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Impact of dementia literacy interventions for non-health professionals: Systematic review and meta-analysis

Abstract

Objectives: To assess evidence regarding the effects of interventions aimed at improving dementia literacy for different groups of non-health professionals.

Methods: A systematic search for relevant interventions was conducted using a range of online databases (e.g. CINAHL, Embase, Medline, ProQuest, and PsycINFO) and hand-searching of reference lists. Eligible interventions were identified based on predefined inclusion/exclusion criteria and methodological quality criteria. Meta analyses were performed using a random-effects model.

Results: The final review included 14 interventions, which were either randomised controlled trials or non-randomised controlled trials. The interventions had varied contents, approaches, settings, and outcome measures. Evidence of improved dementia literacy in various aspects was found, and the intervention effects were strongest on knowledge of dementia.

Discussion: There is evidence for the positive impact of dementia literacy interventions on different groups of non-health professionals. Best practices in intervention contents, approaches, and outcome measures should be examined to guide future interventions.

Key words

Dementia literacy; interventions; systematic review; meta-analysis

Introduction

Considerable attention has been given to dementia on a global scale in the last few decades. Dementia is often referred to as an umbrella term for a wide range of neurodegenerative progressive conditions (Askari, Bilbrey, Garcia Ruiz, Humber, & Gallagher-Thompson, 2018). As a debilitating irreversible disorder, it affects thinking, memory, behaviour, and daily function (Haralambous, Mackell, Lin, Fearn, & Dow, 2018). For this reason, dementia progressively limits the capacity for independent living (Grigsby, Unger, Molina, & Baron, 2017), and leads to physical, psychological, social and economic impacts on both people living with dementia, their caregivers, families, and the wider society (World Health Organization (WHO), 2019a).

According to WHO (2019b), approximately 50 million people have dementia worldwide, with nearly 10 million new cases of dementia every year, and this number is forecast to triple to 152 million by 2050. Due to the high global prevalence and its multi-level impacts, dementia has been identified as a global health priority (Scheltens et al., 2016), with worldwide initiatives to address dementia-related issues emerging. Among such initiatives is the substantial effort in improving dementia literacy, as a response to the WHO Global Action Plan imperative to raise awareness about dementia (WHO, 2017).

Dementia literacy (DL) has been defined as “the knowledge and beliefs regarding dementia that aid recognition, management and prevention” (Low & Anstey, 2009). Specifically, it is an individual’s knowledge and understanding of the causes, evolution, consequences, symptomatology, and treatment, which helps them to recognise symptoms and make appropriate decisions (Lincoln, Chow, & Gaines, 2019; Noble, Hedmann, & Williams, 2015). Building on these early definitions, an operational definition of DL should cover both descriptive dimensions (e.g. causes, risk factors, symptoms, nature, or impacts) and procedural dimensions (e.g. recognition, prevention, or management). DL encompasses the capacity to translate knowledge into changed beliefs, attitudes, decision making and action about assessment, diagnosis, access and use of health services, as well as caregiving and support for people with dementia. In essence, DL covers knowledge and beliefs not only about dementia-related facts, but also about how and when to perform a behaviour, task or skill in relation to this condition. The above operationalized domains of DL were used as the conceptual basis for the current review.

DL of the general public is found to be relatively low in many countries. For example, in some studies, around 40-50% of participants were found to be unaware of the signs and symptoms of dementia (Bogolepova, 2015; Lee et al., 2016). A systematic review of 40 studies by Cahill and colleagues (2015) reported only fair to moderate knowledge of dementia/Alzheimer’s disease. In another review of 38 population-based surveys about prevention and treatment of dementia, Cations and colleagues (2018) reported that about half of the respondents regarded dementia as a normal and non-preventable part of aging. Poor knowledge of dementia, which is argued to contribute to stigma, could impede early diagnosis and cause problematic delays in seeking medical care and other supports (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Cahill et al., 2015). Equally, a higher DL level will enable risk reduction, symptom identification, help-seeking, timely diagnosis, and improved management of dementia (Cations et al., 2018; Leung et al., 2019; Lincoln et al., 2019; Low et al., 2010). As people with dementia progressively rely on others such as family caregivers, relatives, or friends for daily care, those with higher DL are better equipped to provide appropriate support and responses to both the symptoms and needs of those living with dementia (Van Patten & Tremont, 2018). Such evidence supports the need for interventions to increase DL of the general public (Loi & Lautenschlager, 2015; Picco et al., 2018).

Responding to this pressing public health demand, initiatives of various scales and levels have been carried out across regions to increase DL. A variety of stakeholders have been involved in this endeavour, who include both professionals such as physicians, nurses, and allied health care workers, and also non-professionals, such as healthy older adults, informal caregivers of people living with dementia, students and the general public (Burns et al., 2018; Cotter, Welleford, Vesley-Massey, & Thurston, 2003; Grigsby et al., 2017; Magni, Zanetti, Bianchetti, Binetti, & Trabucchi, 1995; Pleasant et al., 2017; Roberts & Noble, 2015; Terayama et al., 2018).

