

Featured Article

The effects of information and communication technologies on informal caregivers of persons living with dementia: A systematic review

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Abstract

Introduction: Information and communication technology (ICT) has emerged as promising to support health care consumers, including informal caregivers. This systematic review seeks to evaluate the state of the science of ICT interventions on the health of informal dementia caregivers.

Methods: We searched PubMed, CINAHL, Web of Science, and PsycINFO using concepts associated with ICT, dementia, and caregiver. Studies were assessed using the Quality Assessment Tool for Quantitative Studies.

Results: We identified 657 full-text publications. After removal of duplicates and title, abstract, and full-text screening, the quality of 12 studies was assessed. Studies varied in technology, implementation, results, and intervention evaluation.

Discussion: The methodological quality of the ICT intervention studies among dementia family caregivers was moderate to strong, yet outcome measurement was not uniform. The evidence is strongest for various forms of telephone-based interventions. However, there is a need for research that includes heterogeneous participants based on gender, race, and ethnicity.

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Keywords:

Information and communication technology; Informal dementia caregivers; Systematic review; Interventions; Randomized controlled trial

1. Introduction

Dementia is a major health problem, affecting an estimated 5.5 million Americans [1]. Up to 75% of people living with dementia in the United States are cared for by family members in their homes [2]. The Alzheimer's Association

estimates that more than 15 million Americans are caring for family members suffering from dementia, providing an estimated 18 billion hours of unpaid care each year [1]. Providing care for an individual with dementia is challenging, and the detrimental effects of dementia caregiving on physical and mental health are well documented [1–3]. Dementia caregiver burden can adversely impact physical health, with 35% of dementia caregivers reporting that their health has deteriorated due to care responsibilities [1]. Evidence suggests that dementia caregivers have higher

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levels of depression, anxiety, and other mood disorders compared with caregivers of older adults without dementia [2,3]. Dementia caregiving is also associated with family conflict and a decrease in social support and social interaction for the caregiver [4].

Information and communication technology (ICT) has emerged as a promising mode of intervention to support health care consumers, including dementia caregivers. Information and communication technology consists of digital and analog technologies, including hardware, software, networks, and media, that facilitate collecting, capturing, storing, processing, transmitting, exchanging, and presenting information, and/or communication [5–7]. ICT interventions can improve decision confidence, reduce emotional strain, improve spousal relationship conflict, decrease activity restriction, increase self-efficacy, and decrease caregiver burden [5–10].

Researchers have demonstrated that technology-based interventions can improve outcomes among people living with chronic disease [11,12]. In a systematic review that assessed the effectiveness of mobile technology interventions, the evidence suggests benefits for particular conditions including reduction of viral load among people living with HIV and increased perceived self-care agency in lung transplant patients [11]. It is less clear whether findings of the use of mobile technology interventions are clinically meaningful in other domains, such as diabetes, dieting, vaccine appointment attendance, cardiopulmonary resuscitation training, asthma control, physical activity, and psychological support, because of its small effects on these outcomes. A meta-analysis of the effectiveness of web-based interventions compared with non-web-based interventions on behavioral outcomes revealed improvements in outcomes for users of web-based interventions with chronic conditions [12]. Specifically, the evidence points to the effectiveness of web-based interventions to increase exercise time, knowledge of nutritional status, knowledge of asthma treatment, and participation in health care; slower health decline; improved body shape perception; and 18-month weight loss maintenance.

Similarly, ICT interventions have been shown to support effective care coordination through the use of telephone and email communication with dementia caregivers, reducing caregiver strain and depression [13,14]. The Alzheimer's Caregiver Support Online intervention, a web- and telephone-based education and support network, was developed for caregivers of persons with progressive dementia [13]. Participants in the Alzheimer's Caregiver Support Online intervention, which was delivered during six web caregiving classes, reported significant pre- to post-test increases in self-efficacy for obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts about caregiving and improvements in emotional caregiver burden, but little or no change in positive aspects of the caregiving experience or time burden in providing caregiving assistance. Information and communication

technology has been used to provide information, communication, and decision support, as well as to make available disease-specific information, private email, question-and-answer forums, and social support. Information and communication technology has also been used to assist caregivers with managing their health care services encounters and executing healthy behaviors for themselves and a family member with dementia [15].

While research on ICT interventions indicates promising effects, the current state of the evidence has not been systematically evaluated among informal family caregivers of persons living with dementia. We conducted this systematic literature review to evaluate the state of the science surrounding the effects of ICT interventions on the health of informal dementia caregivers. We aimed further to critically appraise the quality of the research and findings for the studies included in this systematic literature review.

2. Methods

2.1. Systematic review protocol

The methods of this systematic review have been developed in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement. We used a standardized protocol to identify randomized controlled trials (RCTs) that evaluated ICT interventions and guide data extraction from these studies for this systematic review. Details of the protocol can be found in [Appendix A](#).

