

Review

# Internet-Based Interventions Aimed at Supporting Family Caregivers of People With Dementia: Systematic Review

Jenny Hopwood<sup>1</sup>, MB BChir; Nina Walker<sup>1</sup>, BSc (Hons), MSc; Lorraine McDonagh<sup>2</sup>, BA, PhD; Greta Rait<sup>1</sup>, MSc, MD, MRCP; Kate Walters<sup>1</sup>, MSc, PhD, MRCP; Stephen Iliffe<sup>1</sup>, BSc, MBBS, FRCGP; Jamie Ross<sup>3</sup>, BSc, PhD; Nathan Davies<sup>1,4</sup>, BSc (Hons), MSc, PhD

<sup>1</sup>Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, London, United Kingdom

<sup>2</sup>Research Department of Primary Care and Population Health, University College London, London, United Kingdom

<sup>3</sup>eHealth Unit, Research Department of Primary Care and Population Health, University College London, London, United Kingdom

<sup>4</sup>Centre for Dementia Palliative Care Research, Marie Curie Palliative Care Research Department, University College London, London, United Kingdom

**Corresponding Author:**

Nathan Davies, BSc (Hons), MSc, PhD

Centre for Ageing Population Studies

Research Department of Primary Care and Population Health

University College London

Rowland Hill Street

Royal Free Hospital

London, NW3 2PF

United Kingdom

Phone: 44 2077940500 ext 34141

Email: [n.m.davies@ucl.ac.uk](mailto:n.m.davies@ucl.ac.uk)

## Abstract

**Background:** Caring for someone with dementia is one of the most challenging caring roles. The need for support for family caregivers has been recognized for some time but is often still lacking. With an aging population, demand on health and social care services is growing, and the population is increasingly looking to the internet for information and support.

**Objective:** In this review, we aimed to (1) identify the key components of existing internet-based interventions designed to support family caregivers of people with dementia, (2) develop an understanding of which components are most valued by caregivers, and (3) consider the evidence of effectiveness of internet-based interventions designed to support family caregivers of people with dementia.

**Methods:** We conducted a systematic search of online databases in April 2018. We searched reference lists and tracked citations. All study designs were included. We adopted a narrative synthesis approach with thematic analysis and tabulation as tools.

**Results:** We identified 2325 studies, of which we included 40. The interventions varied in the number and types of components, duration and dose, and outcomes used to measure effectiveness. The interventions focused on (1) contact with health or social care providers, (2) peer interaction, (3) provision of information, (4) decision support, and (5) psychological support. The overall quality of the studies was low, making interpretation and generalizability of the effectiveness findings difficult. However, most studies suggested that interventions may be beneficial to family caregiver well-being, including positive impacts on depression, anxiety, and burden. Particular benefit came from psychological support provided online, where several small randomized controlled trials suggested improvements in caregiver mental health. Provision of information online was most beneficial when tailored specifically for the individual and used as part of a multicomponent intervention. Peer support provided in online groups was appreciated by most participants and showed positive effects on stress. Finally, online contact with a professional was appreciated by caregivers, who valued easy access to personalized practical advice and emotional support, leading to a reduction in burden and strain.

**Conclusions:** Although mixed, the results indicate a positive response for the use of internet-based interventions by caregivers. More high-quality studies are required to identify the effectiveness of internet interventions aimed at supporting family caregivers, with particular focus on meeting the needs of caregivers during the different stages of dementia.

**KEYWORDS**

dementia; caregivers; internet; review

## **Introduction**

Caring for someone with dementia can have a significant impact on the well-being of the caregiver. It is perceived as one of the most stressful and difficult forms of caring, as caregivers can face many years of managing difficult symptoms and making complex decisions [1,2]. Studies report higher levels of depression, emotional distress, and physical strain in caregivers of people with dementia than in caregivers for older adults with physical impairments [1,3].

There are around 670,000 family members and friends providing most care for people with dementia in the United Kingdom. Together, these caregivers are estimated to provide 1.3 billion hours of care per year and save the UK economy £12 billion annually [4]. Without the help of such caregivers, the formal care system would be likely to collapse [5].

With the given emotional and physical impact on caregiver well-being, psychological and practical support for caregivers is essential. There have been several trials of face-to-face interventions to support informal caregivers of people with dementia [6]. Reviews of interventions that provide information and advice have found varied results [7,8], but evidence of benefit has been found for some face-to-face psychological interventions in alleviating caregiver symptoms of depression [9]. However, uptake of such interventions is poor. It is estimated that around 10% of informal caregivers access caregiver support services [10], with the difficulty of leaving the care recipient and stigma being important barriers to uptake [11,12]. Individualizing caregiver interventions is also difficult economically, especially given the financial constraints in health care and the growing demand nationally and internationally due to the aging population [9].

Use of internet-based interventions may be an option to close the support gap for informal caregivers, particularly for those finding it difficult to leave their home or requiring flexibility due to caring responsibilities. Internet-based support interventions have the benefit of being relatively low cost and, by bringing the intervention into the home, may also have a role in reducing the social isolation that can come with caring [13,14]. Previous systematic reviews have suggested that internet-based interventions for informal caregivers of people with dementia have the capacity to improve various aspects of caregiver well-being, including depression, burden, and stress [15-17]. For psychological interventions in general, it is suggested that those with multiple components are better suited to support caregivers of people with dementia [9]. However, no previous reviews have identified what components might be important for interventions delivered via the internet for this group. Previous reviews have also focused predominantly on quantitative effectiveness data, which have been lacking in quality, and a mixed-methods review is important to provide

richer data on how caregivers use and find benefit from internet-based interventions.

This review aimed to (1) identify the key components of existing internet-based interventions designed to support family caregivers of people with dementia, (2) develop an understanding of which components are most valued by caregivers, and (3) consider the evidence of effectiveness of internet-based interventions designed to support family caregivers of people with dementia.

Technology and digital health interventions is a fast-paced research field, and therefore previous reviews are now outdated and require updating. Previous reviews have also focused on the effectiveness of whole interventions, where there are limited data to draw such strong conclusions, and in doing so have neglected a thorough and clear description of the content of interventions and their acceptability by caregivers.

## **Methods**

### **Design**

We conducted a systematic review of randomized controlled trials (RCTs), quasi-experimental designs (pre-post studies), quantitative studies, and qualitative studies, following the guidelines from the Centre for Reviews and Dissemination [18].

### **Inclusion and Exclusion Criteria**

We included articles if they met the following criteria: (1) the intervention was aimed at informal caregivers (defined as a family member or friend providing unpaid care) of people with dementia, (2) the intervention was a digital intervention delivered via the internet, and (3) the article considered a specific intervention and provided a description of this.