These interventions have been delivered in a wide range of forms and media, including theatre performance (Burns et al., 2018), audio-visual novella to improve general public and potential caregiver attitudes toward people with dementia (Grigsby et al., 2017); education and support groups to increase caregiver dementia knowledge, coping, and quality of life (Coen, O'Boyle, Coakley, & Lawlor, 1999; Terayama et al., 2018); educational workshops to increase awareness and understanding of dementia among students, general public and people living with dementia (Di Bona, Kennedy, & Mountain, 2017; Kotler, 1992; Noble et al., 2015); information meetings focusing on improving knowledge and reducing anxiety regarding dementia among general public and non-professional carers (Commissaris, Verhey, Ponds, Jolles, & Kok, 1994); consultations to develop understanding of dementia among general public and people living with dementia (Galvin, Tolea, George, & Wingbermuehle, 2014); and online education programs for university students which focussed on improving dementia knowledge (Innes, Kelly, & McCabe, 2012; Pleasant et al., 2017). The outcomes of such interventions, mainly measured using surveys and knowledge tests, have been reported on different aspects, including dementia-related knowledge, attitudes, beliefs, and behaviours, as well as perceived skills or self-efficacy in dementia caregiving and management.

With these substantial efforts worldwide to improve DL, it is important to undertake systematic reviews to determine the impacts of such interventions. However, no systematic review has been found in relation to the process and/or effectiveness of DL interventions across different groups and with different DL outcomes. The current study aims to address this gap by examining the impacts of interventions designed to enhance DL among different groups of non-health professionals. It contributes to the understanding of how to promote DL among people in the community who are not working in the healthcare industry, such as family caregivers, family members, older adults, or the general public. As the majority (more than 70%) of people living with dementia reside in private community dwellings (National Centre for Social and Economic Modelling (NATSEM), 2017), the DL of non-health professionals plays an important role in ensuring appropriate support and care for people living with dementia and building dementia friendly communities. The findings of this review will inform both policy and the design of future DL initiatives.

Methods

Search strategies

A systematic search for interventions aimed at improving DL was conducted using a range of online databases (e.g. CINAHL, Embase, Medline, ProQuest, and PsycINFO). There was no limit in date of publication. The databases were initially searched for all potentially relevant studies in the title, abstract and keywords fields. The search terms were: Dementia, Alzheimer's disease, Alzheimer, Lewy Body, Lewy Body disease, Vascular dementia, Frontotemporal dementia; AND: intervention, trial, training, activity, program, initiative, education, promotion, strategy, campaign; AND: Health literacy, literacy, knowledge, skill, awareness, attitude, behaviour; belief; AND: Effect, effectiveness,

impact, result, outcome. Hand searching and reviewing of reference lists were also used to identify additional relevant studies.

Inclusion and exclusion criteria

This systematic review included studies designed to improve DL of different groups of non-health professionals, i.e. individuals who were not health professionals or formal paid caregivers, such as family caregivers, family members, older adults, students, volunteers, or the general public. These studies involved the implementation and evaluation of an intervention of any form (e.g. formal/informal education, health promotion initiative, community program), conducted in any platform (e.g. face-to-face and/or online), and any setting. The content of the interventions addressed one or more aspects of dementia knowledge and beliefs, including both descriptive dimensions (e.g. causes, risk factors, symptoms, nature, or impacts) and procedural dimensions (e.g. recognition, prevention, or management). The measured outcomes were knowledge mastery, self-efficacy, and/or changes in beliefs and attitudes. Regarding intervention design, the reviewed studies were either randomised controlled trials (RCTs) or non-randomised controlled trials (NRCTs).

Articles were excluded if they were systematic reviews, discussion papers, or protocols of in-progress studies. We also excluded studies that were purely observational or cross-sectional, or that included an intervention without a control group, or that involved only health professionals or formal paid caregivers as participants. Studies without the three identified outcomes were also excluded. Due to challenges in ensuring translation qualities, only full-text articles in English were included in this review.

Data screening, selection and extraction

The studies retrieved from all sources were exported to EndNote (Version X8). The reviewers worked together in screening and selecting studies after the removal of duplicates. Two reviewers independently screened the titles and abstracts of all studies to exclude obviously irrelevant studies and identify a list of potentially relevant studies. Two reviewers then independently assessed the full texts against the inclusion criteria. Differences or disagreements between the two reviewers were resolved through discussion and consultation with other reviewers until consensus was reached. One of the reviewers also performed a hand search of the reference lists from the included studies to identify other eligible studies, followed by discussion with the reviewer team. At each stage, the reasons for inclusion and exclusion were clearly documented.

Data from the included studies were extracted and documented in a data extraction form. Important extracted factors included research design, participants, time points, intervention contents, intervention duration and formats, outcome measures, and reported effects. Correspondence with the authors of some specific articles were made by one reviewer to request more detailed information about methods and statistical results.