2.2. Criteria for inclusion

We included RCTs of ICT interventions for informal caregivers of persons living with dementia. Informal dementia caregivers include those who are primarily responsible for the well-being of a person living with dementia who requires assistance as a result of mental and/or physical deficits resulting from dementia. Studies were excluded if the person living with dementia was institutionalized, the intervention contained both ICT and non-ICT components, and the caregiver was professional, nonpersonal, or bereaved. Nonpersonal caregivers were defined as those without a prior relationship to the person with dementia. In this systematic review, dementia was identified using the terms dementia, Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies. The dementia could be mild, moderate, or severe. Studies conducted outside of the United States and conducted in languages other than English and Spanish were excluded. We limited studies conducted in the United States because of variation in health care delivery models across countries.

2.3. Selection of studies

We searched PubMed, CINAHL, Web of Science, and PsycINFO using search terms associated with the concepts of ICT, dementia, and caregiver. A detailed list of the terms

harvested in this systematic review can be found in [Appendix B](#). We did not impose date limits. However, this review reflects the latest search through July 2017. We selected studies for appraisal in a two-stage process. First, we searched for RCTs. Then, we searched for systematic reviews to identify RCTs that met the inclusion in this review. We hand-searched references in these review articles to identify studies that may have been missed in the initial search. Two primary reviewers (RW, KL) screened the titles and abstracts found in the initial search to identify potential studies for inclusion in the review. Two secondary reviewers (EAF, AGMP) performed a full-text screening and came to consensus on those studies that met the inclusion criteria. Any uncertainties were resolved through further discussion with comments made by a third reviewer (RJL).

2.4. Data extraction and analysis

Two reviewers (EAF, AGMP) independently recorded key features of each study to identify characteristics of the intervention and its evaluation, with discrepancies resolved by joint review and consensus with the principal investigator (RJL). Reviewers used a data collection form to record information on study author, intervention type, intervention description, who carried out the intervention, intervention

dose, intervention intensity, control group type, dropouts, primary outcomes, and main findings. Studies were categorized based on the main technology that was used for the intervention (e.g., telephone-based) and to facilitate synthesis of the studies.

Two independent reviewers (EAF, AGMP) assessed the quality of the studies included in the review using the Quality Assessment Tool for Quantitative Studies [16]. The Quality Assessment Tool for Quantitative Studies is a reliable and valid instrument that can be used to rate the following criteria: selection bias, study design, confounders, blinding, data collection method, and withdrawals and dropouts. The developers of the Quality Assessment Tool for Quantitative Studies report a Cohen's kappa of 0.74. Each criterion is rated as weak, moderate, or strong. Any differences in quality ratings were clarified with a third reviewer.

3. Results

As illustrated in [Fig. 1](#), the initial search yielded 657 full-text publications with 53 duplicates that were removed. Title and abstract screening resulted in an additional 290 records being excluded (e.g., title and/or abstract did not mention evaluation of an ICT intervention), which resulted in 314 studies being reviewed in full-text for eligibility.