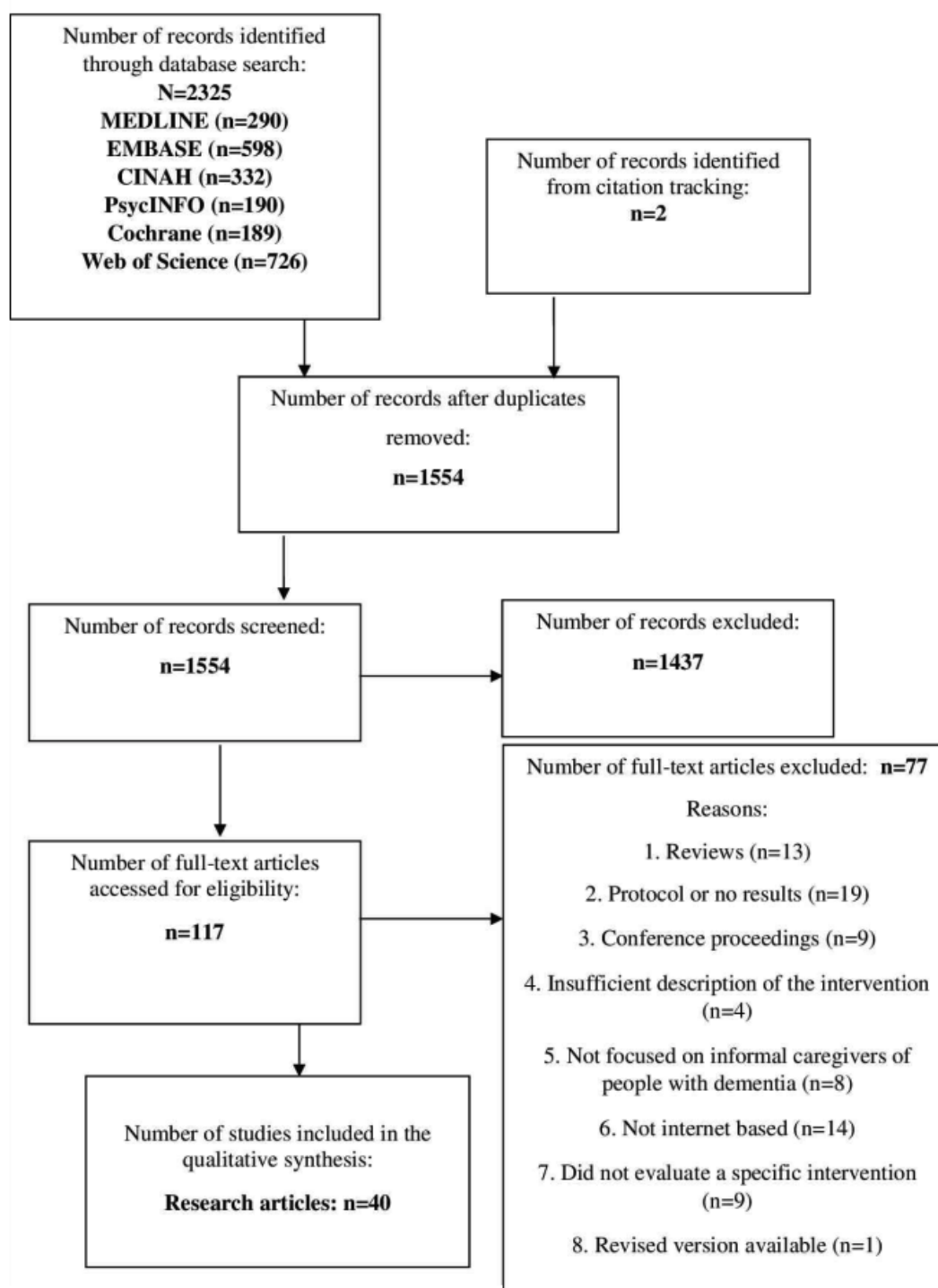
We excluded articles if (1) the intervention was telephone or telehealth based, (2) the interventions solely used Skype or another means of online calling, (3) the intervention had a large face-to-face component, (4) results or outcomes of the intervention were not reported, (5) the intervention was focused on the person with dementia, or (6) the study was not published in a peer-reviewed journal.

As our interest was in digital technologies that could be used by caregivers without input from health professionals, we excluded telephone-based support and those interventions with a large face-to-face component.

### **Search Strategy**

We conducted a systematic literature search in CINAHL, the Cochrane Library, EMBASE, MEDLINE, PsycINFO, and Web of Science for articles published between January 1990 and April 2018. We selected 1990, as this was the period when the internet, including email, started to develop in commercial and public settings.

**Figure 1.** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart describing the search process for articles on digital interventions for caregivers of people with dementia.



We tracked citations using Google Scholar, and hand searched reference lists for any additional relevant articles, in addition to hand searches of relevant journals. We identified literature reviews on the topic and checked them to ensure that our search identified relevant articles. Search terms and index terms (Medical Subject Headings) were identified from the initial scope of the literature. We added synonyms or abbreviations that we felt were appropriate to the search terms. [Multimedia Appendix 1](#) shows an example search strategy from MEDLINE. We contacted experts in the field. We also included gray

literature, including reviews of websites, in the scoping work but not in the review.

### Selection Procedure

Article titles and abstracts were screened and excluded if they did not meet the inclusion criteria by 2 reviewers (JH and ND). We rapidly appraised non-English language articles, using their English abstracts, to ensure that we did not exclude any important articles. Articles considered relevant or where insufficient information was supplied in the abstract and title

were read in full by 2 reviewers (JH and ND). Two reviewers enhanced the validity and reliability of the selection procedure [18]. Any disagreement between reviewers or uncertainty about inclusion of articles would have been decided by a third reviewer, although this was not required. Figure 1 shows a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart detailing the selection process.

### Quality Appraisal

We appraised the literature for quality using the Critical Appraisal Skills Programme tools, using different tools for varying study design, qualitative studies [19], and RCTs [20], and an adapted version of the Critical Appraisal Skills Programme toolkit for quantitative designs [21]. We excluded no studies based on the results of their quality appraisal; rather, we used the study appraisal to develop discussion of the included studies.

### Data Extraction and Synthesis

We developed a standardized data extraction tool to examine the included studies. We extracted data on study design, intervention details and components, duration of the intervention, participant characteristics, outcome measures, key findings, and the conclusions drawn by study authors. As the review included both quantitative and qualitative studies, and quantitative designs were heterogeneous, we could not pool quantitative data to conduct a meta-analysis. Therefore, we performed a narrative synthesis, using tabulation to organize the studies and a thematic analysis to categorize and group the studies. Two reviewers independently coded all studies (JH and ND). The 2 reviewers met to discuss each of their coding frames, discuss any disagreements, and develop a refined coding frame. Using the refined coding frame, all studies were coded by 1 reviewer (JH), and a selection of articles (50%) were blindly coded by a second reviewer (ND) and checked for agreement. Any disagreement was discussed and a third researcher would have been consulted if agreement could not be reached, although this was not required.

## Results

### Description of Studies

We included 40 articles [22-61] addressing 31 different interventions. There were 9 RCTs [22-30] (Multimedia Appendix 2), 7 quasi-experimental studies [31-37] (Multimedia Appendix 3), 4 qualitative studies [38-41] (Multimedia Appendix 4), and 20 studies with mixed or other methods [42-61] (Multimedia Appendix 5). All statistics in the multimedia appendices are reported as per the original articles.

All interventions aimed to address the needs of informal caregivers of people with dementia. One intervention also provided support for professional caregivers [26] and 2 provided support for people with dementia [41,49]. Some interventions limited their inclusion population to address specific caregiver needs, including 3 bilingual websites that addressed the needs of caregivers from minority ethnic groups [46,56,61]. Some restricted their intervention to informal caregivers experiencing stress [23,36,47], burden [24,29,57], depression [24,57], or anxiety [24,57].

Most interventions aimed to address the needs of caregivers providing care to people with all stages and types of dementia. One limited the intervention to spousal caregivers of people with mild cognitive impairment or “mild” dementia [44], 1 was limited to caregivers of people who were housebound with dementia [25], and 2 interventions also included people caring for those with other forms of neurodegenerative disease [36,39,40,52].

Although all interventions were primarily internet based, some had supplementary telephone-delivered components; for example, 1 provided a telephone number on their website for caregivers to contact a health care professional [32], and 1 included monthly telephone calls with caregivers [45].