Assessment of methodological quality

Using a criteria checklist aligned with the Cochrane guidelines (Higgins & Green, 2008), two reviewers independently assessed the methodological quality of each study. These quality assessment criteria were related to selection, performance, attrition, detection, and reporting; the five common types of research bias. For each of the methodological quality criteria, the studies were rated as (+) criterion met, (-) criterion not met, (u) unknown if the criterion was met or not, and (n/a)

not applicable. The two reviewers discussed the quality assessment results among themselves or consulted the other three reviewers as needed.

Data analysis

Among the studies that reported comparable quantitative data, we performed meta-analyses to assess the effects of the interventions on different DL outcomes. All of the analyses were performed using Stata 12.1 software (StataCorp, 2011).

Initially, we extracted data from eligible studies, including mean values and standard deviations (SD) for each outcome at baseline (pre-intervention), post-intervention, and/or follow-up (FUP), separately for the intervention and control groups. Then, we calculated the mean difference (MD) and SD for the change in mean scores between pre- and post-intervention and/or between pre-intervention and FUP. Due to inconsistent scales and instruments used to assess the same outcome across studies, we calculated the study-specific standardised mean difference (SMD) and 95% confidence interval (CI) for the intervention and control groups. The study-specific SMD estimates for each outcome were subsequently combined to create an estimate of the intervention effect using random-effects meta-analysis.

Heterogeneity between studies was evaluated using Q and I^2 statistics. When significant heterogeneity was found, meta-regression was conducted to identify potential heterogeneity sources. Different study-level characteristics were examined, such as study design (RCT and NRCT), geographic region (Europe, America, and Australia), and study participants (family caregivers and others).

In addition, we used Begg's test and visual funnel plots to examine possible publication bias (Begg & Mazumdar, 1994; Egger, Smith, Schneider, & Minder, 1997). A p -value being ≤ 0.10 in Egger's test or an asymmetric plot would suggest a publication bias. For each outcome with a possible publication bias observed, an updated pooled effect size was estimated to examine the effect of the hypothetical 'missing' studies on our results using Duval and Tweedie's trim and fill method (Duval & Tweedie, 2000).

Findings

A total of 3,503 records were retrieved from the search of multiple online databases and 14 from other sources. Removing 1,530 duplicates resulted in 1,987 potentially relevant records. Of these, 1,915 records that were clearly irrelevant (e.g. those with a different topic focus, those without an intervention, etc.) were excluded after the title and abstract screening, and 6 records were not available in full texts. Sixty-six full-text articles were assessed for eligibility, after which 52 studies were excluded. The exclusion reasons were: review or discussion papers, protocol papers, study design, a lack of DL-related outcomes, or non-inclusion of the target population. After the screening and selection process, 14 studies were included in the final review. Figure 1 presents the literature search process, reasons for exclusion, and selection results.

Quality of evidence

Methodological quality was examined using information provided in the retrieved papers. Almost all of the reviewed studies met the criteria of similarity of groups at baseline, inclusion/exclusion criteria specified, description of participants lost to follow-up, and non-selective reporting of outcomes. Half of the reviewed studies were reported as RCTs; however, only one study provided

adequate details about randomization and concealment (de Rotrou et al., 2011). Three studies (Chiverton & Caine, 1989; de Rotrou et al., 2011; Ducharme et al., 2011) reported blinding of outcome assessors, but blinding of participants was not mentioned in any study. Notably, intention to treat analysis and power calculation were not met by many of the reviewed studies. More details about the methodological quality assessment can be found in Supplemental Table 1.

Study characteristics and participants

The reviewed studies were published between the years of 1989 and 2018 in various regions, including North America (e.g. the USA, Canada), Europe (e.g. the Netherlands, France, the UK), and Australia. These interventions were carried out either in a home and community-based setting (12 studies), or formal education setting (Gilmartin-Thomas et al., 2018; Kimzey, Mastel-Smith, & Alfred, 2016). In terms of research design, seven studies were RCTs and seven studies were NRCTs. All interventions were designed to include a control group as opposed to the intervention group; however, they differed in the nature of the comparison treatment. Five studies employed the waitlist design, where the control group received the intervention after the active treatment group (Beauchamp, Irvine, Seeley, & Johnson, 2005; Brodaty, Roberts, & Peters, 1994; de Rotrou et al., 2011). The control group in eight studies received no treatment whereas those in one study received placebo treatment, i.e. provision of a booklet and educational materials (Hattink et al., 2015).

A total of 1,593 individuals participated in the 14 studies under review. Participant numbers across the studies ranged from 40 to 299. Most of the participants (about three fourths) were family caregivers of people living with dementia, and about one fourth were either older adults or undergraduate students enrolled in a health-related program. Table 1 presents details about the design, participants, interventions, outcome measures and results of the reviewed studies.

Interventions

The 14 interventions covered a wide range of dementia literacy aspects, but the core focus of the studies was on awareness and knowledge of the causes, nature, impacts, symptoms of dementia, and/or preventative approaches. As many of the target participants were family caregivers of people living with dementia, different caregiving, management or coping strategies were also included in many interventions.