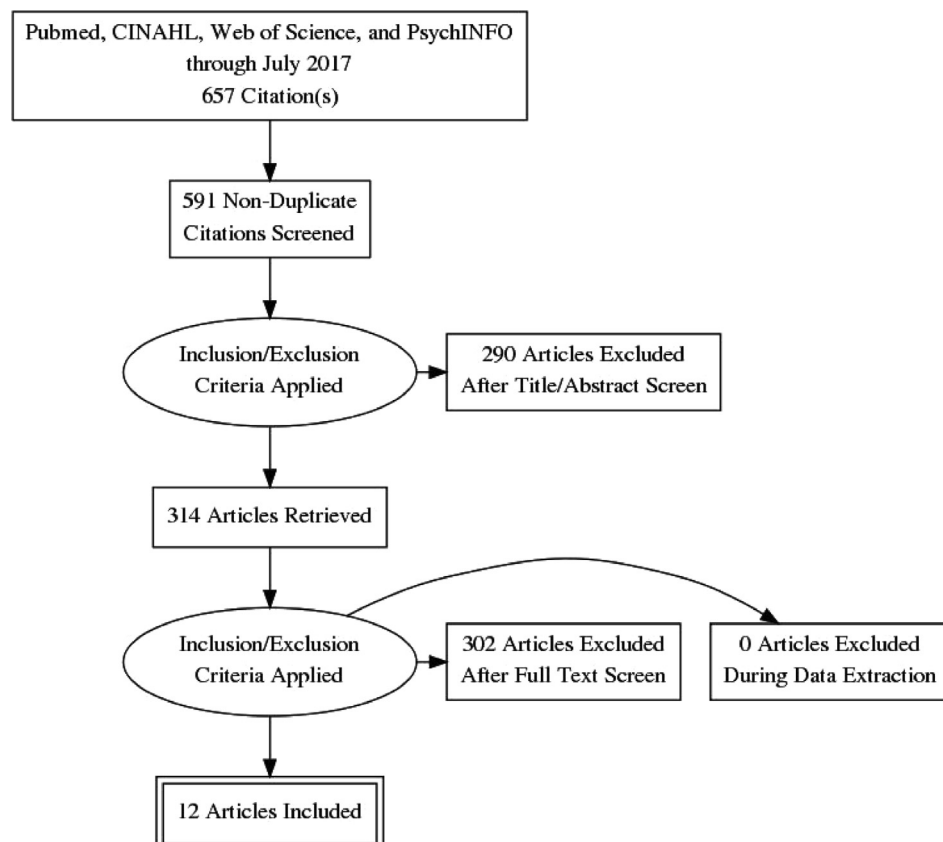


Fig. 1. Flow diagram of the systematic review process.

There were 302 full-text articles excluded based on study inclusion and exclusion criteria and none were removed during data extraction. Data extraction and quality assessments were performed on 12 studies. The 12 RCTs that met our inclusion criteria were aimed at changing 18 caregiving-related outcomes (including outcomes of interest in this review).

3.1. Participant and sample characteristics

Not all of the studies reported the study participant's characteristics (see Table 1) [17,20]. In studies that reported gender [9,18,19,21–27], most participants were female caregivers except in one study that had 100% male caregiver participation [26]. In eight studies that reported race [9,18,19,21–24,27], only white and black race were reported with white caregivers being more than a majority of the participants within each study (i.e., 68.3% to 96.0%). Three of the 14 studies reported ethnicity [18,19,25], including 2% Hispanic in one study, 1.3% Filipino in another study, and 100% Chinese American in a single study.

The type of intervention, the person who carried out the intervention, intervention dose and intensity, and outcome measures varied (see Table 1). Half of the studies evaluated a telephone-based intervention [17–22], four studies tested a video-based intervention [23–26], and the remaining two studies evaluated a computer-based intervention [9,27]. A wide array of individuals, including nurses, social workers, care consultants, behavior change counselors, coaches, and group leaders delivered the intervention in 1 of 6 studies, and therapist delivered the intervention in two studies [20,21]. In four studies [9,18,19,27], the intervention was self-directed and used no interventionist. The intervention dose varied from ad lib intervention self-exposure to daily, weekly, biweekly, and monthly follow-up contacts with an interventionist. The intervention duration ranged from 2 months to 1 year. For studies that reported intervention intensity, telephone-based ranged from 1 minute to 1 hour, video-based included 5- to 90-minute telephone session and multiple video viewings, and computer-based encounters averaged 13 minutes. Of the 12 interventions, ten targeted increasing caregiving support, one aimed to improve caregiver health [24], and one sought to improve caregiver's skills for resource utilization [17]. Most studies reported on a variety of caregiver self-reported emotional and mental health outcome measures, including burden, depression, anxiety, social isolation, relationship strain, satisfaction, decision-making confidence, self-efficacy, personal affect, upset and annoyance, bothersome nature of caregiving, and reactions to problematic behaviors exhibited by the person living with dementia. There were four studies that collected personal and physical health outcome measures; including service utilization, exercise, and self-reported self-care, well-being, and personal gains [17,19,22,24].

3.2. Quality of randomized controlled trials

Inter-rater agreement for two reviewers on the six components of the Quality Assessment Tool for Quantitative Studies was 83.33%. Based on judgment of the raters, four studies were scientifically strong overall (see Table 2) [9,18,21,23]. These four studies reflect diversity in the type of ICT interventions, delivery modes, and dosing and intensity of the interventions. However, the caregiver outcomes measured were similar across the four studies. A closer look at the quality components and ratings of the four studies reveals that the designs and data collection methods were strong in all studies, selection bias was problematic in all studies (i.e., moderate ratings), and blinding was a concern for most studies (i.e., moderate to strong ratings). The five studies that were rated moderately strong overall had one weak component [17,22,23,25,27]. The three weak studies overall had one or two components that were rated as weak [20,24,25].

3.3. Effect of interventions

We categorized the studies into groups based on the technology that was used for the intervention. The three technology groups were telephone-, video-, and computer-based interventions. See Table 1 for detailed descriptions of the studies included in these results.