A large number of different outcome measures were used in the studies. Outcomes included data on the usability of the interventions, as well as impacts on well-being, quality of life, burden, competence, physical health, and mental health. A wide range of validated and nonvalidated rating scales were used to assess the impact of the interventions. Qualitative results mainly focused on usability of the interventions and included observation of use [39-41,44,49], free-text surveys [38,41,49,51,55,61], interviews [38-41,46,47,47,53,54,59,60], and focus groups [42,45,56].

### Quality Appraisal

The articles were of variable quality. Sample sizes ranged from 5 to 299, with many studies being pilot or feasibility studies. A problem with possible selection, performance, detection, or attrition bias was identified in many of the studies; many studies had small convenience samples, high attrition rates, and poor descriptions of randomization in trials and of data collection; and in some cases data collection was completed by nonblinded members of the study team.

### Themes

We identified 5 themes as key components of the interventions: peer support; contact with a health or social care provider; provision of information; decision support; and psychological support.

### Peer Support

Peer support was a key component of the interventions in 25 of the studies [22,25,26,29,31-33,36,38-42,44,45,47-50,52-56,58]. Peer support provided by fellow caregivers online was delivered either in private or in public, where all individuals using the intervention could see interactions. Common uses of peer support included supportive messages, information seeking, discussing the emotional impact of caring, and developing support networks outside of the Web-based intervention.

Private peer support was provided via private email or an online messenger service [22,36,39,40,45,48,49,52,53,55]. For example, the Digital Alzheimer Center allowed users to find others in their area caring for someone with the same diagnosis and then to communicate via private messaging [49]. However, in the few studies that quantified use of private messaging, use varied from very infrequent [49] to being one of the most-used functions [40].

One intervention, Inlife, provided the opportunity for the primary caregiver to develop their own networks of online support with friends, family, or significant others [48]. This allowed them to develop care books providing an overview of contact and practical information regarding the care of the individual, transfer care tasks among individuals, and provide help and assistance to one another.

Some interventions provided peer support in small groups [42]. For example, O'Connor and colleagues developed a virtual reality support group within an avatar environment [55] where groups of 3 to 4 anonymous caregivers communicated via online text. The groups were driven by the caregivers, allowing for exchange of ideas about communication, caring, and information about dementia, with some direction provided by a psychologist. Outcomes evaluated included loneliness, depression, burden, and perceived stress, but the study was underpowered to demonstrate any effects. A similar approach using videoconferencing software was used in another intervention where groups of caregivers met weekly online, initially with a facilitator, then as a peer group alone [39]. More than 90% of caregivers found this a positive experience, and there was a significant decline in stress in the experimental group. Use of the internet to deliver the intervention was felt to be as helpful as meeting people face-to-face by 61% of participants [52]. When this videoconference support group was compared with an internet-based chat group [53], both groups had a significant improvement in self-efficacy, but the video group showed a significantly greater improvement in mental health status. However, this was a pre-post study design with a duration of 6 months.

Public peer support usually consisted of forums [22,29,36,39,40,44,45,47,49,50,52-54,56,58] but also included chat rooms [32,41], shared blogs [25], links to peer groups on social networking sites [26], and video messages [31]. However, use of these tools was variable. Some studies reported that forums were not well used and were negatively reviewed by participants in qualitative reports [29,44]. In 1 study, this was thought to be due to the forum having an unclear purpose, the anonymity of participants, and a perceived high threshold for starting conversations [44]. In another study, 76% of participants visited the forum fewer than 12 times over the 12-week study [54]. However, some studies reported positive views, good rates of use, and a good impact on caregiver outcomes. For example, a 12-month RCT from Bass and colleagues analyzed the impact of the communication function and demonstrated a reduction in physical and emotional strain associated with use of the communication functions for caregivers who were initially under the most strain [22]. McKechnie and colleagues found a statistically significant improvement in the quality of the relationship with the care recipient but found no impact on depression or anxiety [54]. However, this was a smaller pre-post study with a short intervention period of only 12 weeks. Qualitative data suggested that participants found many benefits from peer interaction, including feeling understood through shared experience, finding reward in helping others, having reduced isolation, and being able to access information that would be difficult to find elsewhere [39,42,45,52,54]. However, in the 1 study where social isolation was measured using a

validated scale, peer interaction did not demonstrate a significant benefit [45].

Most interventions that provided private peer interaction also provided the option for public interaction [22,36,39,45,49,52,53]. When comparing private peer interaction with public peer interaction, Brennan and colleagues found that the public forum was used with increased frequency and duration compared with the private mail function [45], a contrast to findings from the Digital Alzheimer Center [49]. In qualitative feedback, participants found it difficult to recall the email addresses of others when using this private mail function so preferred to interact publicly.

The studies suggest that functions that have the potential for visual contact or group interaction may be more promising than simple chat-based functions in improving mental health status.

### **Contact With Professionals**

Of the studies, 11 included components to allow caregivers to have direct contact with and ask questions of either a health or a social care professional [22,25,32,41,45,46,49,56,58-60]. Professionals included nurses [22,45], occupational therapists [46], or social workers [27,46,58]. In some interventions, the role of the professional was not clear; rather, the caregiver was described as having contact with a "medical professional" or "expert" [32,41,49,56,59,60], or a multidisciplinary team [25].

Most interventions required caregivers to contact health professionals themselves [22,25,32,45,46,49,56,58-60]. For example, the eHealthMonitor dementia portal [59,60] provided alerts for health professionals when caregivers entered a question; professionals could then respond online or arrange an appointment via telephone. Only 1 intervention adopted a proactive approach where health professionals contacted caregivers who self-assessed as having severe stress [27]. The intervention as a whole led to a significant decrease in hardship and grief compared with the control group, but there was no significant change in burden, depressive symptoms, or desire for nursing home placement.

On the whole, evaluation data from the studies showed that interaction with professionals was a positive experience for caregivers [45,46,58-60]. Professionals provided personalized practical advice for caregivers at home on caring and dementia, as well as emotional support, and caregivers reported feeling less isolated as a result. However, opinions about seeking this support electronically did vary [46,56], with some caregivers enjoying writing emails, while others felt confused about how much information to include.

### **Provision of Information**

Most interventions provided information for caregivers about dementia, practical aspects of caregiving, or available local and national services. For some, this was the only function of the intervention [30,37,51,61], but for most information provision was part of a multicomponent intervention [22-29,32-36,38-40,42-50,52,53,56-60]. Some RCTs of multicomponent interventions that included the provision of information did demonstrate positive impacts on depression [24], anxiety [24], perceived stress [28,52], and attitudes toward dementia [26].

However, as information was part of a broader intervention, it was difficult to know the impact of this component. One intervention that was analyzed in an RCT that attempted to assess this was ComputerLink [22], which provided information on dementia, caregiving, and local services as part of a multicomponent intervention. Use of the information provision parts of the intervention was associated with reduced strain for caregivers living alone with care recipients and for spousal caregivers. However, other multiple-component interventions evaluated with qualitative methods found that caregivers found other components, such as interaction with professionals, more beneficial than information [40,46], with caregivers expressing frustration when required to review information that did not meet their specific needs [38,56]. When information was individualized, it was considered by caregivers as one of the most useful functionalities of the intervention [37,59]. This suggests that information does appear to be an important part of interventions, but the information should be tailored to the individual caregiver situation and not be the sole focus of the intervention.

### **Decision-Making Support**

Some of the interventions recognized that decision making is a difficult process for caregivers and included decision aids [22,36,41,45,59,60]. However, most studies did not explain in detail how the intervention provided support with decision making; for example, Lorig and colleagues included decision-making assistance in their online workshops and chat forums [36] but lacked further description of how this was achieved. The only well-described decision aid intervention was ComputerLink [45], which included a tool based on multiattribute utility theory [62], where caregivers were led through a series of questions prioritizing important factors in the decision-making process. Use of the decision-making tool significantly improved caregiver confidence prior to having face-to-face discussions when compared with the control group. However, in some studies the decision-making tools were poorly used [41,45] and not appreciated by caregivers [41]. Instead, participants gained decision support from other components of the interventions, such as discussion with peers or professionals [41,45].