The interventions under review were conducted either face-to-face (10 studies) or fully on-line (Beauchamp et al., 2005; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; van der Roest, Meiland, Jonker, & Droes, 2010). In face-to-face settings, the interventions were organised in the form of educational workshops or training sessions for groups. These sessions were mostly conducted with presentations, demonstrations, group discussions, problem solving activities, and personal reflection. Some interventions incorporated follow-up consultations and provision of individual advice (Brodaty et al., 1994; Droes, Meiland, Schmitz, & van Tilburg, 2006). The four online interventions were offered through a web-based multimedia portal with individualised tailoring of content and training on how to use the site.

Outcome measures

All of the reviewed studies assessed outcomes at baseline and post-intervention, but only four studies had follow-up assessments to examine the stability of possible changes (Cristancho-Lacroix et al., 2015; de Rotrou et al., 2011; Droes et al., 2006; Ducharme et al., 2011). Many outcome

measures were subjective self-reported surveys, most of which had been developed and validated by previous researchers in the field. The reviewed studies measured intervention effects on one or more of the DL-related outcomes using varied instruments, including knowledge about dementia (e.g. Alzheimer's Disease Knowledge Scale, Dementia Attitudes Scale - Cognitive component, 22-item and 15-item dementia knowledge questionnaires, Visual Analog Scales); self-efficacy or confidence in caregiving or management of dementia symptoms (e.g. [Short] Sense of Competence Questionnaire, Feeling of Competence Scale, Self-efficacy Scale; Revised Scale for Caregiving Self-efficacy); beliefs and attitudes regarding dementia (e.g. Dementia Attitudes Scale – Affective component, Approaches to Dementia Questionnaires, 12-question questionnaire on beliefs in preventative behaviour change).

Effects on knowledge

All of the eight studies that measured knowledge outcomes had comparable quantitative data at baseline and post-intervention for inclusion in the meta-analysis (Supplemental Table 2). Of these studies, four were RCTs, and the remaining four were NRCTs. The meta-analysis result revealed a statistically significant improvement in dementia knowledge in the intervention group as compared to the control group (pooled SMD 0.51, 95% CI 0.17, 0.84; $p = 0.003$; Figure 2). Between-study heterogeneity was statistically significant ($Q = 29.0$; $p < 0.001$; $I^2 = 76\%$), but there was no evidence that the differences in study design, geographic region, or participant groups contributed to the heterogeneity (Supplemental Table 5).

All of the three studies that had data on knowledge outcomes at baseline and follow-up were included in the meta-analysis, and all of them were RCTs (Supplemental Table 3). There was no statistically significant effect on individuals' knowledge between baseline and follow-up. The pooled SMD was 0.07 (95% CI -0.20, 0.34; $p = 0.622$; Figure 3) without evidence of between-study heterogeneity ($Q = 2.5$; $p = 0.290$; $I^2 = 19\%$).

Effects on self-efficacy

Five studies with comparable quantitative data on self-efficacy outcomes at baseline and post-intervention were included in the meta-analysis (Supplemental Table 4). Four were RCTs and the remaining one was an NRCT. A statistically significant improvement was found in post-intervention self-efficacy with a pooled SMD being 0.20 (95% CI 0.01, 0.38; $p = 0.038$; Figure 4). No evidence of heterogeneity between studies was found ($Q = 5.1$; $p = 0.273$; $I^2 = 22\%$).

Among the four studies that were not suitable for meta-analysis, three reported significant effects on self-efficacy outcomes (Chiverton & Caine, 1989; Drees et al., 2006; Hattink et al., 2015), and one found no significant effect (de Rotrou et al., 2011).

Effects on beliefs and attitudes

Only one study (Clevenger, Cantey, & Quinn, 2010) measured participants' beliefs in their ability to initiate and maintain preventative behaviour change to reduce the risk of dementia and their belief in the positive results of behaviour change. This study found a significant effect of the intervention on such beliefs. Three studies that examined the intervention impact on perceptions and attitudes towards dementia and people living with this condition produced mixed results. Two studies reported statistically significant impact (Gilmartin-Thomas et al., 2018; Kimzey et al., 2016) while one study reported no significant impact (Hattink et al., 2015).

Publication bias assessment

Our Begg's test results (Supplemental Table 6) and visual inspection of the funnel plots (Supplemental Figures 1-3) indicated no evidence of publication bias.

Discussion

The review identified 14 RCT and NRCT studies that involved the implementation and evaluation of an intervention to enhance DL among different groups of non-health professionals (e.g. older adults, family caregivers, and undergraduate students). Overall, although the interventions had varied approaches and focuses tailored to different target participants, the results indicated improvement in different DL outcomes, with clear evidence for improved knowledge about dementia, and improved efficacy in dementia caregiving and management. Evidence regarding the intervention effects on beliefs about preventative behaviour change was limited, while there were mixed findings about attitudes towards dementia.