3.3.1. Telephone-based interventions

Among the twelve studies evaluated, six were telephone-based interventions of which five used an interventionist and one was self-directed. Two studies were scientifically strong overall [18,21]. Three interventions resulted in a significant effect on caregiver-related outcomes and all of these interventions were individual level encounters with interventionists [17,20,21]. Two of the three statistically significant studies aimed to improve coping whereas the other focused on improving utilization of community resources. This was achieved through psychosocial support from a therapist and establishing an individualized plan of care with a care consultant, respectively. The dosing and intensity varied across the three statistically significant interventions. All three studies evaluated the effect of the intervention on multiple caregiver outcomes. In the two studies that used a therapist, the results included a decrease in burden ($P = .01$) [20], depressive symptoms ($P = .003$) [21], and caregiver's reactions to frequency and bother of dementia behaviors ($P = .01$; $P = .009$) [20,21]. In the one study that used care consultants, caregivers decreased service utilization ($P \leq .01$), depression ($P \leq .05$), relationship strain ($P \leq .05$), and had increased satisfaction with managed care ($P \leq .05$) [17].

3.3.2. Video-based interventions

Four studies evaluated primarily video-based interventions, one of which was overall scientifically strong [23].

Table 1

Overview of studies in systematic review of information and communication technology interventions for informal caregivers of persons living with dementia

Study author	Intervention type	N at the baseline, % gender, race/ethnicity in analysis	Intervention description	Who carried out the intervention	Intervention dose (how many times e.g. 1 per week)	Intervention intensity (duration and how long)	Control group type	Drop outs	Primary caregiver outcomes	Main findings
Bass et al., 2003 [17]	Telephone-based	182, % gender and race/ethnicity not reported	Care consultants contacted CGs to establish first contact. Care consultants work with CGs to establish individualized plan of care that can include tasks such as utilizing Alzheimer's Association services. It was then up to CGs.	Care consultants from Alzheimer's Association	Variable, after first session follow-ups ranged from daily to 3-month intervals depending on CG need. Average of 12 contacts in a year.	1 year, duration of sessions not stated.	Usual Care	25	Service utilization, satisfaction with managed care, caregiver depression, care-related strain	Significant decreases in some service utilization (3 of 6 measures—case management visit, direct care community services, non-Alzheimer's Association information and support services), significant increase 3 measures of CG satisfaction with managed care, significant decrease in caregiver depression, significant decrease in relationship strain.
Mahoney et al., 2003 [18]	Telephone-based	100, 80% female, 79% white, 16% black, 2% hispanic, 2% other race/ethnicity	Automated interactive voice response system. The system included numerous support features provided via the telephone including support groups,	Self-directed	Variable, range of 1 to 45 calls with an average of 11 calls over the year.	1 year, duration variable with an average 220 seconds per call. Also, a range of 1-318 minutes and an average of 55 minutes total over the year.	Education materials only	18	Bothersome nature of caregiving, anxiety, depression	No significant differences for the main effects

(Continued)

Table 1

Overview of studies in systematic review of information and communication technology interventions for informal caregivers of persons living with dementia (*Continued*)

Study author	Intervention type	N at the baseline, % gender, race/ethnicity in analysis	Intervention description	Who carried out the intervention	Intervention dose (how many times e.g. 1 per week)	Intervention intensity (duration and how long)	Control group type	Drop outs	Primary caregiver outcomes	Main findings
Martindale-Adams et al., 2013 [19]	Telephone-based	154, 83.75% female, 72.70% white, 29.25% black, 1.3% Filipino	strategies to reduce disruptive behavior, and a distraction call for the care recipient. Telephone-based support groups.	Group leaders	14 sessions over the year. Biweekly for 2 months and then monthly.	1 year, duration of sessions 1 hour.	Education materials only	15	Frequency and bother of dementia behaviors, burden, depression, general well-being	No significant differences
Tremont et al., 2008 [20]	Telephone-based	60, % gender and race/ethnicity not reported	Telephone-based psychosocial intervention to provide support and improve coping.	Therapists	23 sessions over the year. Weekly for six weeks, biweekly for 6 months, monthly for 4 months.	1 year, duration of initial call was approximately 60 minutes, then 15-30 minutes. Total amount of contact over year was approximately 12 hours.	Usual care	27	Burden, frequency and bother of dementia behaviors, depression	Significant decrease in burden and reactions to dementia behaviors
Tremont et al., 2015 [21]	Telephone-based	250, 78% female, 96% white	Telephone-based psychosocial intervention to provide support and improve coping.	Therapists	16 sessions over 6 months. 7 weekly calls, then 9 bi-weekly calls.	6 months, duration of initial call was approximately 60 minutes, then 15-30 minutes.	Attention control	~37.5 (15%)	Depression, burden, frequency and bother of dementia behaviors	Significant decrease in depressive symptoms and reactions to dementia behaviors
Winter et al., 2006 [22]	Telephone-based	103, 100% female, 68.3% white, 31.7% black	Telephone-based support groups.	Social workers	Weekly.	6 months, duration of sessions 1 hour.	Usual care	9	Burden, depression, personal gains	No significant differences in main effects
Chang et al., 1999 [23]	Video-based	87, 100% female, 79.1% white 16.3% black	Videotapes focusing on strategies to improve PWD's dressing and eating skills. Support with	Nurses	Weekly phone calls from a nurse. CG self-reports of viewing videotapes once or twice.	2 months, duration of phone sessions variable with a range of 5-90 minutes and average of 18.3 minutes.	Attention control	22	Burden, satisfaction, anxiety, depression	Significant increase in satisfaction, decrease in depression, decrease in anxiety over time

