

Is training for informal caregivers and their older persons helpful? A systematic review



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ABSTRACT

Background: The steady increase in the number of people suffering from chronic diseases and increasing life expectancy raises new demands on health care. At the same time, the need for informal caregivers is increasing. This study aims to perform a systematic review of the methodologies used to identify effect of different types of training on informal caregivers and their older persons.

Methods: MEDLINE (PubMed), CINAHL and Ovid were searched from December 2016 and April 2017. The following keywords were used; "informal caregiver", "training" "elderly", "older persons". Identified publications were screened by using the following inclusion criteria; systematic reviews, randomized controlled trials, prospective cohort and multicentre studies, English language full text journals, samples or interventions that included caregivers of older persons and published in last 10 years.

Results: Twenty four studies (12 randomised control trials, 8 intervention studies and 4 systematic reviews) were included. Most of the randomized controlled trials involved both caregivers and elderly. Pretests and post-tests were used in intervention studies (5 out of the 8 studies). ICT-based, psychosocial interventions on family caregivers' education program for caregivers were applied. Caregivers following a supportive educative learning had a significantly better quality of life.

Conclusions: The findings of this systematic review suggest that support interventions for caregivers can be effective in reducing caregivers' stress, with a consequent improvement of the quality of care. However, results are based on relatively small studies, reporting somewhat controversial findings supporting the need to perform further research in this field.

1. Background

The steady increase in the number of people suffering from chronic, oncological diseases and increasing life expectancy raises new demands on health care. At the same time, the need for informal caregivers to take care of older persons suffering from chronic diseases is increasing. Informal caregivers are usually family members or friends who provide unpaid care for an individual (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014).

Informal caregivers play a key role in nursing such patients with chronic diseases especially for older persons. According to the European Union statistics 8% of caregivers took care of older persons or disabled patients this less than once a week, 3% did this once a week, 4%

provided care once or twice a week. Experts have estimated that in 2030 (US) the number of caregivers aged 25 and older will reach 21.5 million and they will take care of the sick/provide care for at least 20 h per week (National Alliance for Caregiving & AARP, 2015).

Finding out a diagnosis is a significant stressor for both the patient and their family members. This constitutes an additional fear and challenge that requires informal caregivers to provide direct assistance in the daily activities of patients, the administration of medicine, transportation, cooking, advocating for health care and emotional support (Shebl & Abd Elhameed, 2014; Silva, Teixeira, Teixeira, & Freitas, 2013).

Caregivers who are primarily motivated by a sense of duty, guilt or social pressure are more likely to suffer greater psychological distress

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than caregivers with positive motivations (Bevans & Sternberg, 2012).

Many studies indicate the negative effects of care on informal caregivers: quality of life decreases, there is an aspect of increased costs, feelings of depression, loneliness and economic problems which tend to increase. This is a consequence of insufficient support and unmet needs (Adelman et al., 2014; Peeters, Van Beek, Meerveld, & Francke, 2010).

Caregiver training might have advantages of reducing health care costs, improving the patients' quality of life and at the same time, it reduces the caregiver's anxiety, stress and helps to create better social relations with the care receiver. Also, caregiving can make people confident about their own abilities (Peeters et al., 2010). Furthermore, the needs of patients and caregivers require ongoing nursing assessment and adaptation of interventions in response to changing needs to optimize quality of life for both the older persons and caregiver. Meeting these needs can help caregivers to provide more appropriate care. Our objective was to perform a systematic review of the methodologies used to identify effect of different types of training on informal caregivers and their older persons.

2. Methods

2.1. Design

The methodology used for this systematic review was based on the Preferred Reporting Items for Systematic Reviews and Meta-analysis of studies that evaluate informal caregivers and their older person's healthcare interventions (PRISMA) statement (Liberati et al., 2009; Moher, Liberati, Tetzlaff, & Altman, 2009).

2.2. Search methods

Electronic search strategies used for identifying the relevant studies were performed by the working group between December 2016 and April 2017. Searches were conducted in the following databases: MEDLINE (PubMed), CINAHL and Ovid. The following keywords were used; "informal caregiver", "training" "older persons".