It is encouraging to find that the intervention effects were strongest on participants' knowledge about dementia, especially among family caregivers and undergraduate students. Specifically, post DL intervention, participants have shown significant improvement in one or more of the knowledge aspects of dementia (e.g. causes, signs/symptoms, prevalence, nature, risk factors, assessment, diagnosis, life impacts, relevant health services, caregiving, and management of dementia). This positive finding is consistent with those of one-group design studies regarding the impact of DL interventions on non-health professionals' knowledge (Commissaris et al., 1994; Di Bona et al., 2017; Grigsby et al., 2017; Kotler, 1992; Noble et al., 2015). Although the studies under review employed different types of interventions and targeted different groups of non-health professionals, those that showed positive knowledge outcomes shared some important features. These included opportunities for interactions and exchanges of ideas among the participants either through face-to-face discussions or online forums; and opportunities for reflection on or application of the intervention content (Chiverton & Caine, 1989; Cristancho-Lacroix et al., 2015; de Rotrou et al., 2011; Ducharme et al., 2011; Gilmartin-Thomas et al., 2018). These features are consistent with the literature about effective educational interventions across disciplines, particularly those in healthcare contexts (Davis & Davis, 2010; Morris & Faulk, 2012). However, the follow-up meta-analysis result showed that dementia knowledge improvement was not maintained beyond the intervention period. This could raise questions about the sustainability of the intervention effects, although only three studies measured knowledge outcomes at a follow-up timepoint, with two of these producing positive follow-up results. It is suggested that future DL interventions include repeated measures with the use of follow-up assessments in different target groups to allow for better evaluation of long-term intervention impacts, taking into consideration the distinctive characteristics of these target populations.

Evidence of improved self-efficacy in dementia caregiving and management is another encouraging finding, which highlights the potential/impact of DL interventions in capacity building for family caregivers. Intervention design could be an important contributing factor. A noticeable feature of the interventions with positive efficacy outcomes was the provision of individualised or tailored contents that addressed the identified needs of the participants, either in a web-based or face-to-face setting (Beauchamp et al., 2005; Ducharme et al., 2011; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; van der Roest et al., 2010). Another common design feature of these interventions was the integration of well-aligned factual and procedural content components to assist participants in

understanding the symptoms and nature of dementia, and meeting the needs of people living with dementia, while learning to manage their own emotional and psychological health.

Given that people living with dementia generally show progressive decline in thinking, memory, behaviour, and the ability to function in their daily life (Greal, McMullen, & Greal, 2005), and that the majority of people living with dementia (approximately 70%) reside in their own homes (Department of Health, 2014), it is crucial for family members, friends and others around them to feel confident that they know how to provide the needed support and care, or how to appropriately respond to behaviours/symptoms associated with dementia. It is perhaps the reason why 11 out of 14 studies under review involved family caregivers as their participants. Among different groups of non-health professionals, family caregivers are probably the most in need of enhanced DL due to their crucial role in dementia daily care and management.

Although the reviewed interventions targeted different non-health professional groups, family caregivers were most often involved, hence the emphasis on content related to knowledge and skills that aid support, care, and management of dementia. With limited evidence regarding beliefs and attitudes towards dementia, the potential impacts of the reviewed interventions on prevention and stigma reduction were unclear. Prevention seemed to be rare as a targeted goal for RCT and NRCT interventions; only one study in the review aimed to encourage behaviour change to reduce risk factors of dementia (Clevenger et al., 2010). With numerous efforts in raising public awareness about dementia risk factors and preventative measures emerging (Anstey, Eramudugolla, Hosking, Lautenschlager, & Dixon, 2015; Peters et al., 2019; Rakesh, Szabo, Alexopoulos, & Zannas, 2017; WHO, 2019a), more evidence is needed regarding DL intervention impacts on preventative behaviour outcomes. In addition, to address the widespread stigma associated this condition (Alzheimer's Disease International, 2012; Herrmann et al., 2018), outcomes related to attitudes towards dementia and people living with dementia should also be further explored.

The findings from this review suggest that online delivery could be a worthwhile option for future interventions in enhancing the DL of the public. The four fully online interventions in the review were found to significantly improve at least one of the intended outcomes, including self-efficacy (Beauchamp et al., 2005; Hattink et al., 2015; van der Roest et al., 2010) and knowledge mastery (Cristancho-Lacroix et al., 2015). Online delivery was also noted as a promising approach in other systematic reviews of health promotion and education interventions (Gullier, Griffiths, Christensen, & Brewer, 2012; Samoocha, Bruinvels, Elbers, Anema, & van de Beek, 2010; Taylor et al., 2017; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004) and a recent review of seven online interventions for caregivers of people living with dementia (Parra-Vidales, Soto-Perez, Perea-Bartolome, Franco-Martin, & Munoz-Sanchez, 2017). Apart from the inherent advantages of high user convenience, non-restricted access, consistent delivery of contents, and cost effectiveness (Martin & Copeland, 2003), the four web-based DL interventions under review offered a self-guided, individual-based program, with or without additional features such as user training, printed user manuals, Facebook and LinkedIn networking, or individualised tailoring of content. These features of individualisation and engagement strategies have been highly recommended as effective for web-based interventions (Bennett & Glasgow, 2009).