(Continued)

Table 1

Overview of studies in systematic review of information and communication technology interventions for informal caregivers of persons living with dementia (*Continued*)

Study author	Intervention type	N at the baseline, % gender, race/ethnicity in analysis	Intervention description	Who carried out the intervention	Intervention dose (how many times e.g. 1 per week)	Intervention intensity (duration and how long)	Control group type	Drop outs	Primary caregiver outcomes	Main findings
Connell et al., 2009 [24]	Video-based	157, 100% female, 92.7% white	Exercise intervention for female spouse caregivers of persons with dementia. Intervention included exercise and physical fitness videos and phone sessions from behavior-change counselors.	Behavior-change counselors	Total of 14 calls: Weekly for 2 months, biweekly for 2 months, and monthly for 2 months.	6 months, duration of phone sessions not specified.	Usual Care	20	Exercise, self-efficacy for exercise, self-care, depression, perceived stress, perceived burden	Significant increase in exercise and self-efficacy for exercise and decrease in perceived stress
Gallagher-Thompson et al., 2010 [25]	Video-based	76, 87.14% female, 100% Chinese American	Skill training delivered via DVD to Chinese American caregivers of persons with dementia.	Self-directed	Entire DVD was 2.5 hours: CGs encouraged to watch regularly over the intervention period.	3 months, variable duration with some participants reporting watching DVD multiple times and others reported never completing DVD.	Education materials only	6	Frequency and bother of dementia behaviors, positive affect	Significant decrease in dementia behaviors and increase in positive affect
Gant et al., 2007 [26]	Video-based	32, 100% male, race/ethnicity not reported	10 videos and weekly telephone coaching sessions. Intervention targeted male caregivers.	Coaches	Weekly phone calls.	3 months, duration of coaching calls not reported.	Attention control	4	Upset and annoyance, self-efficacy, positive and negative affect	No significant differences between groups over time

(Continued)

Table 1
 Overview of studies in systematic review of information and communication technology interventions for informal caregivers of persons living with dementia (*Continued*)

Study author	Intervention type	N at the baseline, % gender, race/ethnicity in analysis	Intervention description	Who carried out the intervention	Intervention dose (how many times e.g. 1 per week)	Intervention intensity (duration and how long)	Control group type	Drop outs	Primary caregiver outcomes	Main findings
Brennan et al., 1995 [9]	Computer-based	102, 67% female, 72% white	ComputerLink system that was available for CGs to access at any time. System provided educational information, decision support, and communication features for communication between CGs. Communication boards were also monitored by a nurse who would respond to messages.	Self-directed	Variable, average 2 encounters each week.	1 year, duration of sessions variable with an average of 13 minutes.	Education control-one time training experience to identify local resources	6	Confidence in decision-making, decision-making skill, social isolation	Significantly improved decision-making confidence
Kajiyama et al., 2013 [19]	Computer-based	150, 84% female, 89% white 14% other	Internet based program with eight components consisting of embedded educational video clips.	Self-directed	CGs Encouraged to spend 7 to 10 days on each module. Website accessed an average of 6.42 times per month.	3 months, variable duration (specifics not reported).	Education materials only	47	Stress	Significant decrease in stress

NOTE. All interventions took place in the home. Attention control indicates that phone calls were received.

Table 2
Studies included for Evaluation of Quality Assessment Components and Ratings

Author by intervention type	Evaluation components and ratings														Adjusted global rating*
	A		B		C		D		E		F		Initial global rating*		
	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	
Telephone-based															
Bass et al., 2003 [17]	2	2	1	1	3	3	2	2	1	1	1	1	2	2	2
Mahoney et al., 2003 [18]	2	2	1	1	1	1	1	2	1	1	1	1	1	1	1
Martindale-Adams et al., 2013 [19]	3	3	1	1	1	1	2	2	1	1	1	1	2	2	2
Tremont et al., 2008 [20]	3	3	1	1	1	1	2	2	1	1	3	3	3	3	3
Tremont et al., 2015 [21]	2	2	1	1	1	1	2	2	1	1	1	1	1	1	1
Winter et al., 2006 [22]	3	3	1	1	1	1	2	2	1	1	2	1	2	2	2
Video-based															
Chang et al., 1999 [23]	2	2	1	1	1	1	2	2	1	1	2	2	1	1	1
Connell et al., 2009 [24]	3	3	1	1	3	3	2	2	1	1	1	1	2	3	3
Gallagher-Thompson et al., 2010 [25]	2	2	1	1	3	3	2	2	1	1	1	1	2	3	3
Gant et al., 2007 [26]	3	3	1	1	1	1	1	2	1	1	1	2	2	2	2
Computer-based															
Brennan et al., 1995 [9]	2	2	1	1	1	1	2	2	1	1	1	1	1	1	1
Kajiyama et al., 2013 [27]	3	3	1	1	1	1	2	2	1	1	2	2	2	2	2

