cared for person and peers, and in enabling the carer to take time for themselves whilst the cared for person was involved in activities. Socialisation was often used as the intervention among these studies, rather than the outcome, with analyses of the impact of online or video-based peer support groups on carers' health and ability to care. Derbring et al.⁵⁰ investigated the impact of two different digital communication aids for reminiscence therapy for people with dementia and their unpaid carer. The use of one of these communication aids (CIRCA) was associated with significant improvements in carers' health and wellbeing. Han et al.⁵¹ investigated the use of the 'WeChat' virtual support group. This group included peer, emotional and educational support, and identified reductions in carer stress, depression and helplessness. Similar support groups were examined by Harding et al.⁵² and Huis In Het Veld et al., 53 respectively looking at peer support for unpaid carers

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in rarer, non-memory led dementias and self-management eHealth support for managing behaviour and mood symptoms in dementia. Carers felt greater compassion from peers, heightened resilience and coping,⁵² improved self-management in caring, response to behavioural symptoms, and increased contact with professional services.⁵³

Few studies focused on interventions encompassing professional support. However, the FamTechCare intervention does include telehealth consultations with practitioners, following observations of recordings of carer-cared for dyads at home. In a randomised control trial (RCT) of a FamTechCare intervention, the intervention group had greater reductions in depression and gains in caregiver competence than the control group.⁵⁴ Torkamani et al.⁵⁵ devised an online platform for carers to access education and self-management content. There were limited significant findings, and although they noted no significant intervention changes over time on carer burden, stress or depression, carers' QoL did show significant improvements.

3.4.2 | Carers' ability to provide care

There were several studies exploring other measures of caring as intervention outcomes. Some demonstrated positive experiences and improvements when using technology, including people with severe dementia benefitting from technology-based clinical appointments.³⁶ However, several demonstrated either no significant findings or negative experiences and outcomes. When investigating technology use in dementia during COVID-19,44 internet-mediated interventions, 41 and telehealth interventions for both members of the care dyad, ¹⁹ no significant findings were noted, with barriers to using interventions via technology in dementia highlighted. Although demonstrating improvements in caregiver QoL, Williams et al.⁵⁴ also found an increased desire to institutionalise the cared for person over time. However, positive outcomes were noted when Han et al.⁵¹ evaluated the WeChat virtual support groups, Baruah et al. 56 compared users and non-users of the iSupport online caregiver support program, and Kovaleva et al.⁵⁷ evaluated experiences of the telesavvy program following hospital admissions for people with dementia. These studies respectively demonstrated increased selfefficacy, improvements in carer attitudes towards the cared for, and better understanding of caregiving and dementia.

In an evaluation of an internet support forum, McKechnie et al.³⁵ illustrated that carers want to enhance their knowledge from discussions with other carers. Jeong et al.⁵⁸ looked at the relationship between unpaid carers use of technology for measures of coping. The study highlighted that greater communication was associated with better coping techniques and coping measures. There was limited investigation of formal healthcare via technology for people with dementia, but the evidence indicates better access to specialty healthcare,⁴⁸ and positive experiences and outcomes from telehealth for occupational therapy.⁵⁹

3.5 | Impact on health

Thirteen studies explored the impact on health. Talbot and Briggs⁶⁰ identified that technology helped to increase wellbeing among people with dementia, but greater use during COVID-19 also led to fatigue, headaches, and concentration issues. Capozzo et al. 15 demonstrated the benefits of telemedicine for identifying symptom changes during COVID-19 among people with frontotemporal dementia. During telehealth interviews, clinicians were able to identify worsening of behaviour and language functions from pre-COVID-19. In an examination of the TELEFAMILIES intervention (monthly counselling focused on caregiver needs) among 216 unpaid carers, the authors found significantly higher ADL and IADL among the intervention group.61 Meng et al.62 compared healthcare use and associated expenditure among African-American unpaid caregivers who received either in-person, or telephone-based cognitive behavioural therapy. Both delivery methods resulted in similar healthcare use and expenditure.