Overall, our review findings are relatively positive, but interpretations of these findings should be made with caution. Firstly, the included studies tend to have moderate methodological quality, with the majority of studies (11 out of 14) successfully satisfying at least half of the twelve quality criteria.

Of note was the poor adherence to intention to treat and power calculation, as well as lack of details regarding randomization, concealment or blinding. Future research efforts are recommended to fully address and report on these potential areas of bias. Secondly, our review includes articles published in English only; therefore, it might have overlooked research evidence published in other languages. Thirdly, all of the reviewed studies were conducted in more developed countries. Intervention designs and impacts might be different from those in developing countries. For this reason, the findings should be interpreted with reference to relevant regional/local factors. Lastly, the number of eligible studies forming the pooled estimate for each outcome was less than required (≥ 10) for the exploration of heterogeneity between studies using meta-regression. Our review underscores the need to have more robust research evidence regarding various outcomes of DL interventions for different groups of people. In addition, to aid interpretation and evaluation of research findings, a more comprehensive and consistent approach to reporting research is needed.

Conclusion

In conclusion, although there were noted differences across studies, this review suggests that DL interventions targeting non-health professionals can be effective in improving a range of DL outcomes. Towards the goals of awareness and capacity building, there is evidence for the impact of these interventions in improving knowledge about dementia as well as self-efficacy in dementia caregiving and management. Interventions that incorporate participant-centred elements of individualised needs-based approach, interactivity, and real-life application of or reflection on the content are more likely to lead to positive DL outcomes. More evidence related to impacts on dementia beliefs, attitudes, and preventative behaviours of the general public is needed. To our knowledge, this is the first attempt to systematically summarise the impact of RCT and NRCT interventions aiming to enhance DL. This is a much-needed addition to the literature which offers evidence-based implications for both practice and policy.

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List of tables

Table 1: Characteristics of the reviewed studies

Author (Year), Country	Design, Participants, Time points	Intervention contents	Intervention duration & format	Outcome measures	Specific outcomes	Reported effects *	
						Post-intervention	Follow-up
Beauchamp et al., 2005 The USA	RCT N = 299 FC IG = 150 CG = 149 BL, PI	- <i>Treatment</i> : Caregiver's Friend _ Dealing with Dementia: A web-based intervention modelling positive caregiving strategies - <i>Control</i> : usual care, waitlist, no attention placebo	30 days Individualized tailoring of online content	2 screening questions 6 self-efficacy questions The Revised Ways of Coping Caregiver Strain Instrument Positive Aspects of Caregiving survey CES Depression Scale State-Trait Anxiety Inventory	Frequency & level of stress Self-efficacy in caregiving Intention to get support Ways of coping Caregiver strain Caregiver gain Depression Anxiety	P < .001 (GT) P < .05 (GT) P < .01 (GT) NS P < .05 (GT) P < .05 (GT) P < .01 (GT) P < .05 (GT)	
Brodady et al., 1994 Australia	NRCT N = 81 FC IG = 33 CG = 22 26 Non-completers BL, IP	- <i>Treatment</i> : The programme covered disease process, communicative & behavioural problems, impact on the carer, stress management, problem-solving and behavioural management. - <i>Control</i> : waitlist	18 hrs, 4 months: 1 workshop, 3 training sessions, 1 review session; Didactic teaching, group work, problem solving	Family Burden Interview General Health Questionnaire Satisfaction with Life Scale Positive and Negative Affect Scales Happiness Scale A 22-item and a 15- item American multiple-choice questionnaires	Caregiver burden Psychological morbidity Caregiver satisfaction with life Caregiver affect Emotional well-being Knowledge (causes and nature of dementia)	P < .05 NS NS NS NS	
(Chiverton & Caine, 1989)	NRCT	- <i>Treatment</i> : The education program covers the disease process, role changes,	3x 2-hr sessions during 3 or 4 wks;	Health Specific Family Coping Index for non-institutional care (HSFCI)	Physical independence	NS	