2.3. Study selection

Identified publications were screened by using the following inclusion criteria; systematic reviews, randomized controlled trials (RCTs), prospective cohort and multicentre studies, English language full text journals, samples or applications that included caregivers of older persons and published in last 10 years. Conference abstracts, letters to the editor, case studies, qualitative researches, commentaries or professional caregivers were excluded. All eligible articles were screened first by title and abstract independently by the working group. Then two reviewers made the final decision.

2.4. Search strategy

At the initial search 1.158 articles were identified. After first selection based on abstracts, 90 full-text articles were examined in detail. Twenty four articles were selected for this systematic review. A flow chart of the search strategy is presented in Fig. 1.

3. Results

A total of 24 studies were included: 12 randomised control trials (RCT), 8 intervention studies and 4 systematic reviews. The methodological characteristics of the studies are summarized in Tables 1–3.

A total of 14.201 informal caregivers was included: $n = 1854$ in RCT (Table 1), $n = 1185$ in intervention studies (Table 2), and $n = 11.162$ in systematic reviews (Table 3).

3.1. Randomized control trials

Most of the randomized controlled trials involved both caregivers and patients. Informal caregivers and patients took part in both groups. Multicomponent educational programmes, methods of problem solving therapy, group psycho-educational intervention, case management and skills building strategies were applied in experimental groups. While the results of intervention studies had mostly positive effect on the informal caregivers' burden, stress levels, annual family caregiving costs, time that patients spent in hospital, older person's physical activity level and, food consumption, some interventions did not have any effect on these issues (see Table 1).

3.2. Intervention studies

Pre-tests and post-tests were used in intervention studies (5 out of the 8 studies). During these tests the carers' knowledge of memory and communication strategies, burden, positive perceptions of caregiving, and perceptions of problem behaviours were assessed. Interventions such as ICT-based, psychosocial intervention on family caregivers', education program for caregivers were applied with respect of study participants. Following these interventions, there was an improvement in caregivers' social contact with and support from other carers with similar experiences, and less need for information about the cared-for person's illness and caring. Also, the training group caregivers reported a reduction in the frequency of care recipient disruptive behaviours and increased perceptions of positive aspects of caregiving, both at a level approaching significance. In addition, follow-up visits (5 out of the 8 studies) took place after 3, 6 and 12 months, with a purpose to evaluate long-term effectiveness and benefits of training. Study results indicate that the maximum training effectiveness was after 3 and 6 months (Table 2).

3.3. Systematic reviews

A total of 4206 informal caregivers were included in systematic reviews. In one (Berthelsen & Kristensson, 2015) systematic reviews (6956 patients and their informal caregivers), a case management approach was applied in four studies, while three other studies used a psycho-educational intervention with core components of case management. Results of these interventions reduced patients' time to institutionalisation, municipal care costs and emotional health when informal caregivers were involved. A significant effect was also found on informal caregivers' decrease in depressive symptoms over time. In 13 studies using the pre-post design to investigate the effectiveness of a community-based educational program for family caregivers and improvement in caregivers' health-related quality of life was reported. (Table 3). Caregivers following a supportive educative learning had a significantly better quality of life (Berthelsen & Kristensson, 2015; Chiu et al., 2009; Marshall, Bauer, Capra, & Isenring, 2013; Núñez-Naveira et al., 2016; Oupra, Griffiths, Pryor, & Mott, 2010; Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008).

4. Discussion

The findings of this systematic review, based on relatively small studies, suggest that support interventions for caregivers can be effective in reducing caregivers' stress, with a consequent improvement of the quality of care.