There were also physical health and wellbeing changes from more novel interventions. Derbring et al.⁵⁰ examined the impact of digital communication aids on the QoL and self-rated health measures among people with dementia. The findings highlight that although memory and physical health deteriorated, the use of communication aids improved their overall QoL. Park et al.⁴⁰ explored chair yoga via videoconferencing software, demonstrating several health and wellbeing improvements, including better sleep, more energy, greater flexibility, and heightened concentration. Speciality dementia care via telehealth reduced stress and anxiety for carers and cared for.⁴⁸ A mixed-methods examination of Alzheimer's Society UK's Talking point online forum (online support forum; now called 'Dementia Support Forum') demonstrated improved health-related outcomes for people with dementia, and reduced caregiver anxiety.³⁵

Though some positive health effects are noted, the evidence of the impact of technology is mixed. An interprofessional virtual healthcare neighbourhood showed no impact on sleep duration or quality among people with dementia.⁶³ Caregiver isolation and wellbeing were assessed when caregiver participants were given access to support materials via an electronic tablet. Access to the content did not show any improvement in caregivers' loneliness or self-perceived satisfaction.⁶⁴ Torkamani et al.⁵⁵ conducted an RCT using an online platform which encompassed educational material and facilitated contact with peers and clinicians (ALADDIN). The evaluation demonstrated poorer outcomes for people accessing the platform, including more severe dementia, poorer cognition, and lower physical weight. Another RCT using the FamTechCare intervention demonstrated no significant differences between the intervention and control groups' (people with dementia) behavioural or psychosocial symptoms, dementia expectations, or measures of ADL. 65 Elfrink et al. 66 also demonstrated no significant impacts when looking at the effectiveness of an online story book for reminiscence therapy, on either caregiver outcomes or neuropsychiatric symptoms among people with mild dementia.

3.6 | Impact on relationships

A total of 12 papers had findings focusing on the impact on relationships, whether in relationships between members of the care dyad, peers living with dementia or caregiver peers. Banbury et al. 38,43 conducted two studies, both assessing the implementation and benefits of telehealth peer-support programs in populations of unpaid dementia caregivers in Australia. Although the implementation of telehealth groups can take time to setup and run, there are great benefits to carers. Carers reported benefits during the program and continued meeting up with peers once the program ended. Participants discussed building of networks and having an outlet for their experiences making them feel valued and respected. Social connectedness with peers was also identified in several studies: among online memory café members 16; during COVID-19, a youngonset population using videoconferencing 45; caregivers using online support services⁴⁷; people with mild/moderate dementia using technology⁶⁰; and care dyads accessing clinical video-telehealth in rural locations.⁶⁷ From these studies, online delivery made access easier, improved peer contact and supported existing and new relationships. They also helped promote a sense of community and control, and a greater sense of empathy by generating an accessible platform, particularly during times when it may be difficult to access or get to in-person events, for example, during COVID-19.

Five of the studies also highlighted that using technology impacted the dyadic relationships between the person with dementia and their unpaid carer. Harding et al.⁵² aimed to understand the nature of social support via virtual caregiver peer-support for carers of people with rarer dementia, and Huis In Het Veld et al.⁵³ explored the use of an eHealth tool, also focussing on carers' responses to behavioural symptoms. In both studies participants felt they were more understanding and resilient in the face of behavioural symptoms, meaning less confrontation and an improved response. Some studies also highlighted the potential of using technology to provide stimulation for the person they cared for, and strengthening their bond through a joint activity. During COVID-19 the use of digital technology helped with social inclusion, and also provided an escape from dementia and the isolation of COVID-19.18 Studies which focused on specific interventions or technology-based programs also identified this strengthening of relationships between unpaid carers and the cared for person. McKechnie et al. 35 demonstrated that an online peer support platform improved carers' views of the quality of the dyadic relationship. However, unpaid carers' responses to technology were not always wholly positive. Peri et al. 49 investigated caregivers' experiences when accessing vCST during COVID-19. Although some participants felt their relationship with the person they cared for was stronger and it helped to create a connectedness at a time when this was missing generally, there were carers that felt the use of vCST placed additional pressure on them.

3.7 | Inequalities and variations in outcomes

Ten studies demonstrated inequalities and variations among people with dementia or unpaid carers, which came in two strands: Firstly, in

the likelihood or quality of technology use for service access; and secondly, in the health and social outcomes associated with technology-based support programs or healthcare. Technology can provide a better chance to overcome the barriers of in-person services and provide improved experiences. ^{18,45} However, there can be issues. Gerritzen et al. ⁴⁵ examined videoconferencing support for people with young-onset dementia (YOD). This study demonstrated people with YOD were often unaware that online peer support groups were available to them, and those that were felt these services were aimed towards older people with dementia. Additionally, rurality and deprivation can be a barrier to accessing support and social participation, ^{68,69} in-part due to limited availability of technology (i.e. cost of technology and internet connectivity), with restricted technology access increasing feelings of isolation if no inperson alternative is available or they are fearful of using technology.