NOTE. A: selection bias, B: study design, C: confounders, D: blinding, E: data collection methods, F: withdrawals and dropouts; R1 is quality assessment rater 1 and R2 is quality assessment rater 2; 1 = strong, 2 = moderate, 3 = weak.

*Each rater assigned an initial global rating and disagreements were discussed with the principal investigator to determine the adjusted global rating.

The video-based interventions were either stand-alone or had an additional ICT component (e.g., telephone follow-up), and self-directed or delivered by an interventionist. Three interventions had statistically significant effects on seven caregiver outcomes [23–25]. The interventions were targeted at improving caregiver health (i.e., physical fitness) and providing caregiver support (i.e., teaching caregiving strategies for promoting independence of the person living with dementia and coping skills). None of the studies had a prescribed dose, but the intervention duration varied from 2 to 6 months. Three of the four interventions included telephone support throughout the study period. The frequency of telephone contact was only reported in one study. A nurse made weekly support phone calls. The video-only intervention resulted in an increase in positive affect ($P = .01$) and a decrease in the bother of dementia behaviors ($P = .012$) [25]. With the video plus telephone support intervention, caregivers increased their satisfaction ($P = .015$) [23], physical activity ($P < .01$) [24], exercise self-efficacy ($P < .01$) [24], and decreased depression ($P = .02$) [23], anxiety ($P = .01$) [23], and stress ($P < .05$) [24].

3.3.3. Computer-based interventions

We identified two studies that evaluated computer-based interventions. Only one of the studies was scientifically strong overall [9]. Nonetheless, both studies evaluated interventions that had significant effects on caregiver outcomes. The interventions consisted of educational modules and videos, decision support, and communication features. There was no prescribed dose for these self-directed inter-

ventions that lasted 3 months and 1 year. On average, caregivers accessed the interventions six to eight times each month. While the aims of the interventions were alike (i.e., provide caregiver support), the caregiver outcome in Kajiyama's study (2013) was stress, whereas caregiver decision-making confidence and social isolation were the outcomes of Brennan's study (1995). Kajiyama's computer-based intervention had a significant effect ($P = .017$) in decreasing stress, and Brennan's significantly improved decision-making confidence ($P < .01$) but did not affect social isolation ($P = .51$) [9,27].

4. Discussion

Our systematic review of ICT interventions for informal caregivers of persons living with dementia identified 12 studies describing 11 different interventions. There was no uniformity of outcome measurement, and among these studies, 18 caregiver-related outcomes were evaluated. The studies varied in the intervention technology, methods of implementation, results, and the quality of intervention evaluation. In general, the methodological quality of the included studies was moderate to strong, with three weak studies. Six of the studies used telephone technology alone and an additional two studies included telephone communication with a primary technology (i.e., video).

While one might have assumed that we would have identified more computer-based interventions, with the advent of the computer and rapid advances in information and communication via the web, there were very few that satisfied our inclusion criteria. Moreover, the two computer-based studies

that were included were not necessarily dependent on advances in technology. In fact, the study conducted by Brennan et al. in 1995 was the first among ICT interventions in this review to evaluate whether the use of a computer-based network could positively influence confidence in decision-making among caregivers. Even though both computer-based interventions aimed to provide caregiver support, each study evaluated the effects of the ICT intervention on different caregiver outcomes (i.e., stress and decision-making). Nevertheless, Brennan's evaluation of a computer-based network was one of four scientifically strong studies found in this systematic review.

Different forms of affective responses to caring for a person living with dementia, such as burden, stress, and anxiety, fit within the conceptualization of a stress response that could be mediated by effective coping [28]. More than 200 non-ICT dementia caregiver interventions have been found to be efficacious in RCTs during the past 3 decades [29]. Nevertheless, these studies typically rely on convenience samples, which may limit generalizability of the findings [30]. Like previous non-ICT studies, the ICT caregiver intervention studies we reviewed applied a stress response framework and relied heavily on convenience samples. The result is that the health (e.g., biophysiological health maintenance and/or promotion) and health care needs (i.e., annual primary care wellness visits) of caregivers often goes unaddressed by most dementia caregiver interventions. However, there was one exception in which the ICT intervention had a statistically significant positive effect on caregiver's exercise and exercise self-efficacy [24].