### **Psychological Support**

Many interventions included components of psychological support [23,24,26-29,32-36,39,44,46,47,55], which were self-guided or professionally guided. Few used standardized forms of psychological interventions or therapy, but therapeutic relaxation techniques were commonly used.

Self-guided psychological support most often consisted of modules that caregivers worked through, and several were tested in RCTs. For example, Beauchamp and colleagues delivered a modular intervention that provided videos on cognitive and behavioral strategies to cope with difficult emotions [23]. In an RCT of the intervention, the experimental group had significantly greater improvements in stress, self-efficacy, intention to get support, strain, gain, depression, and anxiety. Similar results were found in other RCTs of similar psychological interventions, with reductions found in caregiver stress in 1 intervention [28] and improvements in attitudes

toward dementia, distress, empathy, and perspective in another [26]. However, the durations of these RCTs were short, ranging from 1 to 4 months.

Some interventions provided self-directed modules to work through, but caregivers were supported by a professional coach, who was most often a psychologist [24,33,38,44,57]. Caregivers were required to complete assignments, homework, reflective diaries, or regular assessments of their well-being. An RCT of 1 such intervention showed a reduction in symptoms of anxiety and depression with moderate and small effect sizes, respectively [24].

Some studies provided professionally delivered psychological therapies online, either via individual interaction with a therapist using email [35,46] or online interaction with a small group of caregivers [32,36,39,40,52,53,55]. In the ADCarer.com intervention [35], the professional (a psychologist, social worker, or counsellor) would respond to online messages from the caregiver within 48 hours using cognitive behavioral therapy techniques. In a pre-post assessment, the multicomponent intervention did lead to a significant reduction in caregiver distress. Interactive groups were delivered either using videoconferencing software [32,39,40,52,53] or an avatar-based format [55] and allowed small groups of caregivers to interact, guided by a professional. Improvements were found in caregiver mental health and quality-of-life outcomes, but with these interventions as with many others, it is difficult to tease out the specifics of components, as in both cases the virtual support group offered peer support as well as psychological support.

Overall, studies assessing psychological support suggested a positive effect on a variety of factors, including improving caregiver distress, depression, anxiety, and strain. However, some stressed the importance of cultural appropriateness. Kajiyama and colleagues used the popularity of Spanish-language telenovela (a type of television serial drama or soap opera produced mainly in Latin America) to appeal to Hispanic and Latino family caregivers [34].

## **Discussion**

### **Principal Findings**

Unlike previous reviews in this area, this review explored the key components of internet-based interventions to support family caregivers of people with dementia. We identified a broad variety of interventions, which focused on providing peer support, engaging with health and social care professionals, and providing information, decision support, and psychological support. Although effectiveness was not a focus of this review, some multiple-component interventions showed promise in reducing stress, anxiety, and depressive symptoms for family caregivers and in increasing self-efficacy [44,57]. However, as with previous reviews [15-17], the limited number of high-quality RCTs, as well as the multiple-component nature of many interventions, makes it difficult to report which aspects of the interventions were effective.

Peer support was a key component of many of the interventions discussed. Caring for someone with dementia has often been described as not only a lonely role but also one in which there

is a great deal of uncertainty. The peer support components of the interventions identified in this review aimed to target these feelings and were described positively by many participants, but no significant effect for peer interaction and social isolation was found [45]. However, qualitative data in this review suggest that peer support offered a form of socialization. Previous evidence is mixed on whether use of the internet reduces or enhances loneliness [63,64], but this review suggests that internet-based peer interaction may have a benefit for family caregivers. However, it is evident that the way that peer support is delivered is important, with opportunities for group interaction or videoconferencing being more beneficial than public-facing forums and private messaging functions.

The qualitative data suggest that interactions with health professionals are viewed positively; however, it is unclear whether this positivity was linked to the provision of contact online or whether caregivers may prefer this interaction face-to-face. The mix of professionals providing support in the studies suggests there is a lack of consensus on who is best to deliver professional support. This may reflect ambiguity caregivers feel about who is the most appropriate person to talk to when they need advice.

The provision of information was often at the core of interventions, and this supports findings from previous research where most caregivers preferred to receive information online rather than in paper format [65].

This review demonstrated that interventions that focused solely on decision making were, in general, not favored by family caregivers. However, decision-making tools were viewed more positively when they were used alongside other components, such as peer support. Decision making is often left to family caregivers when the person with dementia no longer has capacity, making this a difficult and challenging time for family caregivers. However, results from this review suggest that face-to-face meetings may be required to make decisions, and internet resources are only used as a method of preparation for discussions. This adds to our understanding of barriers to making decisions, which include a lack of information, poor communication, difficult dynamics and conflict within families, and limited emotional and practical support [66-70].

Interventions including online psychological support showed some of the most promising findings, with individual studies reporting significant reductions in caregiver stress, strain, depressive symptoms, and anxiety, in addition to increases in self-efficacy [23,26,28]. Although studies of both professionally guided and self-guided interventions indicated a positive outcome for participants, including caregiver mental health outcomes, they were quasi-experimental (pre-post studies), feasibility studies, and small RCTs, suggesting these conclusions should be made with caution.

Qualitative evaluations of the interventions demonstrated positive views from most caregivers toward internet-based support interventions, although it is clear that not all would benefit from such interventions. It may be that the internet is most beneficial for those who are classified as most vulnerable (ie, more stressed) [22].

## Implications for the Development of Future Internet-Based Interventions for Caregivers

In developing an internet intervention for family caregivers, several issues need to be addressed. Questions of privacy and security were highlighted [59,60], reflected in the contrast of public versus private messaging approaches and password-protected websites. The details discussed by many on the websites are very personal and emotional topics. Sillence and colleagues discussed a series of factors that influence the mistrust and trust of health websites [71]. The design of the site contributed to most of the reasons for rejecting and mistrusting a website, including complex and busy layout, corporate look, and irrelevant content. However, the reasons for selecting and trusting a website were more focused on the content of the website, including unbiased information and personalized content.

Another issue is complexity. Some caregivers found functions such as private messaging, decision aids, and login screens complex, which affected their use. Using familiar-sounding language [71] and a strong iterative approach, in which the intervention undergoes multiple cycles of development and optimization [72], with future interventions are two ways to help overcome this challenge. Tailoring can reduce the quantity of information and resources caregivers must review, and caregivers may be more motivated to use an intervention they feel is applicable to their circumstances. This review found that where interventions were not personalized, caregivers found this frustrating and their needs were not met [47]. Finally, there is the question of internet literacy and access to the internet: the digital divide [73]. There appears to still be a gap between those who use or can use the internet and those who don't, with a study in 2015 highlighting that almost all adults over 70 years of age had difficulty using the intervention [41]. Many of the studies included in this review consisted of participants who were predominantly younger caregivers, whereas many people caring for someone with dementia are more likely to be older. Reducing the complexity of interventions, supporting access with potential support from health professionals, and highlighting the benefits of such interventions to understand their potential value may aid in bridging the divide. For most of the studies, this digital divide was ignored, as a requirement for participation was computer literacy [61], and observational studies assessed the usability of the interventions with caregivers who had already received training in using the website.