Benefitting from technology for health services and peer support can depend on carers' knowledge and expertise. 18.69,70 Bardach et al. 71 explored knowledge gaps among unpaid carers from rural areas engaged with a year-long telemedicine program. The study identified the questions frequently asked by unpaid carers via the telemedicine program and demonstrated a lack of initial knowledge of dementia and understanding of risk management and behavioural symptoms. Efthymiou and colleagues conducted two studies identifying how carer knowledge and health literacy can vary based on socio-demographic factors. The first looked at carers' use of the internet for dementia knowledge-development, 70 and the second explored health and eHealth literacy among carers. 72 These studies highlighted carers' level of education, years caring and being a younger caregiver were associated with greater health and technological literacy, and knowledge of dementia.

There were few studies to investigate health and social outcomes for unpaid carers and people with dementia. David et al.⁷³ noted variation in health via measurements of physical health conditions over time among people with different dementia subtypes. Both Rice et al.⁶¹ and Williams et al.⁵⁴ evaluated the impact of telehealth interventions on caregiver outcomes. Evaluation of the TELEFAMILIES intervention demonstrated that being married was associated with improved reactions to behavioural symptoms and, higher income was associated with reduced caregiver depression, and improvements in both ADL and IADL.⁶¹ Evaluation of the FamTechCare intervention highlighted rurality and lower education were associated with lower caregiver competence. Higher education was associated with lower caregiver burden and improved reaction to behavioural symptoms.

4 DISCUSSION

This systematic review highlights a limited evidence base, which varies in its aims, methods, and findings. There are various positive and negative impacts that technology, or a lack of technology, can have on people with dementia and unpaid carers. Evidence suggests that although technology can be beneficial in accessing services and can help to facilitate access to peer and formal support, there are issues in the proliferation of technology among a population who may need added support or face additional challenges in its use. The

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COVID-19 pandemic and subsequent lockdowns expedited an already growing reliance on technology in delivering health and social care services, and as an avenue for gathering information and peer support.⁷⁴ The increase of technology in service delivery is not universally beneficial, and its use is not entirely appropriate or accessible for some people with dementia.²¹ The use of remote and technology-based services in dementia requires a considered approach, to reduce the exacerbation of existing inequalities.²³ There is also a need to mitigate the potential for negative impacts on people with dementia and unpaid carers, that can result from a lack of digital access to care and support.⁷⁵

The evidence demonstrates that positive experiences of remote services, or technology-based access to health and social care, can be achieved. Remote services can widen the pool of peer support available via online services by reducing geographic barriers, improving socialisation, and reducing the financial cost and potential stress involved in preparing for and travelling to face-to-face appointments. However, there are barriers to using technology for accessing health and social care services in dementia.⁷⁶ Some may not have the technology and purchasing up-to-date equipment (e.g. computers, tablets and software) can be costly, 77,78 Being able to access the internet is not ubiquitous, as both older people and people living in rural areas more likely to have slower, intermittent or no internet connection.⁷⁹ Additionally, these technologies are not designed with people with dementia in mind and may not be appropriate, meaning using such technology can come with additional challenges due to impaired cognition or concentration.⁷⁴

Beyond the practicalities of accessing online or remote services via technology, this review highlighted that the effective use of technology can be reliant on a variety of factors, including the availability of unpaid carers who are digitally literate, particularly young adult carers. Carer education was also a factor in technology adoption, with the health and eHealth literacy of the person with dementia or their unpaid carer helping to facilitate better experiences of technology.⁷² However, not all people with dementia have unpaid carers, 80 and many older people with dementia are cared for by their spouses⁵ who may not be overly tech-literate.²¹ However, the reliance on unpaid carers is not practical and places additional strain on them to support technology use, or to learn new skills alongside ADL and caregiving. There are also issues in the expectation of people with dementia to use technology-based services, especially when they do not have unpaid carers to provide technical and practical support in doing so.81 Evidence demonstrates that a greater proportion of older people prefer in-person contact, can be reticent and less likely to use technology if they do not have support to do so.⁷⁴ These factors emphasise the need to provide technologies, and training and support in the use of technology to people with dementia, unpaid carers, and the general population, which can provide access to a greater range of options.82