The effect of telephone or email contacts, meditation and psychotherapy seems to play a role in determining an improvement in caregivers' quality of life. Two relatively small RCT performed in the United States (Chiu, Pauley, Wesson, Pushpakumar, & Sadavoy, 2015; Oken et al., 2010) gave a reduction in caregivers' distress; these results were obtained by mindfulness meditation intervention and the use of telephone contact, multi-component educational and psychotherapy,

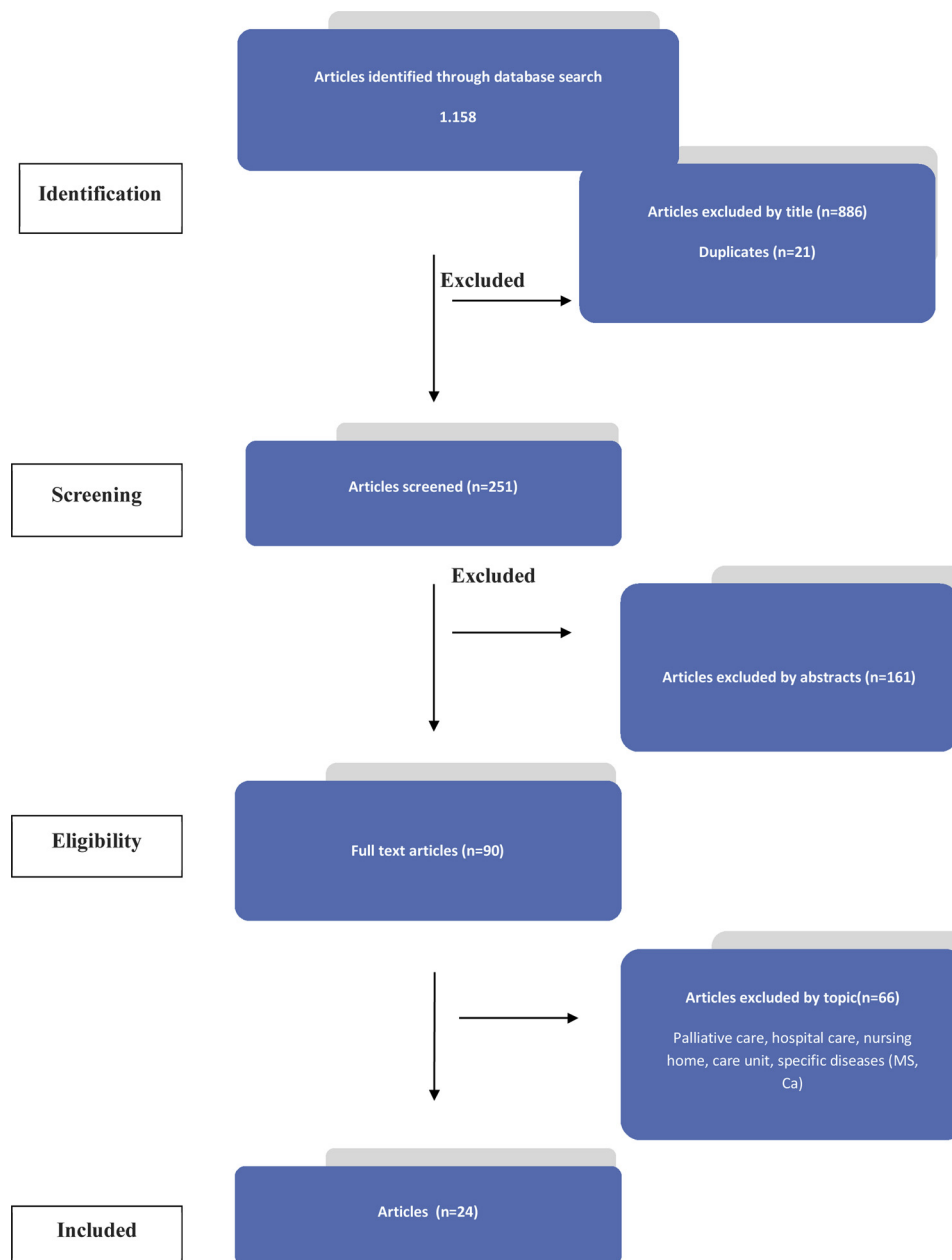


Fig. 1. PRISMA flowchart of literature search.

respectively. In their randomized controlled trial of 2014 in Spain, the EDUCA-II Randomized Trial, Carrasco et al recruited 238 dementia caregivers. One hundred fifteen of them were randomized to the psychoeducational intervention group (PIP), the remaining 123 were randomized to standard care. Results showed that psychoeducational intervention, on a level of group intervention was not better than standard care to reduce caregiver burden and overall psychological distress or to improve quality-of-life domains (Carrasco, Domínguez-Panchón, Fraile, Muñoz-Hermoso, & Ballesteros, 2014). Chodosh et al studied 151 patient-caregiver dyads in 2015, Los Angeles, USA. They compared in person visits at home and/or in the community as well as telephone and mail contact vs telephone and mail contact only. In both arms of the study, the quality of care improved substantially over time. Other endpoints, such as caregiver burden, care-recipient problem behavior, retention and health care utilization did not show any difference between the two groups (Chodosh et al., 2015).