## Implications for Policy, Clinical Practice, and Further Research

This review demonstrated the need for high-quality research to evaluate the effectiveness of internet-based interventions for caregivers of people with dementia, in particular larger phase 3 trials. Importantly within these studies, it would be useful to describe the interventions in more detail and to understand which aspects of the interventions are used more than others and provide the most benefit. Future research should also focus on which aspects of the interventions are most beneficial for different groups—for example, adult children compared with spouses—and how the interventions can best be delivered to address issues such as the digital divide. Future research would

also benefit from including theoretical considerations of how interventions are thought to provide support to caregivers.

This review identified a gap in the development of interventions targeting specific stages of the dementia trajectory. Many of the interventions in this review were broad and generic to the entire dementia trajectory. However, the needs of family caregivers vary at different stages of the disease and transition points; for example, around the end of life of the person with dementia, caregivers face specific challenges around decision making and management of difficult symptoms. Future interventions and research should address these different stages when developing digital interventions to support family caregivers [49].

### Strengths and Limitations

Similarly to previous reviews in this area [15-17], comparison between studies was difficult, as the interventions used were complex and varied, with wide-ranging study designs and outcome measures. The review was also limited by the quality of some of the studies and the methods employed. There were relatively few RCTs from which to derive effectiveness data. Many of the studies were feasibility and pilot studies, so we were unable to draw definitive conclusions surrounding effectiveness and acceptability. For many of the studies, there were high levels of dropouts and for some interventions participants made limited use of some of the components of the interventions, therefore making it difficult to draw conclusions [46,49]. Few studies provided information on the effectiveness of individual components of the interventions, and some studies explored only usefulness and usability with reference to the

design and layout of the interventions, which on the whole were not well described. This is helpful only to an extent because, to develop or build on existing interventions, there needs to be an understanding of which elements have a positive effect on family caregivers and so should be included in new interventions.

Our literature search was limited by including only peer-reviewed publications, and there may have been several other interventions that were being practically used and applied but not published via academic routes. However, the search of the academic literature was thorough and we used a rigorous search strategy, updated before publication.

This review has built on previous literature by identifying the core components of interventions for family caregivers, which will be useful for future intervention development. As our inclusion criteria were much more comprehensive, this review provides a larger evidence base than previous reviews. Unlike previous reviews, we have particularly considered how caregivers are supported with decision making through Web-based interventions and we included data from many qualitative studies, providing richer information on how the interventions were perceived and valued by caregivers.

### Conclusions

The evidence base for internet-based interventions for caregivers of people with dementia remains limited. Although this review recognizes that for some caregivers, a face-to-face intervention may be preferred, our findings highlight the promising potential of digital interventions to support caregivers, which warrants further development and testing.

---

### Acknowledgments

This work was supported by the UK National Institute for Health Research School for Primary Care Research (NIHR SPCR) FR11 and Capacity Award 6 programs. This paper presents independent research funded by the NIHR. The views expressed are those of the authors and not necessarily those of the UK National Health Service, the NIHR, or the UK Department of Health and Social Care.

---

### Conflicts of Interest

None declared.

---

### Multimedia Appendix 1

MEDLINE search terms and strategy.

[\[PDF File \(Adobe PDF File\), 24KB-Multimedia Appendix 1\]](#)

---

### Multimedia Appendix 2

Characteristics, components, outcomes, and key findings of randomized controlled trials.

[\[PDF File \(Adobe PDF File\), 47KB-Multimedia Appendix 2\]](#)

---

### Multimedia Appendix 3

Characteristics, components, outcomes, and key findings of quasi-experimental (pre-post) studies.

[\[PDF File \(Adobe PDF File\), 42KB-Multimedia Appendix 3\]](#)

---

### Multimedia Appendix 4

Characteristics, components, outcomes, and key findings of qualitative studies.



[\[PDF File \(Adobe PDF File\), 27KB-Multimedia Appendix 4\]](#)

## Multimedia Appendix 5

Characteristics, components, outcomes, and key findings of mixed-methods and other methods studies.

[\[PDF File \(Adobe PDF File\), 65KB-Multimedia Appendix 5\]](#)

## References

1. Cuijpers P. Depressive disorders in caregivers of dementia patients: a systematic review. *Aging Ment Health* 2005 Jul;9(4):325-330. [doi: [10.1080/13607860500090078](https://doi.org/10.1080/13607860500090078)] [Medline: [16019288](#)]
2. Kneebone II, Martin PR. Coping and caregivers of people with dementia. *Br J Health Psychol* 2003 Feb;8(Pt 1):1-17. [doi: [10.1348/135910703762879174](https://doi.org/10.1348/135910703762879174)] [Medline: [12643813](#)]
3. Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999 Apr;39(2):177-185. [Medline: [10224714](#)]
4. Alzheimer's Society. Dementia UK update. London, UK: Alzheimer's Society; 2014 Nov. URL:[https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_uk\\_update.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf) [accessed 2018-05-24] [WebCite Cache ID [6zel2XXXKV](#)]
5. Alzheimer's Society. Carer support. 2013. URL:<https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/carers-support> [accessed 2018-02-14] [WebCite Cache ID [6xE0DR7ht](#)]
6. Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, et al. Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMJ* 2013 Oct 25;347:f6276 [FREE Full text] [Medline: [24162942](#)]
7. Corbett A, Stevens J, Aarsland D, Day S, Moniz-Cook E, Woods R, et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *Int J Geriatr Psychiatry* 2012 Jun;27(6):628-636. [doi: [10.1002/gps.2762](https://doi.org/10.1002/gps.2762)] [Medline: [22038644](#)]
8. Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatr* 2007;7:18 [FREE Full text] [doi: [10.1186/1471-2318-7-18](https://doi.org/10.1186/1471-2318-7-18)] [Medline: [17662119](#)]
9. Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *J Affect Disord* 2007 Aug;101(1-3):75-89. [doi: [10.1016/j.jad.2006.10.025](https://doi.org/10.1016/j.jad.2006.10.025)] [Medline: [17173977](#)]
10. Beesley L. Informal care in England. London, UK: The King's Fund; 2006. URL:<https://www.kingsfund.org.uk/sites/default/files/informal-care-england-wanless-background-paper-lucinda-beesley2006.pdf> [accessed 2018-05-29] [WebCite Cache ID [6zelDHwCU](#)]
11. Brodaty H, Thomson C, Thompson C, Fine M. Why caregivers of people with dementia and memory loss don't use services. *Int J Geriatr Psychiatry* 2005 Jun;20(6):537-546. [doi: [10.1002/gps.1322](https://doi.org/10.1002/gps.1322)] [Medline: [15920707](#)]
12. Serafini JD, Damianakis T, Marziali E. Clinical practice standards and ethical issues applied to a virtual group intervention for spousal caregivers of people with Alzheimer's. *Soc Work Health Care* 2007;44(3):225-243. [doi: [10.1300/J010v44n03\\_07](https://doi.org/10.1300/J010v44n03_07)] [Medline: [17548277](#)]
13. Heo J, Chun S, Lee S, Lee KH, Kim J. Internet use and well-being in older adults. *Cyberpsychol Behav Soc Netw* 2015 May;18(5):268-272. [doi: [10.1089/cyber.2014.0549](https://doi.org/10.1089/cyber.2014.0549)] [Medline: [25919967](#)]
14. Milligan C, Passey D. Ageing and the Use of the Internet - Current Engagement and Future Needs: State-of-the-Art Report. Lancaster, UK: University of Lancaster; 2011.
15. Boots LMM, de Vugt ME, van Knippenberg RJM, Kempen GIJM, Verhey FRJ. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014 Apr;29(4):331-344. [doi: [10.1002/gps.4016](https://doi.org/10.1002/gps.4016)] [Medline: [23963684](#)]
16. McKechnie V, Barker C, Stott J. Effectiveness of computer-mediated interventions for informal carers of people with dementia-a systematic review. *Int Psychogeriatr* 2014 Oct;26(10):1619-1637 [FREE Full text] [doi: [10.1017/S1041610214001045](https://doi.org/10.1017/S1041610214001045)] [Medline: [24989249](#)]
17. Powell J, Chiu T, Eysenbach G. A systematic review of networked technologies supporting carers of people with dementia. *J Telemed Telecare* 2008;14(3):154-156. [doi: [10.1258/jtt.2008.003018](https://doi.org/10.1258/jtt.2008.003018)] [Medline: [18430288](#)]
18. Centre for Reviews and Dissemination. Systematic reviews: CRD's guidance for undertaking reviews in health care. York, UK: Centre for Reviews and Dissemination, University of York; 2009. URL:[https://www.york.ac.uk/media/crd/Systematic\\_Reviews.pdf](https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf) [accessed 2018-05-24] [WebCite Cache ID [6zelYyI2G](#)]
19. Critical Appraisal Skills Programme. CASP qualitative checklist. 2017. URL:[http://docs.wixstatic.com/ugd/dded87\\_25658615020e427da194a325e7773d42.pdf](http://docs.wixstatic.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf) [accessed 2018-02-14] [WebCite Cache ID [6xDz3wBsA](#)]
20. Critical Appraisal Skills Programme. CASP Randomised Controlled Trial Checklist. 2017. URL:[http://docs.wixstatic.com/ugd/dded87\\_4239299b39f647ca9961f30510f52920.pdf](http://docs.wixstatic.com/ugd/dded87_4239299b39f647ca9961f30510f52920.pdf) [accessed 2018-02-14] [WebCite Cache ID [6xDz89ZeG](#)]