Whilst the COVID-19 pandemic and associated lockdowns expedited the implementation of remote services in dementia,²³ the sharp transition and reduced availability of in-person services which remain is not optimal for all people with dementia.⁸³ This is

particularly the case among people with rarer forms of dementia, or with more severe symptomatology and increased additional health and social care needs. 13 Some feel that remote consultations do not provide clinicians with the full presentation of a person's dementia, or their initial and changing care needs as their condition progresses. 13 Furthermore, the technology used-including assistive technology such as telemedicine-is not specifically designed for or with the person with dementia.⁸⁴ This creates the risk of services employing technology-based care and support methods that will cause more barriers and challenges for people with dementia attempting to access appropriate care.⁸³ Remote, technology-based service delivery can provide an additional avenue through which people with dementia and unpaid carers can access support and care, 85 but its use should be complementary to face-to-face contact.²⁴ and be appropriate, and adapted or catered to the individual's needs.86

4.1 | Limitations

To our knowledge this is one of the first systematic reviews to synthesise the existing evidence-base of experiences of technology to access health and social care among people with dementia and their unpaid carers. The studies encompassed within his review were generally of good methodological quality, but some limitations of the process and evidence-base should be noted. Due to a lack of resources, only one author conducted quality rating on the entirety of the 44 papers. However, a secondary quality rating was conducted by another study member of a 10%, random selection of the papers. The quality rating by a second reviewer promotes rigour and veracity of the findings.⁸⁷ Uncertainties in quality ratings were discussed by the team with an agreement on the scores decided upon by the study team. Most of the papers included came from a few countriesspecifically, Australia, North America, UK and Western Europe. This could limit the generalisability of findings, particularly related to a topic such as technology, which is not as freely available in some regions of the world, or among countries with greater deprivation.^{88,89} The variety of methods employed, interventions conducted, and outcome measures examined amongst the research in this review, means the evidence-base is not succinct, and the research in this area is somewhat sporadic. However, with services modifying the way they deliver care since COVID-19, 23,83 to hybrid delivery, there is a call for more research of the benefits and challenges to remote and technology-based access and use of health and social care services.

4.2 | Notable studies

There have been some notable papers published in the intervening time between the literature search as conducted, and publication. Unfortunately, due to time and resource limitations, it is not possible to conduct an updated electronic and grey literature search. Although these more recently published papers would not have

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altered the overall themes or findings, it is necessary to provide some detail of these notable studies in the topic area. Gerritzen et al. 90 conducted qualitative interviews with people with YOD, to understand why people may be hesitant to use online peer support groups, and how to overcome these hesitancies and improve engagement. The barriers to accessing online peer support tended to be personal or systemic, with expectations of what is expected of them in the group, and making sure that the group would give them what they need, both reasons that people didn't engage. As with many of the studies highlighted in this systematic review, Gerritzen et al. 90 also noted the advantages of online groups compared to in-personspecifically not having to travel and the greater potential to develop ad hoc relationships outside of support group meetings. Rapley et al. 91 also demonstrated positive responses when exploring the use of videoconferencing for peer support among family carers of people with rarer dementia. Across interviews with nine carers, participants emphasised that digital peer support helped them to maintain their relationship with their cared for person, demonstrate and acknowledge compassion from others, take time to have a personal life and balance this alongside caring, as well as being cognisant of the role they are in and maintaining positivity in it. In a study exploring unpaid dementia carers' experiences of using technology in caring, Damant et al. 92 demonstrated carers used social media and videoconferencing or peer support, and daily activities in their personal life, and in supporting them in caring. However, participants emphasised the issues of reliance on technology, and the barriers in terms of access and cost of not only the enabling technology, but in the running costs. Although these studies do not illustrate any additional findings to the existing review, they do further demonstrate the themes noted, specifically in relation to the potential positive aspects of digital technologies in the care of people with dementia, as well as the need for careful thought in their application given the potential for furthering inequalities with some lacking access to the technology.

5 | CONCLUSIONS

The evidence from this review demonstrates that there is a paucity of research exploring technology-based service delivery for health and social care access in dementia. The available evidence in this area provides mixed findings on its benefits and accessibility. There is a need to investigate technology-based service delivery for health and social care in dementia, both in conjunction with, and in comparison to, traditional methods of service delivery. Services need to be cognisant of the challenges that the symptoms of dementia can bring in using and adapting to technology to access health and social care service. People with dementia and unpaid carers need to be consulted to understand their preferred method of service access, and how they can be supported in achieving the best quality of care possible. People with dementia and unpaid carers require greater formal support in accessing technology and its ongoing use, specifically in the more advanced stages of the condition. Additionally, the design of technology for use by people with dementia needs input to