There is limited evidence about the benefits of ICT interventions for population subgroups by race/ethnicity, gender, geographic location, and long-distance and multiple caregivers [29]. We found that most participants included in the studies for this review were female and white. Notably, ethnicity was only reported in three studies. Information and communication technology innovations are advancing at a rapid pace and most enable low cost interventions. Notably, ICT interventions can be tailored with content based on race/ethnicity, location, caregiver responsibilities, and age of caregivers, as well as the health and health care concerns they face during the life-course of dementia [11]. However, there is much to be learned about the effects of ICT interventions on different groups of informal family caregivers of persons living with dementia.

The studies identified for this systematic review varied in methodological quality. Although most studies had at least moderate quality, all were found to have selection bias by both raters that compromises the reliability and validity of the intervention evaluation. Nearly all of the outcome measures were self-reported. Although this is typical in caregiver studies, self-report is subject to bias from over- and under-reporting of affective responses to caring for a person living with dementia [31]. Studies varied considerably with respect to intervention dose and intensity, thus making it difficult to integrate the study's findings. A similar problem applies to

the configuration of the interventions: they varied in the unit of exposure (i.e., individual vs. group), information and communication technologies used (e.g., video-based only or video- and telephone-based), use of the technology (e.g., direct telephone contact with an interventionist vs. automated interactive voice telephone response system), and those who carried out the intervention (i.e., an interventionist or self-directed). A number of studies reported analyses of multiple affective outcomes, but none reported adjusting for multiple hypothesis testing. Some significant findings may therefore have been attributable to chance [32]. These issues made it difficult to come to a general conclusion about the effect of ICT interventions.

4.1. Limitations of systematic review

We recognize that our systematic review has limitations. First, because we included only RCTs in our systematic review, ICT interventions such as television media campaigns not evaluated using an RCT design might have had a significant effect on caregiver outcomes. Next, we chose not to attempt to include ICT interventions that targeted professional caregiver behaviors that could affect informal caregiver outcomes because our aim was to identify the effects of ICT interventions in the developing field of consumer health informatics rather than to assess the effectiveness of a particular intervention or categories of interventions. Finally, it is possible that our review missed some ICT intervention trials that had a statistically significant effect on caregiver outcomes because we included only four of ten types of dementia, but this seems unlikely given that Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies are the most common.

5. Conclusions

The findings of this systematic review provide the first glimpse at the effects of ICT interventions for informal caregivers. We identified a limited number of ICT intervention studies that reported a statistically significant effect on informal caregiver outcomes. Nonetheless, a range of ICT interventions including, telephone-, video-, and computer-based interventions appear to be successfully targeting caregiver support for a range of affective caregiver outcomes, including burden, depression, and anxiety. The evidence, although limited, is strongest for various forms of telephone-based interventions based on the quality of the studies and the effects of the interventions. Telephone technology can be used effectively as a stand-alone intervention or in tandem with other ICTs. Further research is needed to validate current ICT interventions to establish generalizability of each modality. Our review serves as a comprehensive survey of the current state of effective ICT interventions for informal caregivers which can be used by policymakers and researchers to guide further development of interventions strategies in improving caregiver health.

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Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.trci.2018.11.003>.

RESEARCH IN CONTEXT

1. Systematic review: The authors searched PubMed, CINAHL, Web of Science, and PsycINFO using concepts associated with information and communication technology (ICT), dementia, and caregiver. Technology-based caregiver interventions can improve informal dementia caregiver outcomes. The literature was evaluated to identify the state of the science on ICT interventions for informal dementia caregiver health.
2. Interpretation: There is variation in the type of technology, including telephonic, video, and computerized, used for ICT interventions. The evidence of the effects of ICT interventions on informal dementia caregivers is limited, and strongest among various forms of telephone-based interventions. Participation was constrained narrowly to white female caregivers.
3. Future directions: We identified the need to improve sampling of participants, outcome measurement, treatment exposure, and statistical analyses in future ICT intervention studies. With the aging of a diverse society, it is critical to include participants from different gender and racial/ethnic groups.