21. Critical Appraisal Skills Programme. Critical Appraisal Skills Programme 2017. 2017. URL:<http://www.casp-uk.net/casp-tools-checklists> [accessed 2018-03-01] [WebCite Cache ID 6xb7GYWHW]
22. Bass DM, McClendon MJ, Brennan PF, McCarthy C. The buffering effect of a computer support network on caregiver strain. *J Aging Health* 1998 Feb;10(1):20-43. [doi: [10.1177/089826439801000102](https://doi.org/10.1177/089826439801000102)] [Medline: [10182416](https://pubmed.ncbi.nlm.nih.gov/10182416/)]
23. Beauchamp N, Irvine AB, Seeley J, Johnson B. Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist* 2005 Dec;45(6):793-801. [Medline: [16326661](https://pubmed.ncbi.nlm.nih.gov/16326661/)]
24. Blom MM, Zarit SH, Groot ZRBM, Cuijpers P, Pot AM. Effectiveness of an Internet intervention for family caregivers of people with dementia: results of a randomized controlled trial. *PLoS One* 2015;10(2):e0116622 [FREE Full text] [doi: [10.1371/journal.pone.0116622](https://doi.org/10.1371/journal.pone.0116622)] [Medline: [25679228](https://pubmed.ncbi.nlm.nih.gov/25679228/)]
25. Fowler CN, Kott K, Wicks MN, Rutledge C. An interprofessional virtual healthcare neighborhood: effect on self-efficacy and sleep among caregivers of older adults with dementia. *J Gerontol Nurs* 2016 Nov 01;42(11):39-47. [doi: [10.3928/00989134-20160901-02](https://doi.org/10.3928/00989134-20160901-02)] [Medline: [27598270](https://pubmed.ncbi.nlm.nih.gov/27598270/)]
26. Hattink B, Meiland F, van der Roest H, Kevern P, Abiuso F, Bengtsson J, et al. Web-based STAR e-learning course increases empathy and understanding in dementia caregivers: results from a randomized controlled trial in the Netherlands and the United Kingdom. *J Med Internet Res* 2015;17(10):e241 [FREE Full text] [doi: [10.2196/jmir.4025](https://doi.org/10.2196/jmir.4025)] [Medline: [26519106](https://pubmed.ncbi.nlm.nih.gov/26519106/)]
27. Hicken BL, Daniel C, Luptak M, Grant M, Kilian S, Rupper RW. Supporting Caregivers of Rural Veterans Electronically (SCORE). *J Rural Health* 2017 Jun;33(3):305-313. [doi: [10.1111/jrh.12195](https://doi.org/10.1111/jrh.12195)] [Medline: [27437642](https://pubmed.ncbi.nlm.nih.gov/27437642/)]
28. Kajiyama B, Thompson LW, Eto-Iwase T, Yamashita M, Di Mario J, Marian TY, et al. Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program. *Aging Ment Health* 2013;17(5):544-554 [FREE Full text] [doi: [10.1080/13607863.2013.775641](https://doi.org/10.1080/13607863.2013.775641)] [Medline: [23461355](https://pubmed.ncbi.nlm.nih.gov/23461355/)]
29. Núñez-Naveira L, Alonso-Búa B, de Labra C, Gregersen R, Maibom K, Mojs E, et al. UnderstAID, an ICT platform to help informal caregivers of people with dementia: a pilot randomized controlled study. *Biomed Res Int* 2016;2016:5726465 [FREE Full text] [doi: [10.1155/2016/5726465](https://doi.org/10.1155/2016/5726465)] [Medline: [28116300](https://pubmed.ncbi.nlm.nih.gov/28116300/)]
30. Van Mierlo LD, Meiland FJM, Van de Ven PM, Van Hout HPJ, Dröes R. Evaluation of DEM-DISC, customized e-advice on health and social support services for informal carers and case managers of people with dementia; a cluster randomized trial. *Int Psychogeriatr* 2015 Aug;27(8):1365-1378. [doi: [10.1017/S1041610215000423](https://doi.org/10.1017/S1041610215000423)] [Medline: [25872457](https://pubmed.ncbi.nlm.nih.gov/25872457/)]
31. Davis B, Shehab M, Shenk D, Nies M. E-mobile pilot for community-based dementia caregivers identifies desire for security. *Gerontechnology* 2015;13(3):332-336. [doi: [10.4017/gt.2015.13.3.003.00](https://doi.org/10.4017/gt.2015.13.3.003.00)]
32. Glueckauf RL, Ketterson TU, Loomis JS, Dages P. Online support and education for dementia caregivers: overview, utilization, and initial program evaluation. *Telemed J E Health* 2004;10(2):223-232. [Medline: [15319052](https://pubmed.ncbi.nlm.nih.gov/15319052/)]
33. Griffiths PC, Kovaleva M, Higgins M, Langston AH, Hepburn K. Tele-Savvy: an online program for dementia caregivers. *Am J Alzheimers Dis Other Demen* 2018 Jan 01;1533317518755331. [doi: [10.1177/1533317518755331](https://doi.org/10.1177/1533317518755331)] [Medline: [29544342](https://pubmed.ncbi.nlm.nih.gov/29544342/)]
34. Kajiyama B, Fernandez G, Carter EA, Humber MB, Thompson LW. Helping Hispanic dementia caregivers cope with stress using technology-based resources. *Clin Gerontol* 2018;41(3):209-216. [doi: [10.1080/07317115.2017.1377797](https://doi.org/10.1080/07317115.2017.1377797)] [Medline: [29236621](https://pubmed.ncbi.nlm.nih.gov/29236621/)]
35. Kwok T, Au A, Wong B, Ip I, Mak V, Ho F. Effectiveness of online cognitive behavioral therapy on family caregivers of people with dementia. *Clin Interv Aging* 2014;9:631-636 [FREE Full text] [doi: [10.2147/CIA.S56337](https://doi.org/10.2147/CIA.S56337)] [Medline: [24748781](https://pubmed.ncbi.nlm.nih.gov/24748781/)]
36. Lorig K, Thompson-Gallagher D, Traylor L, Ritter P, Laurent D, Plant K. Building better caregivers: a pilot online support workshop for family caregivers of cognitively impaired adults. *J Appl Gerontol* 2013;31(3):423-437. [doi: [10.1177/0733464810389806](https://doi.org/10.1177/0733464810389806)]
37. van der Roest HG, Meiland FJM, Jonker C, Dröes R. User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness. *Aging Ment Health* 2010 May;14(4):461-470. [doi: [10.1080/13607860903311741](https://doi.org/10.1080/13607860903311741)] [Medline: [20455122](https://pubmed.ncbi.nlm.nih.gov/20455122/)]
38. Kovaleva M, Blevins L, Griffiths PC, Hepburn K. An online program for caregivers of persons living with dementia: lessons learned. *J Appl Gerontol* 2017 Apr 01;733464817705958. [doi: [10.1177/0733464817705958](https://doi.org/10.1177/0733464817705958)] [Medline: [28460557](https://pubmed.ncbi.nlm.nih.gov/28460557/)]
39. Marziali E, Donahue P, Crossin G. Caring for others: internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's disease. *Fam Soc* 2018 May 03;86(3):375-383. [doi: [10.1606/1044-3894.3435](https://doi.org/10.1606/1044-3894.3435)]
40. Marziali E, Damianakis T, Donahue P. Internet-based clinical services: virtual support groups for family caregivers. *J Technol Hum Serv* 2006 Jul 18;24(2-3):39-54. [doi: [10.1300/J017v24n02\\_03](https://doi.org/10.1300/J017v24n02_03)]
41. Span M, Smits C, Jukema J, Groen-van de Ven L, Janssen R, Vernooij-Dassen M, et al. An interactive web tool for facilitating shared decision-making in dementia-care networks: a field study. *Front Aging Neurosci* 2015;7:128 [FREE Full text] [doi: [10.3389/fnagi.2015.00128](https://doi.org/10.3389/fnagi.2015.00128)] [Medline: [26217221](https://pubmed.ncbi.nlm.nih.gov/26217221/)]
42. Austrom MG, Geros KN, Hemmerlein K, McGuire SM, Gao S, Brown SA, et al. Use of a multiparty web based videoconference support group for family caregivers: innovative practice. *Dementia (London)* 2015 Sep;14(5):682-690 [FREE Full text] [doi: [10.1177/1471301214544338](https://doi.org/10.1177/1471301214544338)] [Medline: [25062788](https://pubmed.ncbi.nlm.nih.gov/25062788/)]