make it more acceptable, usable and therefore generate greater engagement and improved potential for positive outcomes. Further research can identify the scale of the benefits to people with dementia, of varying severity and subtypes, to unpaid carers and services. With constant changes in technology, and as such, the methods through which services can be accessed and delivered, there needs to be a more standardised method of assessing digitised services. With the cost and availability of internet connections and technology, research also needs to identify the impact of health literacy, sociodemographic and socio-economic factors on the accessibility of remote services, and uptake and effective use of remote services for health and social care access in dementia. Remote services can provide financial and social benefits to people with dementia, unpaid carers, and the health and social care system. In situations benefits can be attained, there needs to be practical schemes to facilitate and support people with dementia and unpaid carers in having and using technology to improve care access.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Clarissa Giebel https://orcid.org/0000-0002-0746-0566

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APPENDIX A

TABLE A1 Summary characteristics of included papers.

Author(s)	Year	Country	Study type	Research methods	Population (n)	Population type	Technology evaluated	Outcome measures
Arighi et al.	2021	Italy	Quantitative	Cohort	74	PLWD	Clinician tele-visits for outpatients	Socio-demography in successful tele-visit
Banbury	2019	Australia	Qualitative	SSI	69	Carers	Peer-support videoconferencing	Perceptions of technology use, differences in VC and tech support needed
Banbury	2021	Australia	Qualitative	SSI	6	Carers	Telehealth caregiver support	Group connectedness, feelings of support and knowledge/skill transfer
Bardach	2021	USA	Quantitative	Questionnaire/ survey	294	Carers	Telemedicine in carer informational needs	Dementia-related knowledge and gaps
Baruah	2021	India	Qualitative	SSI	15	Carers	Online carer training/ support	Adaptations to 'iSupport' and user's acceptability of changes
Baruah (2)	2021	India	Quantitative	Case/control	151	Carers	Online carer training/ support	Self-rate depression and caregiver burden; attitude, self- efficacy, mastery and self-rated health
Capozzo	2020	Italy	Quantitative	SSI	32	28 carers/ 4 dyads	Telemedicine for care	Satisfaction with neurological interview; QoL and clinical outlook; behaviour changes, language functions
Chirico	2022	UK, Italy, Austria and Poland	Qualitative	SSI	142	127 carers/ 15 PLWD	General use of tech	Use of technology and perceived effect of tech use
Chiu	2010	China	Quantitative	Multiphase, longitudinal study	46	Carers	Internet-mediated intervention for carers	Technology acceptance > service use; use frequency > attitude to tech and perceived caregiver competence; perceived burden
David	2023	UK, Italy, Austria and Poland	Quantitative	Observational cohort	82	PLWD	Remote monitoring	Benefits of remote physiology monitoring
Debring	2021	Sweden	Quantitative	Intervention study	314	187 carers/ 118 PLWD/ 9 relatives	Digital reminiscing	QoL, health and wellbeing, carers' rating of usefulness of digital communication aids
Efthymiou	2020	Greece	Quantitative	Descriptive study	580	PLWD	Internet-based dementia-service use	Socio-demographic predictors of dementia-specific information searches; internet use > hours of care and socio- demographic variables
Efthymiou	2022	Greece & Cyprus	Quantitative	Descriptive study	174	Carers	eHealth literacy	Caregiving self-efficacy and problematic/dysfunctional coping
Elfrink	2021	Netherlands	Quantitative	RCT	42	Dyads	Digital reminiscing	Neuropsychiatric symptoms (PLWD), distress and carer QoL
Fowler	2016	USA	Quantitative	RCT	28	Carers	Virtual healthcare neighbourhood	Sleep quality and quantity, self- efficacy, insomnia pre- and post-intervention
Gaber	2020	UK	Quantitative	Questionnaire/ survey	64	64 PLWD/ 64 w/out	Social participation through technology	Social participation, technology use and social deprivation

(Continues)

TABLE A1 (Continued)