Caregiver-oriented interventions as support for caregivers or multicomponent interventions have been investigated. A caregiver-oriented

intervention programme including 158 post stroke patients, improved the quality of care provided by family caregivers and a decreased likelihood of institutionalisation (Shyu, Kuo, Chen, & Chen, 2010). Elonemi-Sulkava et al. (2009) included couples with dementia at random to the intervention or control group. A multicomponent intervention program with a family care coordinator, a geriatrician, support groups for caregivers, and individualized services was provided and gave an approximately 30% savings in total costs per family per year, whereas the intervention did not result in a significant long term (2 years) difference in the need for institutional care. Alternatively, a study investigating the effect of the intervention of case managers did not show any effect on caregivers (Jansen et al., 2011).

In Canada, Chiu et al performed a concurrent, matched cohort design in 2015. Fifty six caregivers were equally allocated to a problem-solving techniques-based intervention group, or the control arm. The problem-solving technique-based interventions were based on adapted Problem Solving Therapy (PST) methods. Carers in the intervention group showed significantly improved task-oriented coping, mastery,

Table 1
Methodological characteristics of the included RCT studies.

Authors, year, country	Study design	Population	Intervention	Outcomes (Results)
Gant et al., 2007 USA (Gant, Steffen, & Lauderdale, 2007)	RCT (Blinded outcome assessment)	32 men who were caring for a family member with dementia	Telephone Multi-component Educational Psychotherapy	There was a significant effect for time across both the educational booklet/check-in call group and the video/coaching groups. Both conditions showed a reduction in caregivers' distress.
Shyu et al., 2009 Taiwan (Shyu et al., 2010)	Randomised experimental design	158 older patients with stroke (72 in the experimental group and 86 in the control group) and their family caregivers	Caregiver-oriented intervention programme	Intervention programme succeeded in improving quality of care provided by family caregivers to older patients with stroke and in decreasing the likelihood of their institutionalisation
Eloniemi-Sulkava et al., 2009 Finland (Eloniemi-Sulkava et al., 2009)	RCT (two armed). Measurements at screening, baseline, 6, 12/18 and 24 months	Couples with dementia (N = 125) were allocated at random to the intervention (n = 63) or control group (n = 62)	Multicomponent intervention program with a family care coordinator, a geriatrician, support groups for caregivers, and individualized services	Individualized and coordinated care and working in collaboration with the couples reduced the use of municipal services and suggested approximately 30% savings in total costs per family per year but the intervention did not result in a significant difference in the need for institutional care after 2 years
Oken et al., 2010 Oregon/USA (Oken et al., 2010)	Pilot randomized trial. Two comparison groups: an education class based on Powerful Tools for caregivers serving as an active control group and a respite-only group serving as a pragmatic control.	Community-dwelling 33 caregivers aged 45–85 years of close relatives with dementia	Mindfulness meditation intervention adapted from the Mindfulness-Based Cognitive Therapy program	There was a significant effect on RMBPC by group covarying for baseline RMBPC, with both active interventions showing improvement compared with the respite-only group. There was an intervention effect on the caregiver self-efficacy measure and on cognitive measures. Although mindfulness was not impacted by the intervention, there were significant correlations between mindfulness and self-rated mood and stress scores.
Jansen et al., (2011) The Netherlands (Jansen et al., 2011)	RCT (two armed)	99 dyads of persons with early symptoms of dementia and their primary informal caregiver	Case management and usual care Traditional case management: assessment, advice giving, coordination, organising collaboration and monitoring of care	Both mindfulness and education interventions decreased the self-rated caregiver stress compared to the respite-only control.
Chiatti et al., 2014 Italy (Chiatti et al., 2015)	RCT	Community-dwelling patients with moderate stage Alzheimer's disease and their caregivers. 438 patient-caregiver dyads were recruited and randomized	Composed of case management interventions, nurse visits, assistive technology and educational brochures (The UP-TECH project)	Linear mixed model analyses showed no statistically significant and clinically relevant differences over time between the two groups.
Carrasco et al., 2014 Spain (Carrasco et al., 2014)	2-arm parallel randomized trial The EDUCA-II Randomized Trial	The trial recruited 238 dementia caregivers from 22 research sites (115 randomized to PIP, 123 randomized to standard care)	Group psychoeducational intervention (PIP) and standard care in dementia caregivers	There is only baseline data.
Chodosh et al., 2015 Los Angeles, USA (Chodosh et al., 2015)	RCT (two arms)	151 patient-caregiver dyads	In-person visits at home and/or in the community plus telephone and mail, versus telephone and mail only	PIP in modality of group intervention was not better than standard care to reduce caregiver burden and overall psychological distress or to improve quality-of-life domains
Chiu et al., 2015 Toronto-Canada (Chiu et al., 2015)	A concurrent, matched cohort design.	56 carers were equally allocated to a problem-solving techniques-based intervention group or a control arm.	Problem-solving techniques-based intervention based on adapted Problem-solving therapy (PST) methods	Care quality improved substantially over time in both arms. Caregiver burden, care-recipient problem behaviours, retention, and health care utilization did not differ across arms
Tanner et al., 2015 Baltimore (Tanner et al., 2015)	RCT (18 month)	289 community-living care recipient (CR)/ informal caregiver dyads.	Caregiver dementia education and skill building strategies; and care progress monitoring by an interdisciplinary team	Caregivers in the intervention group showed significantly improved task-oriented coping, mastery, and competence and significantly reduced emotion-oriented coping, burden and stress. Control carers showed no change.