43. Boots LM, de Vugt ME, Smeets CM, Kempen GI, Verhey FR. Implementation of the blended care self-management program for caregivers of people with early-stage dementia (Partner in Balance): process evaluation of a randomized controlled trial. *J Med Internet Res* 2017 Dec 19;19(12):e423 [FREE Full text] [doi: [10.2196/jmir.7666](https://doi.org/10.2196/jmir.7666)] [Medline: [29258980](https://pubmed.ncbi.nlm.nih.gov/29258980/)]
44. Boots LM, de Vugt ME, Withagen HE, Kempen GI, Verhey FR. Development and initial evaluation of the internet-based self-management intervention 'Partner in Balance' for spousal caregivers of people with early-stage dementia. *JMIR Res Protoc* 2016 Mar 01;5(1):e33 [FREE Full text] [doi: [10.2196/resprot.5142](https://doi.org/10.2196/resprot.5142)] [Medline: [26932438](https://pubmed.ncbi.nlm.nih.gov/26932438/)]
45. Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nurs Res* 1995;44(3):166-172. [Medline: [7761293](https://pubmed.ncbi.nlm.nih.gov/7761293/)]
46. Chiu T, Marziali E, Colantonio A, Carswell A, Gruneir M, Tang M, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with alzheimer disease and related dementia. *Can J Aging* 2009 Dec;28(4):323-336. [doi: [10.1017/S0714980809990158](https://doi.org/10.1017/S0714980809990158)] [Medline: [19925698](https://pubmed.ncbi.nlm.nih.gov/19925698/)]
47. Cristancho-Lacroix V, Wrobel J, Cantegreil-Kallen I, Dub T, Rouquette A, Rigaud A. A web-based psychoeducational program for informal caregivers of patients with Alzheimer's disease: a pilot randomized controlled trial. *J Med Internet Res* 2015;17(5):e117 [FREE Full text] [doi: [10.2196/jmir.3717](https://doi.org/10.2196/jmir.3717)] [Medline: [25967983](https://pubmed.ncbi.nlm.nih.gov/25967983/)]
48. Dam AEH, van Boxtel MPJ, Rozendaal N, Verhey FRJ, de Vugt ME. Development and feasibility of Inlife: a pilot study of an online social support intervention for informal caregivers of people with dementia. *PLoS One* 2017;12(9):e0183386 [FREE Full text] [doi: [10.1371/journal.pone.0183386](https://doi.org/10.1371/journal.pone.0183386)] [Medline: [28886056](https://pubmed.ncbi.nlm.nih.gov/28886056/)]
49. Hattink B, Droes R, Sikkes S, Oostra E, Lemstra AW. Evaluation of the Digital Alzheimer Center: testing usability and usefulness of an online portal for patients with dementia and their carers. *JMIR Res Protoc* 2016 Jul 21;5(3):e144 [FREE Full text] [doi: [10.2196/resprot.5040](https://doi.org/10.2196/resprot.5040)] [Medline: [27444209](https://pubmed.ncbi.nlm.nih.gov/27444209/)]
50. Jajor J, Rosofek M, Skorupska E, Krawczyk-Wasielewska A, Lisi ski P, Mojs E. UnderstAID - a platform that helps informal caregivers to understand and aid their demented relatives - assessment of informal caregivers - a pilot study. *J Med Sci* 2016;84(4):229-234 [FREE Full text]
51. Lewis ML, Hobday JV, Hepburn KW. Internet-based program for dementia caregivers. *Am J Alzheimers Dis Other Demen* 2010 Dec;25(8):674-679. [doi: [10.1177/1533317510385812](https://doi.org/10.1177/1533317510385812)] [Medline: [21131674](https://pubmed.ncbi.nlm.nih.gov/21131674/)]
52. Marziali E, Donahue P. Caring for others: internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist* 2006 Jun;46(3):398-403 [FREE Full text] [Medline: [16731880](https://pubmed.ncbi.nlm.nih.gov/16731880/)]
53. Marziali E, Garcia LJ. Dementia caregivers' responses to 2 Internet-based intervention programs. *Am J Alzheimers Dis Other Demen* 2011 Feb;26(1):36-43. [doi: [10.1177/1533317510387586](https://doi.org/10.1177/1533317510387586)] [Medline: [21282276](https://pubmed.ncbi.nlm.nih.gov/21282276/)]
54. McKechnie V, Barker C, Stott J. The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study. *J Med Internet Res* 2014;16(2):e68 [FREE Full text] [doi: [10.2196/jmir.3166](https://doi.org/10.2196/jmir.3166)] [Medline: [24583789](https://pubmed.ncbi.nlm.nih.gov/24583789/)]
55. O'Connor M, Arizmendi BJ, Kaszniak AW. Virtually supportive: a feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment. *J Aging Stud* 2014 Aug;30:87-93 [FREE Full text] [doi: [10.1016/j.jaging.2014.03.001](https://doi.org/10.1016/j.jaging.2014.03.001)] [Medline: [24984911](https://pubmed.ncbi.nlm.nih.gov/24984911/)]
56. Pagán-Ortiz ME, Cortés DE, Rudloff N, Weitzman P, Levkoff S. Use of an online community to provide support to caregivers of people with dementia. *J Gerontol Soc Work* 2014;57(6-7):694-709 [FREE Full text] [doi: [10.1080/01634372.2014.901998](https://doi.org/10.1080/01634372.2014.901998)] [Medline: [24689359](https://pubmed.ncbi.nlm.nih.gov/24689359/)]
57. Pot AM, Blom MM, Willemsse BM. Acceptability of a guided self-help Internet intervention for family caregivers: mastery over dementia. *Int Psychogeriatr* 2015 Aug;27(8):1343-1354. [doi: [10.1017/S1041610215000034](https://doi.org/10.1017/S1041610215000034)] [Medline: [25648589](https://pubmed.ncbi.nlm.nih.gov/25648589/)]
58. Rentz M, Von Hoene A. Online coaching for caregivers: using technology to provide support and information. *Alzheimer's Care Today* 2010;11(3):206-209. [doi: [10.1097/ACQ.0b013e3181ebc878](https://doi.org/10.1097/ACQ.0b013e3181ebc878)]
59. Schaller S, Marinova-Schmidt V, Gobin J, Criegee-Rieck M, Griebel L, Engel S, et al. Tailored e-Health services for the dementia care setting: a pilot study of 'eHealthMonitor'. *BMC Med Inform Decis Mak* 2015 Jul 28;15:58 [FREE Full text] [doi: [10.1186/s12911-015-0182-2](https://doi.org/10.1186/s12911-015-0182-2)] [Medline: [26215731](https://pubmed.ncbi.nlm.nih.gov/26215731/)]
60. Schaller S, Marinova-Schmidt V, Setzer M, Kondylakis H, Griebel L, Sedlmayr M, et al. Usefulness of a tailored ehealth service for informal caregivers and professionals in the dementia treatment and care setting: the eHealthMonitor Dementia Portal. *JMIR Res Protoc* 2016 Apr 05;5(2):e47 [FREE Full text] [doi: [10.2196/resprot.4354](https://doi.org/10.2196/resprot.4354)] [Medline: [27050401](https://pubmed.ncbi.nlm.nih.gov/27050401/)]
61. Weitzman P, Neal L, Chen H, Levkoff SE. Designing a culturally attuned bilingual educational website for US Latino dementia caregivers. *Ageing Int* 2008 Feb 28;32(1):15-24. [doi: [10.1007/s12126-008-9000-9](https://doi.org/10.1007/s12126-008-9000-9)]
62. von Winterfeldt D, Edwards W. *Decision Analysis and Behavioral Research*. Cambridge, UK: Cambridge University Press; 1986.
63. Sum S, Mathews RM, Hughes I, Campbell A. Internet use and loneliness in older adults. *Cyberpsychol Behav* 2008 Apr;11(2):208-211. [doi: [10.1089/cpb.2007.0010](https://doi.org/10.1089/cpb.2007.0010)] [Medline: [18422415](https://pubmed.ncbi.nlm.nih.gov/18422415/)]
64. Tsai H, Tsai Y. Changes in depressive symptoms, social support, and loneliness over 1 year after a minimum 3-month videoconference program for older nursing home residents. *J Med Internet Res* 2011;13(4):e93 [FREE Full text] [doi: [10.2196/jmir.1678](https://doi.org/10.2196/jmir.1678)] [Medline: [22086660](https://pubmed.ncbi.nlm.nih.gov/22086660/)]
65. Chang E, Easterbrook S, Hancock K, Johnson A, Davidson P. Evaluation of an information booklet for caregivers of people with dementia: an Australian perspective. *Nurs Health Sci* 2010 Mar;12(1):45-51. [doi: [10.1111/j.1442-2018.2009.00486.x](https://doi.org/10.1111/j.1442-2018.2009.00486.x)] [Medline: [20487325](https://pubmed.ncbi.nlm.nih.gov/20487325/)]