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Author(s)	Year	Country	Study type	Research methods	Population (n)	Population type	Technology evaluated	Outcome measures
Gerritzen	2023	UK	Qualitative	Focus groups	20	PLWD	Video meeting peer support	Perceptions of tech: barriers and facilitators; social connectedness and digital exclusion
Han	2022	China	Quantitative	Single-group repeat measures	159	Carers	Online peer support groups	Depression, perceived stress, helplessness, self-efficacy, gathering information and obtaining support
Harding	2023	UK	Qualitative	Direct content analysis	25	Carers	Online videoconference peer support groups	Support in rare dementias; esteem, carer emotional and information support
Hicks	2023	UK	Qualitative	SSI	42	Carers	Digital technologies for social inclusion	Social inclusion and connectedness, tech literacy
Hoel	2022	Germany	Qualitative	Case study of SSI	3	Dyads	Use of social technology to reduce social isolation	Value of tech in social participation
Huis	2018	Netherlands	Qualitative	Focus groups	32	Carers	eHealth in self- management of behaviour and mood changes	Opinions and potential for tailored support
Huis	2020	Netherlands	Quantitative	RCT	81	Carers	eHealth in self- management of behaviour and mood changes	Self-efficacy, symptomatology coping, PLWD-carer relationship quality
lyer	2023	USA	Qualitative	Observational, grounded theory	67	Carers	Tele-dementia care	Facilitators and barriers, use and quality of tele-dementia care
Jeong	2018	South Korea	Quantitative	Survey; structural equation modelling	154	Carers	Cyber-coping for carers	Caregiver coping and stress; PLWD physical health
Kovaleva	2023	USA	Qualitative	SSI	15	Carers	Telehealth online education intervention	Caregiver acceptability and experience following hospital discharge. Understanding of dementia and caring
Laver	2020	Australia	Quantitative	RCT	63	Dyads	Telehealth intervention	Caregiving mastery, caregiver perception of change, ADL function, type and frequency of behavioural symptoms
Masoud	2021	USA	Qualitative	SSI	17	5 PLWD/12 carers	Virtual memory cafes for social connectedness	Benefits of memory cafes (PLWD and carers)
McKechnie	2014	UK	Mixed methods	Questionnaires > SSI	61> 15	Carers	Online support forum for carers	Anxiety, depression, PLWD-carer relationship quality
McLoughlin	2023	UK & Ireland	Mixed methods	Questionnaires > SSI	39> 16	Carers	Videoconferencing support groups	Facilitators and barriers; benefits and negatives
Meng	2021	USA	Quantitative	RCT	109	Carers	Telephone CBT	Healthcare use and expenditure
Moo	2020	USA	Quantitative	Questionnaires	38	Dyads	Telemedicine for dementia management	PLWD/carer satisfaction

I A B L E A 1	L (Cor	itinuea)						
Author(s)	Year	Country	Study type	Research methods	Population (n)	Population type	Technology evaluated	Outcome measures
Nguyen	2022	USA	Quantitative	Pre- post- surveys	124	Carers	Online tool for education/support/care	Social isolation and loneliness
Nissen	2018	USA	Qualitative	Focus groups	6	1 PLWD/5 carers	Telehealth and teleOT (occupational therapy)	Skills, use and perceptions of tech, carer burden
O'Connor	2023	USA	Qualitative	SSI	10	Carers	Telehealth support (FSP)	Satisfaction with FSP
Park	2023	USA	Qualitative	Focus groups	17	8 PLWD/9 carers	Online, supervised chair yoga	Benefits, challenges and facilitators
Peri	2023	New Zealand	Qualitative	SSI	12	Carers	vCST	Experiences of vCST and social contact
Powers	2018	USA	Quantitative	Descriptive study	45	Dyads	CVT	Satisfaction with CVT, caregiver stress
Rice	2022	USA	Quantitative	Cohort	216	Carers	Telehealth intervention	Efficacy of 'teleFAMILIES' for carers; caregiver burden and depression; behavioural symptom management
Roach	2021	Canada	Qualitative	SSI	21	1 PLWD/19 carers	Telemedicine	Barriers and facilitators to virtual medicine
Shaw	2020	USA	Quantitative	RCT	84	Dyads	Video-based intervention	Caregiver confidence in managing dementia
Talbot	2022	UK	Qualitative	SSI	19	PLWD	Digital technology use in ADL	Social connection, self- actualisation, well-being and support
Torkamani	2014	UK, Spain and Greece	Quantitative	RCT	30	Carers	Online support platform (ALADDIN)	QoL, caregiver burden and stress
Williams	2019	USA	Quantitative	RCT	42	Carers	Tailored telephone dementia-care support ('FAMTECHCARE')	Caregiver stress, competence, reaction to behavioural symptoms

Abbreviations: ADL, activities of daily life; ALADDIN, A technology pLatform for the Assisted living of Dementia elDerly INdividuals and their carers; CBT, cognitive behavioural therapy; CVT, clinical video-telehealth; FSP, family support program; OT, occupational therapist; PLWD, people living with dementia; QoL, quality of life; RCT, randomised control trial; SSI, semi-structured interview; VC, video conferencing; vCST, virtual cognitive stimulation therapy.