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Table 1 (continued)

Authors, year, country	Study design	Population	Intervention	Outcomes (Results)
James et al., 2015 Australia (James et al., 2015)	Two-group pragmatic RCT	Cancer survivors and carers (n = 174) At 20-weeks, (n = 46) of the intervention group, and (n = 48) of the control group were retained.	Theory-based, group-delivered, face-to-face multiple health behaviour change intervention. The Exercise and Nutrition Routine Improving Cancer Health (ENRICH)	potentially clinically-relevant reduction in self-reported number of hours caregivers spent with the CR for MIND participants compared with controls At 20 weeks, the intervention group had increased by 478 steps, and the control group had decreased by 1282 steps; Significant intervention effects for secondary outcomes, included a half serving increase in vegetable intake, weight loss (kg) and change in body mass index No significant intervention effects were found for self reported PA, total sitting time, waist circumference, fruit, energy, fibre, alcohol, meat, or fat consumption. The caregivers in the experimental group significantly decreased their depressive symptomatology, but a possible benefit on their feelings of competence and satisfaction with the caring experience was also observed.
Núñez-Naveira et al., 2016 Denmark, Poland, and Spain (Núñez-Naveira et al., 2016)	A pilot randomized controlled pre-post intervention trial	61 informal caregivers of people with dementia; experimental (n = 30) or control (n = 31) groups.	An e-learning platform (understAID application) was tested by informal caregivers.	

Table 2
Methodological characteristics of the included intervention studies.

