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, Delgano, 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 Elnagheem, 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
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,
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). Eloniemi-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,
There was a significant effect on RMBPC by group. 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. The Mindfulness meditation intervention, adapted from the Mindfulness-Based Cognitive Therapy program, 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. Both mindfulness and education interventions decreased the self-rated caregiver stress compared to the respite-only control. Linear mixed model analyses showed no statistically significant differences over time between mindfulness and self-rated mood and stress.

Table 1

<table>
<thead>
<tr>
<th>Authors, year, country</th>
<th>Study design</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes (Results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jansen et al., 2011</td>
<td>RCT (two armed)</td>
<td>Community-dwelling patients with early symptoms of dementia, 49 caregivers</td>
<td>Mindfulness and education intervention adapted from the Mindfulness-Based Cognitive Therapy program</td>
<td>Caregiver-oriented intervention program: Multicomponent intervention program with a family care coordinator, a geriatrician, support groups for caregivers, and individualized services. Care quality improved substantially over time in both arms. Caregiver burden, case-report problem behaviors, retention, and health care utilization did not differ across arms.</td>
</tr>
</tbody>
</table>

There is only baseline data.

There were no significant group differences in most caregiver outcomes, except for self-rated mood and stress, where mindfulness showed a significant and clinically relevant difference over time between the two groups.  

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<th>Population</th>
<th>Intervention</th>
<th>Outcomes (Results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot randomized trial</td>
<td>99 dyads of persons aged 45–64 years and their family caregivers</td>
<td>Mindfulness and education intervention adapted from the Mindfulness-Based Cognitive Therapy program</td>
<td>Care quality improved substantially over time in both arms. Caregiver burden, case-report problem behaviors, retention, and health care utilization did not differ across arms.</td>
</tr>
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<td>RCT (two armed)</td>
<td>Community-dwelling patients with early symptoms of dementia, 49 caregivers</td>
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<tbody>
<tr>
<td>James et al., 2015</td>
<td>Two-group pragmatic RCT</td>
<td>Cancer survivors and carers (n = 174) At 20-weeks, (n = 46) of the intervention group, and (n = 48) of the control group were retained.</td>
<td>Theory-based, group-delivered, face-to-face multiple health behaviour change intervention. The Exercise and Nutrition Routine Improving Cancer Health (ENRICH)</td>
<td>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.</td>
</tr>
<tr>
<td>Núñez-Naveira et al., 2016</td>
<td>A pilot randomized controlled pre-post intervention trial</td>
<td>61 informal caregivers of people with dementia; experimental (n = 30) or control (n = 31) groups.</td>
<td>An e-learning platform (underAID application) was tested by informal caregivers.</td>
<td>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.</td>
</tr>
</tbody>
</table>
The family caregivers in the intervention group had a significantly better quality of life than the comparison group. A significant improvement was found in caregivers' support, and frequent users showed reduced burden and disappointment after 6 months, and this trend remained after 12 months.

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.

### Table 2

<table>
<thead>
<tr>
<th>Author(s), Year, Country</th>
<th>Study Design</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes (Results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Torp et al., 2008, Norway (Torp et al., 2008)</td>
<td>Pilot intervention study</td>
<td>140 stroke survivors</td>
<td>Internet-based caregiver support</td>
<td>Decreased subjective burden, improved quality of life.</td>
</tr>
<tr>
<td>Andren et al., 2008, Sweden (Andrén &amp; Elmståhl, 2008)</td>
<td>Pre-post-test controlled trial program</td>
<td>70 patients with dementia and 155 caregivers</td>
<td>Integrated care intervention by general practices (the Walcheren Integrated Care Model WICM)</td>
<td>Improved health outcomes, reduced subjective burden.</td>
</tr>
<tr>
<td>Oupra et al., 2010, Canada (Chiu et al., 2009)</td>
<td>Quasi experimental study</td>
<td>140 family caregivers</td>
<td>WICM reduced subjective burden of informal caregivers.</td>
<td>Promising but modest effects.</td>
</tr>
<tr>
<td>Liddle et al., 2012, Australia (Liddle, Smith-Conway, Baker, et al., 2012)</td>
<td>Pre-post-test research design</td>
<td>6-month follow-up interview with caregivers</td>
<td>Integrated care intervention (with 3-mo follow-up interview)</td>
<td>Improved health outcomes, reduced subjective burden.</td>
</tr>
</tbody>
</table>

The effects of the WICM on informal caregivers are promising but modest.
Table 2 (continued)

<table>
<thead>
<tr>
<th>Authors, year, country</th>
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<th>Population</th>
<th>Intervention</th>
<th>Outcomes (Results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No effects were observed on perceived health, time investment and QoL</td>
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</table>

Table 3

Methodological characteristics of the included systematic reviews.

<table>
<thead>
<tr>
<th>Authors, year, country</th>
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<th>Intervention</th>
<th>Outcomes (Results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hurley et al., 2014 (Hurley, Patterson, &amp; Cooley, 2014)</td>
<td>Review of the empirical literature</td>
<td>Eight studies (181 caregivers)</td>
<td>Empirical study of a meditation-based intervention</td>
<td>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.</td>
</tr>
<tr>
<td>Marshall et al., 2013 (Marshall et al., 2013)</td>
<td>Systematic review</td>
<td>Nine studies (2333 caregivers)</td>
<td>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. 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.</td>
<td></td>
</tr>
<tr>
<td>Berthelsen et al., 2015 (Berthelsen &amp; Kristensson, 2015)</td>
<td>Systematic review</td>
<td>Seven studies (5 RCTs) including a total of 6956 patients over the age of 65 and their informal caregiving spouses, family members, and close relatives) all in community-care settings were found eligible and included in the review</td>
<td>A case management approach (coordination, assessment, giving advice and information, planning, organizing, 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</td>
<td>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.</td>
</tr>
<tr>
<td>Akyar et al., 2016 (Akyar, Dionne-Odom, &amp; Bakitas, 2016)</td>
<td>Systematic review</td>
<td>13 studies; Ten studies were cross-sectional descriptive design, 2 were qualitative, one was intervention (1692 caregivers)</td>
<td>Pre-post design to investigate the effectiveness of a community-based educational program for family caregivers of patients with Alzheimer disease (one study)</td>
<td>Structured education intervention was effective in improving caregivers’ health-related quality of life.</td>
</tr>
</tbody>
</table>
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 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-Navéria 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-Navéria 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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