TABLE A2 Quality rating checklist and applied scores for qualitative studies and qualitative part of mixed-methods studies.

	Quality assessment criteria scores for qualitative papers/qualitative part of mixed-methods papers														
Author (year)	Α	В	С	D	E	F	G	Н	1	J	Total	Maximum	% score		
Banbury et al. (2019) ³⁸	2	2	1	1	2	1	1	0	2	1	13	20	65.0%		
Banbury et al. (2021) ⁴³	2	2	2	1	1	1	2	2	2	0	15	20	75.0%		
Baruah et al. (2021) ³⁹	2	2	2	2	1	1	1	2	1	0	14	20	70.0%		
Chirico et al. (2022) ⁴⁴	2	2	2	2	2	1	2	2	2	0	17	20	85.0%		
Gerritzen et al. (2023) ⁴⁵	2	2	2	2	2	2	2	2	2	0	18	20	90.0%		
Harding et al. (2023) ⁵²	2	2	2	2	1	1	2	2	2	2	18	20	90.0%		
Hicks et al. (2023) ¹⁸	2	2	2	2	2	1	2	1	2	1	17	20	85.0%		
Hoel et al. (2022) ⁶⁹	2	2	2	2	1	1	2	2	1	2	17	20	85.0%		

(Continues)

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TABLE A2 (Continued)

	Quality assessment criteria scores for qualitative papers/qualitative part of mixed-methods papers													
	Qua	iity ass	essillei	it crite	ia scoi	es ior	qualita	піче ра	pers/qu	antati	ve part or	illixeu-illetilous	papers	
Author (year)	Α	В	С	D	Ε	F	G	Н	1	J	Total	Maximum	% score	
Huis In Het Veld et al. (2018) ⁵³	2	2	1	2	2	1	2	1	2	0	15	20	75.0%	
lyer et al. (2023) ⁴⁸	2	2	2	1	1	1	2	2	2	1	16	20	80.0%	
Kovaleva et al. (2023) ⁵⁷	2	2	2	2	2	2	2	2	2	2	20	20	100.0%	
Masoud et al. (2021) ¹⁶	2	2	2	2	2	2	2	2	2	1	19	20	95.0%	
McKechnie, Barker and Stott (2014) ³⁵	2	2	2	2	2	1	2	2	2	1	18	20	90.0%	
McLoughlin et al. (2023) ³⁶	2	2	2	1	2	2	2	1	2	1	17	20	85.0%	
Nissen et al. (2018) ⁵⁹	2	2	1	2	1	2	2	2	2	1	17	20	85.0%	
O'Connor et al. (2023) ⁴⁷	2	2	2	2	1	2	2	2	1	1	17	20	85.0%	
Park et al. (2023) ⁴⁰	2	2	1	2	2	1	2	2	2	1	17	20	85.0%	
Peri et al. (2023) ⁴⁹	2	2	2	2	1	2	2	1	2	1	17	20	85.0%	
Roach et al. (2021) ⁴⁶	2	2	2	1	2	2	2	1	2	1	17	20	85.0%	
Talbot and Briggs (2022) ⁶⁰	2	2	1	2	1	1	2	1	2	1	15	20	75.0%	

Note: Quality assessment criteria for qualitative papers: (A) Question/objective sufficiently described. (B) Study design evident and appropriate. (C) Context for the study clear? (D) Connection to a theoretical framework/wider body of knowledge. (E) Sampling strategy described, relevant and justified. (F) Data collection methods clearly described and systematic. (G) Data analysis clearly described and systematic. (H) Use of verification procedure(s) to establish credibility. (I) Conclusions supported by the results? (J) Reflexivity of the account?

TABLE A3 Quality rating checklist and applied scores for quantitative studies and quantitative part of mixed-methods studies.