Authors, year, country	Study design	Population	Intervention	Outcomes (Results)
Torp et al., 2008 Norway (Torp et al., 2008)	Pilot intervention study	19 older persons spousal carers of older persons with dementia or stroke	ICT-based ACTION [use of information and communication technology (ICT)] (At the outset of the study, participant families received a modern broadband-linked personal computer (PC), and an ICT course consisting of three 3-hour classes dispersed over a 3-week period)	At follow-up, quantitative measures did not reveal any reduction in carer stress or mental health problems. After taking part in the study for a year carers reported extensive use of the ICT service, more social contacts and increased support and less need for information about chronic illness and caring social and practical support
Andren et al., 2008 Sweden (Andrén & Elmståhl, 2008)	Psychosocial intervention	308 family caregivers: 153 caregivers who underwent intervention and 155 control caregivers	Psychosocial intervention on family caregiver's (5-week programme and 3-month conversation group)	The proportion of low burden increased in both groups after 6 months, and all indices except disappointment improved. The intervention group experienced significantly lower strain and disappointment after 6 months, and this trend remained after 12 months Non-users reported higher levels of burden post-intervention, and frequent users showed post-intervention reduction in experienced burden
Chiu et al., 2009 Canada (Chiu et al., 2009)	Intervention study - Quantitative study	28 family caregiver of older persons with Alzheimer disease	Internet-based caregiver support	The family caregivers in the intervention group had a significantly better quality of life than the comparison group and they also reported less strain
Oupra et al., 2010 Taiwan (Oupra et al., 2010)	Non-randomised comparative study with concurrent controls, using a two-group pre-test and post-test design.	A total of 140 stroke survivors and 140 family caregivers were recruited; 70 patients / caregiver pair in each group.	Supportive Educative Learning programme for family caregivers (SELF)	
Liddle et al., 2012. Australia (Liddle, Smith-Conway, Baker, Angwin, & Gallois, 2012)	Pre-post-test controlled trial program	Twenty-nine dyads (13 training group, 16 control group) Care givers-care recipients dyads (living at home)	DVD based training program Measures of the carers' knowledge of memory and communication strategies, burden, positive perceptions of caregiving, and perceptions of problem behaviours were taken pre- and three months post intervention.	A significant improvement was found in caregivers' knowledge for the training group. The training group caregivers reported a reduction in the frequency of care recipient disruptive behaviours and increased perceptions of positive aspects of caregiving, both at a level approaching significance. The training group care recipients had increased frequency of verbally communicated depressive behaviours. The frequency of observed depressive behaviours was not significantly different between groups.
Bass et al., 2013 USA (Bass et al., 2013)	Intervention study (with comparison group)	486 caregivers. The 6-month follow-up interview collected data on shorter-term outcomes and was completed by 394 of the 486 caregivers (81.1%); the 12-month follow-up interview collected data on longer-term outcomes and was completed by 324 of the 486 caregivers (66.7%)	Effectiveness of PDC, a model care-coordination program delivered through a partnership between a healthcare organization and community service organization Partners in Dementia Care (PDC), integrates and improves access to medical and nonmedical services, while strengthening the informal care network and providing information, coaching, and emotional support.	In the first 6-month, the intervention group had significantly lower scores for four of the five adverse outcomes (unmet need, role captivity, physical health strain, depression) and higher scores for both positive outcomes (caregiver support service use, number of informal helpers). Equations for 12-month outcomes had fewer significant intervention- and comparison-group differences. Only unmet need and relationship strain significantly improved for the intervention group in the second 6 months, and both of these were conditional effects. Caregivers showed a significant gain in knowledge of how to effectively assist with communication and nutrition, transfers and toileting, and bathing and dressing of their care recipients WICM reduced subjective burden of informal caregivers. The effects of the WICM on informal caregivers are promising but modest.
DiZazzo Miller et al., 2014 USA (DiZazzo-Miller, Samuel, Barnas, & Welker, 2014)	Pre-test-post-test research design with a 3-mo follow-up	72 family caregivers	Manualized education program for caregivers. The 6-hr training was delivered to caregivers over 3 consecutive weeks (2 hr/wk) by trained clinicians	Integrated care intervention by general practices (the Walcheren Integrated Care Model WICM)
Janse et al., 2014 The Netherlands (Janse, Huijsman, & Fabbricotti, 2014)	Quasi experimental questionnaire before-after 12 months	Frail older persons individuals living independently (75,+ age, 375 person) and their informal caregivers (103 person) experiment and control groups		

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Table 2 (continued)

Authors, year, country	Study design	Population	Intervention	Outcomes (Results)
				No effects were observed on perceived health, time investment and QoL.

Table 3
Methodological characteristics of the included systematic reviews.