The USA	N = 40 FC IG = 20 CG = 20 BL, PI	communication and behavioural management, ADL strategies. - <i>Control</i> : not specified	Didactic presentation, group discussion		Therapeutic competence Knowledge of condition General hygiene Health attitudes Emotional competence Family living Physical environment Community resources	P < .01 P < .001 NS NS P < .05 NS NS NS	
(Clevenger et al., 2010) The USA	RCT N = 53 OA IG = 33 CG = 20 BL, PI	- <i>Treatment</i> : Maintain Your Brain workshops (MYB): Your brain, cardiovascular factors, cognitive stimulation, social and dietary factors. - <i>Control</i> : not specified	4 weekly 1-hr sessions; Lecture, discussion, demonstration	Self-efficacy for behaviour change to reduce dementia (AD) risks	Efficacy expectations Outcome expectations	P < .05 P < .001	
(V. Cristancho-Lacroix et al., 2015) France	RCT N = 49 FC IG = 25 CG = 24 BL, PI, FU	- <i>Treatment</i> : A web-based psychoeducational program (Diapason): Stress, understanding the disease, autonomy, reactions, behavioural management, communication, daily life improvement, falls prevention, pharmacological and non-pharmacological interventions, social & financial support, the future - <i>Control</i> : usual care	3 months: 15-20 minute weekly sessions; Training on how to use the website, a printed user's manual, and a notebook record application of the program's content	Perceived Stress Scale Revised Scale for Caregiving Self-Efficacy Revised Memory and Behavior Problems Checklist Zarit Burden Interview Structured interviewed, standard questionnaires and Visual Analog Scale Beck Depression Inventory	Caregiver stress Self-efficacy in care-giving Perception and reaction to cognitive or behavioural symptoms Subjective burden Knowledge of AD Overall stress Self-efficacy for coping with AD	NS NS NS NS P < .01 NS NS NS	NS NS NS NS NS NS

				French version of the Nottingham Health Profile	Caregiver-carer receiver relationship Caregiver depression Self-perceived health	NS NS	NS NS
(Ducharme et al., 2011) Canada	RCT N = 111 FC IG = 62 CG = 49 BL, PI, FU	- <i>Treatment</i> : Learning to Become a Family Caregiver psychoeducational program: care perceptions, coping strategies, communication and joy, building on strengths and experiences, social support, knowledge of and access to services, planning ahead for the future - <i>Control</i> : usual care	7x weekly 90-minute individual sessions; Workbooks)	Self-efficacy Scale Preparedness for Caregiving scale Revised Scale for Caregiving Self-Efficacy Planning for Future Care Needs scale & Knowledge of Services scale Carers' Assessment of Managing Index Inventory of Socially Supportive Behaviors Family Caregiver Conflict scale	Caregiver confidence in dealing with caregiving situations Self-perceived preparedness Self-efficacy in care-giving Planning for Future Care Needs Knowledge of Formal Services Problem solving Reframing Stress management Informal social support Family conflicts	P < .01 ** P < .001 P < .05 P < .05 P < .001 P < .05 P < .01 NS NS NS	
(Droes et al., 2006) The Netherlands	NRCT N = 84 FC IG = 71 CG = 13 BL, PI	- <i>Treatment</i> : Meeting Centres Support program: A social club in community centres for the person with dementia (3 days/wk), and informative meetings and long-term discussion group for the caregivers - <i>Control</i> : Regular psychogeriatric day care	7 months, 8–10 informative meetings and a bi-weekly long-term discussion groups	General Health Questionnaire Modified version of the Sense of Competence Scale, the Jalowiec Coping Scale, the Social Support list, the adapted Use of Services checklist, the Loneliness Scale and the NeuroPsychiatric Inventory	Psychological and psychosomatic symptoms Caregiver burden determinants (sense of competence, coping strategies, experienced social support, loneliness an emotional impact on the carer)	NS NS (across all sub-categories)	

(Droes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004) The Netherlands	NRCT N = 55 FC IG = 36 CG = 19 BL, IP, FU	- <i>Treatment</i> : The Amsterdam Meeting Centres Support Program: information on dementia and coping with the consequences of the disease and emotional support - <i>Control</i> : Regular care	10 informative meetings and a bi-weekly long-term discussion group + A weekly consultation hour for personal advice and a monthly centre meeting	Carer Strain Questionnaire and the Philadelphia Geriatric Centre Morale Scale General Health Questionnaire Loneliness Scale, the modified version of the Feeling of Competence Scale; the Jalowiec Coping Scale, the Social Support list and the Services list	Feelings of stress Dissatisfaction with life Psychological and Psychosomatic complaints Loneliness Feeling of competence Coping strategies Experienced social support	NS NS NS NS NS NS P < .01	NS NS NS NS P < .05 NS NS
(Gilmartin-Thomas et al., 2018) Australia	NRCT N = 278 ST IG = 80 CG = 198 BL, PI	- <i>Treatment</i> : A multisensory, virtual simulation of light, sound, colour, and visual content to experience the cognitive and perceptual difficulties faced by people with dementia, allowing students to consider improved approaches to caring, environmental issues, & related modifications. - <i>Control</i> : waitlist	1.5 hour simulation; Facilitator-guided personal reflection and follow-up group discussion	Dementia Attitudes Scale (DAS) (Affective and cognitive components)	Comfort associated with interacting with people with dementia Knowledge of dementia	P < .001 P < .001	
(Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001) The USA	RCT N = 171 FC IG = 93 CG = 78 BL, PI	- <i>Treatment</i> : A multicomponent program: dementia and impact of the environment on behaviours, simplifying household objects, breaking down tasks, and use of social support - <i>Control</i> : educational materials and a booklet about home environment safety tips	3 months; Five 90-min home visits by occupational therapists, every other week	Caregivers were asked to rate their confidence in managing the items in the MBPC and FIM Caregivers were asked to rate their level of upset for each behavioural occurrence of IADL and ADL items	ADL Self-efficacy IADL self-efficacy Behaviour self-efficacy ADL upset IADL upset	NS NS NS NS NS	