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	Quality assessment scores for quantitative papers/quantitative part of mixed-methods papers																
Author (year)	Α	В	С	D	E	F	G	Н	ı	J	К	L	М	N	Total	Maximum	% score
Arighi et al. (2021) ³⁷	1	2	1	2	N/A	N/A	N/A	2	1	2	2	1	1	2	17	22	77.3%
Bardach et al. (2021) ⁷¹	2	1	2	0	N/A	N/A	N/A	2	2	1	N/A	0	1	1	12	20	60.0%
Baruah et al. (2021) ⁵⁶	2	2	2	2	2	0	2	2	1	2	2	2	2	2	25	28	89.3%
Capozzo et al. (2020) ¹⁵	2	2	2	1	N/A	N/A	N/A	1	1	1	2	N/A	2	1	15	20	75.0%
Chiu and Eysenbach (2010) ⁴¹	2	1	2	2	N/A	N/A	N/A	2	2	2	2	2	2	1	20	22	90.9%
David et al. (2023) ⁷³	2	2	2	2	N/A	N/A	N/A	2	0	2	2	0	2	2	18	22	81.8%
Derbring et al. (2023) ⁵⁰	2	2	2	2	0	0	0	2	0	2	2	0	2	2	18	28	64.3%
Efthymiou et al. (2020) ⁷⁰	2	2	2	2	N/A	N/A	N/A	2	0	2	2	2	2	2	20	22	90.9%
Efthymiou et al. (2022) ⁷²	2	2	2	2	N/A	N/A	N/A	2	2	2	2	2	2	2	22	22	100.0%
Elfrink et al. (2021) ⁶⁶	2	2	2	2	2	0	N/A	2	0	2	2	1	2	1	20	26	76.9%
Fowler et al. (2016) ⁶³	2	2	2	2	2	0	N/A	2	1	2	2	0	2	2	21	26	80.8%
Gaber et al. (2020) ⁶⁸	2	2	1	2	N/A	N/A	N/A	1	1	2	2	2	2	1	18	22	81.8%
Han et al. (2022) ⁵¹	2	2	1	2	N/A	N/A	N/A	2	1	1	2	0	2	0	15	22	68.2%
Huis In Het Veld et al. (2020) ⁹³	2	2	2	2	2	N/A	N/A	2	1	2	0	2	2	2	21	24	87.5%
Jeong et al. (2018) ⁵⁸	2	2	1	1	N/A	N/A	N/A	1	1	2	2	1	2	1	16	22	72.7%
Laver et al. (2020) ¹⁹	2	2	2	2	2	2	N/A	2	2	2	2	2	2	2	26	26	100.0%
McKechnie et al. (2014) ³⁵	2	2	1	2	N/A	N/A	N/A	2	1	2	2	0	2	1	17	22	77.3%
McLoughlin et al. (2023) ³⁶	1	2	1	2	N/A	N/A	N/A	1	0	1	0	0	0	1	9	22	40.9%
Meng et al. (2021) ⁶²	2	2	2	2	0	0	N/A	2	0	2	2	2	1	2	19	26	73.1%
Moo et al. (2020) ⁴²	2	2	1	2	N/A	N/A	N/A	1	0	2	2	0	2	1	15	22	68.2%

TABLE A3 (Continued)

	Qu	Quality assessment scores for quantitative papers/quantitative part of mixed-methods papers															
Author (year)	Α	В	С	D	E	F	G	Н	1	J	K	L	М	N	Total	Maximum	% score
Nguyen et al. (2024) ⁶⁴	2	2	2	1	N/A	N/A	N/A	2	1	2	2	0	1	2	17	22	77.3%
Powers and Buckner (2018) ⁶⁷	1	2	2	0	N/A	N/A	N/A	2	1	1	0	0	1	1	11	22	50.0%
Rice et al. (2022) ⁶¹	2	1	1	2	0	N/A	N/A	2	1	2	2	0	2	1	16	24	66.7%
Shaw et al. (2020) ⁶⁵	2	2	1	2	2	2	2	1	1	2	2	0	2	2	23	28	82.1%
Torkamani et al. (2014) ⁵⁵	2	2	2	0	0	N/A	N/A	1	1	2	2	0	2	1	15	24	62.5%
Williams et al. (2019) ⁵⁴	2	2	2	2	2	N/A	N/A	2	1	2	2	2	2	1	22	24	91.7%

Note: Quality assessment criteria for quantitative papers: (A) Question/objective sufficiently described. (B) Study design evident and appropriate. (C) Method of subject/comparison group selection or source of information/input variables described and appropriate. (D) Subject (and comparison group, if applicable) characteristics sufficiently described. (E) If interventional and random allocation was possible, was it described? (F) If interventional and blinding of investigators was possible, was it reported? (G) If interventional and blinding of subjects was possible, was it reported. (H) Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias. (I) Sample size appropriate. (J) Analytic methods described/justified and appropriate. (K) Some estimate of variance is reported for the main results. (L) Controlled for confounding. (M) Results reported in sufficient detail. (N) Conclusions supported by the results.