References

- [1] Alzheimer's Association. 2017 Alzheimer's disease facts and figures. *Alzheimer's Dement* 2017;13:325-73.
- [2] Tremont G. Family caregiving in dementia. *Med Health R* 2011; 94:36-8.
- [3] Seeher K, Low LF, Reppermund S, Brodaty H. Predictors and outcomes for caregivers of people with mild cognitive impairment: a systematic literature review. *Alzheimers Dement* 2013;9:346-55.
- [4] Eters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008;20:423-8.
- [5] Gagnon MP, Legare F, Labrecque M, Fremont P, Pluye P, Gagnon J, et al. Interventions for promoting information and communication technologies adoption in healthcare professionals. *Cochrane Database Syst Rev* 2009:CD006093.
- [6] Lindberg B, Nilsson C, Zotterman D, Soderberg S, Skar L. Using Information and Communication Technology in Home Care for Communication between Patients, Family Members, and Healthcare Professionals: A Systematic Review. *Int J Telemed Appl* 2013; 2013:461829.
- [7] The World Bank Group. Information and communication technologies: A world bank group strategy. Washington, D.C.: World Bank; 2002.
- [8] Bass DM, McClendon MJ, Brennan PF, McCarthy C. The buffering effect of a computer support network on caregiver strain. *J Aging Health* 1998;10:20-43.
- [9] Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nurs Res* 1995;44:166-72.
- [10] Glueckauf RL, Loomis JS. Alzheimer's Caregiver Support Online: lessons learned, initial findings and future directions. *NeuroRehabilitation* 2003;18:135-46.
- [11] Free C, Phillips G, Galli L, Watson L, Felix L, Edwards P, et al. The effectiveness of mobile-health technology-based health behaviour change or disease management interventions for health care consumers: a systematic review. *PLoS Med* 2013;10:e1001362.
- [12] Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. *J Med Internet Res* 2004;6:e40.
- [13] 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;10:223-32.
- [14] Marziali E, Donahue P. Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease. *Gerontologist* 2006;46:398-403.
- [15] Iribarren S, Stonbraker S, Suero-Tejeda N, Granja M, Luchsinger JA, Mittelman M, et al. Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer's disease and related dementias. *Inform Health Soc Care* 2018:1-20.
- [16] Thomas BH, Ciliska D, Dobbins M, Micucci S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews Evid Based Nurs* 2004;1:176-84.
- [17] Bass DM, Clark PA, Looman WJ, McCarthy CA, Eckert S. The Cleveland Alzheimer's managed care demonstration: outcomes after 12 months of implementation. *Gerontologist* 2003;43:73-85.
- [18] Mahoney DF, Tarlow BJ, Jones RN. Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *Gerontologist* 2003;43:556-67.
- [19] Martindale-Adams J, Nichols LO, Burns R, Graney MJ, Zuber J. A trial of dementia caregiver telephone support. *Can J Nurs Res* 2013; 45:30-48.
- [20] Tremont G, Davis JD, Bishop DS, Fortinsky RH. Telephone-Delivered Psychosocial Intervention Reduces Burden in Dementia Caregivers. *Dementia (London)* 2008;7:503-20.
- [21] Tremont G, Davis JD, Papandonatos GD, Ott BR, Fortinsky RH, Gozalo P, et al. Psychosocial telephone intervention for dementia caregivers: A randomized, controlled trial. *Alzheimers Dement* 2015; 11:541-8.
- [22] Winter L, Gitlin LN. Evaluation of a telephone-based support group intervention for female caregivers of community-dwelling individuals with dementia. *Am J Alzheimers Dis Other Dement* 2006;21:391-7.
- [23] Chang BL. Cognitive-behavioral intervention for homebound caregivers of persons with dementia. *Nurs Res* 1999;48:173-82.
- [24] Connell CM, Janevic MR. Effects of a Telephone-Based Exercise Intervention for Dementia Caregiving Wives: A Randomized Controlled Trial. *J Appl Gerontol* 2009;28:171-94.
- [25] Gallagher-Thompson D, Wang PC, Liu W, Cheung V, Peng R, China D, et al. Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: results of a preliminary study. *Aging Ment Health* 2010; 14:263-73.

- [26] Gant JR, Steffen AM, Lauderdale SA. Comparative outcomes of two distance-based interventions for male caregivers of family members with dementia. *Am J Alzheimers Dis Other Demen* 2007;22:120–8.
- [27] Kajiyama B, Thompson LW, Eto-Iwase T, Yamashita M, Di Mario J, Marian Tzuang Y, 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; 17:544–54.
- [28] Garcia-Alberca JM, Cruz B, Lara JP, Garrido V, Gris E, Lara A, et al. Disengagement coping partially mediates the relationship between caregiver burden and anxiety and depression in caregivers of people with Alzheimer's disease. Results from the MALAGA-AD study. *J affective Disord* 2012;136:848–56.
- [29] Gitlin LN, Marx K, Stanley IH, Hodgson N. Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps. *Gerontologist* 2015; 55:210–26.
- [30] Pruchno RA, Brill JE, Shands Y, Gordon JR, Genderson MW, Rose M, et al. Convenience samples and caregiving research: how generalizable are the findings? *Gerontologist* 2008;48:820–7.
- [31] O'Rourke N, Haverkamp BE, Rae S, Tuokko H, Hayden S, Beattie BL. Response biases as a confound to expressed burden among spousal caregivers of suspected dementia patients. *Psychol Aging* 1996; 11:377–80.
- [32] Shaffer JP. Multiple Hypothesis-Testing. *Annu Rev Psychol* 1995; 46:561–84.