					Behaviour upset	NS
(Hattink et al., 2015) The Netherlands and the United Kingdom	RCT N = 83 FC & Vol IG = 37 CG = 46 BL, PI	- <i>Treatment</i> : The European Skills Training and Reskilling (STAR) project, a multilingual web-based portal about dementia care: Dementia and living with dementia, diagnosis, daily difficulties and support strategies, emotional impact and coping strategies, positive and empathic communication. - <i>Control</i> : waitlist	4 months; a web-based portal & Facebook & LinkedIn communities for peer support and opportunities to contact other dementia care professionals	Alzheimer's Disease Knowledge Scale Alzheimer's disease survey and Approaches to Dementia Questionnaire Interpersonal Reactivity Index (IRI) Quality of Life (2 question) Burden (1 question) Short Sense of Competence Questionnaire	Knowledge of dementia Attitudes regarding dementia Distress in tense interpersonal setting Empathy Fantasy Perspective QoL Burden Sense of competence	NS NS P < .01 P < .001 NS P < .001 NS NS P < .05
(Kimzey et al., 2016) The USA	NRCT N = 94 ST CG = 34 IG1 = 34 IG2 = 33 BL, PI	- <i>Treatment</i> : <i>Intervention 1</i> : AD online module: cognitive assessment, person-centered care, changes in thinking, impact on behavior, and behaviour as communication; <i>Intervention 2</i> : Engaged with people with AD at a memory care unit and dementia day center – one, six-hour clinical day at each location - <i>Control</i> : no dementia-specific intervention	A one-hour post conference followed clinical experiences and offered the opportunity for reflection on working with people with AD	Alzheimer's Disease Knowledge Scale Dementia Attitudes Scale	AD knowledge (risk factors, assessment, diagnosis, symptoms, life impact, caregiving, and treatment and management) General perceptions of persons with Alzheimer Disease and Related Dementias and feelings toward this population.	P < .05 P < .05

(van der Roest, Meiland, Jonker, & Drees Dr, 2010) The Netherlands	NRCT N = 28 FC IG = 14 CG = 14 BL, PI	- <i>Treatment</i> : DEM-DISC provides general and tailored information on available dementia care and welfare services: diagnosing dementia, practical support, coping, finding company, and information provisioning on local services - <i>Control</i> : no access to DEM-DISC	2 months; DEM-DISC is accessible via the internet	Camberwell Assessment of Need for the Elderly Use of services list Short Sense of Competence Questionnaire Pearlin Mastery Scale	Needs assessment Actual care and welfare use Feeling of competence Self-efficacy	P < .05 NS P < .05 NS	
(de Rotrou et al., 2011) France	RCT N = 167 FC-patient dyads IG = 81 dyads CG = 86 dyads BL, PI, FU	- <i>Treatment</i> : Psycho-educational program (PEP): different aspects of dementia, problem-solving techniques and coping strategies, behavioural management, communication, crisis management, resource information and practical advice - <i>Control</i> : usual care, waitlist	12 x weekly 2-hr structured sessions, including groups of 6–10 caregivers	Montgomery and Asberg Depression Rating Scale Zarit Caregiver Burden Interview Sense of Competence Questionnaire Visual Analogue Scales (VAS)	Depressive symptoms Burden Sense of competence Disease understanding Ability of coping	NS NS NS P < .01 NS	NS NS NS P < .001 P < .05

Keys: RCT: Randomised Controlled Trial; NRCT: Non-Randomised Controlled Trial; FC: Family/informal caregiver; Vol: Volunteers; OA: Older adults; ST: Students; IG: Intervention Group; CG: Controlled Group; ADL: Activities of daily living; IADL: Instrumental activities of daily living; * Significant main (group) effects in favour of the intervention group (if not otherwise noted); ** Significant effects between PI and FU; GT: Group x Time interaction effect; NS: Not significant; BL: Baseline; PI: Post-intervention; FU: Follow-up; wks: weeks; hrs: hours; AD: Alzheimer's Disease; QoL: Quality of life

Figure captions

Figure 1: Flow diagram of the review process according to PRISMA guidelines

Figure 2. Standardised mean difference (SMD) in pre- and post-test knowledge scores between intervention and control groups (8 studies; $p=0.003$)

Figure 3. Standardised mean difference (SMD) in pre-test and follow-up knowledge scores between intervention and control groups (3 studies; $p=0.622$)

Figure 4. Standardised mean difference (SMD) in pre- and post-test self-efficacy scores between intervention and control groups (5 studies; $p=0.038$)