Authors, year, country	Study design	Population	Intervention	Outcomes (Results)
Hurley et al., 2014 (Hurley, Patterson, & Cooley, 2014) Marshall et al., 2013 (Marshall et al., 2013)	Review of the empirical literature Systematic review	Eight studies (181 caregivers) Nine studies (2333 caregivers)	Empirical study of a meditation-based intervention Intervention studies on nutrition-related interventions delivered to or by informal carers and non-clinical community care workers on malnutrition-related health outcomes of community-dwelling older adults	Meditation-based interventions do indeed improve levels of depression and burden in family dementia caregivers Five interventions were targeted at identifying, preventing and/or treating malnutrition specifically. As a result of these interventions, nutritional status improved or stabilized. No study reported an improvement in functional status but two successfully prevented further decline in their participants Significant effects of case management interventions were seen on patients' time to institutionalisation, municipal care costs and emotional health when informal caregivers were involved. A significant effect was also found on informal caregivers' decrease in depressive symptoms over time.
Berthelsen et al., 2015 (Berthelsen & Kristensson, 2015)	Systematic review	Seven studies (5 RCTs) including a total of 6956 patients over the age of 65 and their informal caregivers (spouses, family members, and close relatives) all in community-care settings were found eligible and included in the review	A case management approach (coordination, assessment, giving advice and information, planning, organising, collaborating and monitoring of care) was claimed in four studies and the remaining three studies used a psycho-educational intervention with core components of case management consistent with the literature	
Akyar et al., 2016 Turkey (Akyar, Dionne-Odom, & Bakitas, 2016)	Systematic review	13 studies; Ten studies were cross-sectional descriptive design, 2 were qualitative, one was intervention (1692 caregivers)	Pre-post design to investigate the effectiveness of a community-based educational program for family caregivers of patients with Alzheimer disease) (one study)	Structured education intervention was effective in improving caregivers' health-related quality of life.

and competence and significantly reduced emotion-oriented coping, burden and stress. Control carers showed no change (Chiu et al., 2015).

Tanner et al studied 289 dyads of community living care-recipients with the diagnosis dementia and their informal caregivers. The used intervention was MIND at home, a program to educate caregivers, and offer them skill building strategies. Care progress was monitored by an interdisciplinary team in both arms of the 18 month during study. Total percent of unmet caregiver needs declined in both groups from baseline to 18 months, but there was no statistically significant between-group difference. There were no significant group differences in most caregiver burden measures, depression or quality of life. There was a potentially clinically-relevant reduction in self-reported number of hours caregivers spent with the care recipient enrolled in MIND at home participants compared with controls (Tanner et al., 2015).

Very interestingly, a study investigating multiple health behaviour change intervention in cancer survivors and carers found that physical activity was increased in participants who were educated to change their health behaviour. Within the framework of a randomized controlled trial, participants were allocated to an intervention group (n = 46) or control group (n = 48). A theory-based, group-delivered, face-to-face multiple health behaviour change intervention was implemented (the Exercise and Nutrition Routine Improving Cancer Health (ENRICH)). At 20 weeks, the intervention group had increased their physical activity with 478 steps, compared with a decrease of 1282 steps in the control group. Secondary outcomes such as vegetable intake increase, weight loss and change in body mass index also improved (James et al., 2015).

Eventually, considering the time we are living the effect of an e-learning platform has been investigated. A pilot randomized controlled pre-post intervention trial was conducted by Núñez-Naveira different countries in Europe. Informal caregivers of patients with dementia were divided between the experimental (n = 30) and the control group (n = 31). An e-learning platform (understAID application) was tested by informal caregivers. Caregivers in the experimental showed a significant decrease in depressive symptoms. Also a benefit on feelings of competence and satisfaction with the caring experience also observed (Núñez-Naveira et al., 2016).

In conclusion, in this systematic review we have found that support interventions for caregivers can reduce caregivers' stress, with a possible consequent improvement of the quality of patients' care. However, results are based on relatively small studies, reporting somewhat controversial findings supporting the need to perform further research in this field.

Conflict of interest

There are no known conflicts of interest.

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