66. Davies N, Maio L, Rait G, Iliffe S. Quality end-of-life care for dementia: what have family carers told us so far? A narrative synthesis. *Palliat Med* 2014 Jul;28(7):919-930 [FREE Full text] [doi: [10.1177/0269216314526766](https://doi.org/10.1177/0269216314526766)] [Medline: [24625567](https://pubmed.ncbi.nlm.nih.gov/24625567/)]
67. Hirschman KB, Kapo JM, Karlawish JHT. Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person? *Am J Geriatr Psychiatry* 2006 Aug;14(8):659-667. [doi: [10.1097/01.JGP.0000203179.94036.69](https://doi.org/10.1097/01.JGP.0000203179.94036.69)] [Medline: [16861370](https://pubmed.ncbi.nlm.nih.gov/16861370/)]
68. Caron CD, Griffith J, Arcand M. End-of-life decision making in dementia. *Dementia* 2016 Jul 26;4(1):113-136. [doi: [10.1177/1471301205049193](https://doi.org/10.1177/1471301205049193)]
69. Mezey M, Kluger M, Maislin G, Mittelman M. Life-sustaining treatment decisions by spouses of patients with Alzheimer's disease. *J Am Geriatr Soc* 1996 Feb;44(2):144-150. [Medline: [8576503](https://pubmed.ncbi.nlm.nih.gov/8576503/)]
70. Davies S, Nolan M. 'Making the best of things': relatives' experiences of decisions about care-home entry. *Ageing Soc* 2003 Jun 25;23(04):429-450. [doi: [10.1017/S0144686X03001259](https://doi.org/10.1017/S0144686X03001259)]
71. Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? *Soc Sci Med* 2007 May;64(9):1853-1862. [doi: [10.1016/j.socscimed.2007.01.012](https://doi.org/10.1016/j.socscimed.2007.01.012)] [Medline: [17328998](https://pubmed.ncbi.nlm.nih.gov/17328998/)]
72. Murray E, Hekler EB, Andersson G, Collins LM, Doherty A, Hollis C, et al. Evaluating digital health interventions: key questions and approaches. *Am J Prev Med* 2016 Nov;51(5):843-851. [doi: [10.1016/j.amepre.2016.06.008](https://doi.org/10.1016/j.amepre.2016.06.008)] [Medline: [27745684](https://pubmed.ncbi.nlm.nih.gov/27745684/)]
73. Bernhardt JM. Health education and the digital divide: building bridges and filling chasms. *Health Educ Res* 2000 Oct;15(5):527-531. [Medline: [11184212](https://pubmed.ncbi.nlm.nih.gov/11184212/)]

## Abbreviations

**RCT:** randomized controlled trial

*Edited by G Eysenbach; submitted 01.12.17; peer-reviewed by K Harrison-Dening, C Callahan, Y Hu, R Pankomera; comments to author 11.01.18; revised version received 02.03.18; accepted 08.05.18; published 12.06.18*

*Please cite as:*

*Hopwood J, Walker N, McDonagh L, Rait G, Walters K, Iliffe S, Ross J, Davies N*

*Internet-Based Interventions Aimed at Supporting Family Caregivers of People With Dementia: Systematic Review*

*J Med Internet Res* 2018;20(6):e216

URL: <http://www.jmir.org/2018/6/e216/>

doi: [10.2196/jmir.9548](https://doi.org/10.2196/jmir.9548)

PMID: [29895512](https://pubmed.ncbi.nlm.nih.gov/29895512/)

©Jenny Hopwood, Nina Walker, Lorraine McDonagh, Greta Rait, Kate Walters, Stephen Iliffe, Jamie Ross, Nathan Davies. Originally published in the *Journal of Medical Internet Research* (<http://www.jmir.org>), 12.06.2018. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the *Journal of Medical Internet Research*, is properly cited. The complete bibliographic information, a link to the original publication on <http://www.jmir.org/>, as well as this copyright and license information must be included.