Psychosocial Interventions for Caregivers for Persons with Dementia to Increase Caregiver Well-being

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Introduction

Dementia has been reported as a healthcare issue of epidemic proportions (Mendez & Cummings, 2003). In countries such as the United States, Canada, and Western Europe where life expectancies are longer, the prevalence of dementia among the elderly is about 8% to 10%. (Evans, Scherr, Smith, Albert & Frankenstein, 1990). There are about 5 million Americans living with the progressive disease of dementia, in the United States (Alzheimer's Association, 2013). In 2012, it was estimated that 15.4 million caregivers provided 17.5 billion hours of unpaid care, and that the average age of caregivers for individuals with dementia is between 50 to 64 years of age (Alzheimer's Association, 2013). Sixty percent of caregivers are women with 83% being relatives (Thinnes & Padilla, 2011).

The role of a caregiver can be a stressful 24-hour-per-day job and can lead to a decreased occupational balance. More than half of dementia caregivers rate the emotional stress of caregiving as high, and often will experience symptoms of decreased well-being, including: increased amounts of denial, anger, social withdrawal, anxiety, depression, exhaustion, sleepiness, irritability, lack of concentration, and lack of interest in previously desired occupations. This can lead to additional health problems (Alzheimer's Association, 2013).

Background Literature

Evidence has shown that caregivers of people with dementia visit healthcare professionals more often, have increased health problems, use more medication than other people their age, and commonly suffer from social isolation (Van Mierlo, Meiland, Van der Roset & Droes, 2011). Effective psychosocial interventions can prevent caregivers from feeling overburdened. Caregivers often have unmet needs, including information or support related to symptoms of dementia, social interaction, health, and safety (Van Mierol et al., 2011). Additionally, caregiver's stress can lead to increased frequency of negative outcomes, including caregiver burden and illness (Van Mierlo et al., 2011).

According to Van Mierlo et al., (2011) researchers examined which characteristics of dementia patients or of their living situation were connected to positive outcomes of psychosocial interventions. This research provided a detailed overview of effective psychosocial interventions designed for the person with dementia (Van Mierlo et al., 2010). Our review is different. We are addressing effective psychosocial interventions for the caregiver rather than the client with dementia. Furthermore, we are addressing how this intervention increases caregiver well-being.

Due to increased incidence of dementia in the United States, more research is required. Other countries have been quicker to address this issue. In addition, we know that the burden placed on the caregiver can be onerous and should be reduced when possible. Evidence shows that those who care for people with dementia are more likely to experience depressed mood, report a higher burden, and have poor general health compared to those caring for people with other long-term conditions (Brodaty & Green, 2002). However, we do not know how effective psychosocial interventions are in increasing well-being. Psychosocial interventions use cognitive-behavioral, behavioral, and supportive interventions to relieve burden (Pain Research Center, n.d.). These include patient education, interventions for stress management, psychotherapy, and group support (Pain Research Center, n.d.). Improved well-being can be defined as decreased caregiver burden, stress, anxiety, and depression, as well as increased quality of life (QOL) (Alzheimer's Association, 2013). Education is a key component of successful psychosocial interventions because it teaches caregivers effective coping strategies and problem solving. Psychosocial interventions are prevalent and most utilized by caregivers in the home when the client is in early stages of dementia. Because the majority of our evidence supports home-based interventions, we also want to explore whether psychosocial interventions had any effect on caregivers of persons with dementia in long-term care (LTC).

Evidence supports that health care providers should attempt to provide preventative support that monitors the health and well-being of the caregiver. By providing psychosocial interventions for family caregivers through training and support, caregivers can maintain their own well-being. Occupational therapy that includes cognitive and behavioral interventions for people with dementia and their caregivers has been shown to be cost effective, increase caregiver competence, and improve QOL (Graf et al., 2009). In addition, caregiver support groups bring caregivers together to provide useful coping strategies (Zarit & Zarit, 2008).

Objectives

Caregivers often experience increased burden of care. Family members who care for a person with dementia often experience chronic stress, which can have detrimental effects on the caregiver. This leads to the question: do family caregivers for persons with dementia who receive psychosocial interventions at home or in LTC experience improved well-being? Based on previous research on interventions for these caregivers, the aim of this systematic review is to identify an effective intervention that reduces the burden placed on the caregiver. Through research we found that psychosocial interventions were commonly found to be effective. The purpose of this review is to examine previously conducted evidenced-based research on this topic to see if caregivers experience improved well-being. It is important for healthcare professionals to find effective interventions that increase the overall QOL of a caregiver by providing appropriate care and support. Additional information is required to judge the effectiveness of this type of interventions for caregivers.

Statement of the Problem

Caregiver burden and well-being is a major concern that requires attention for caregivers of dementia patients. Often, caregivers experience increased stress, anxiety, and depression. Healthcare professionals should address this problem and utilize effective psychosocial interventions aimed to relieve caregiver burden and improve well-being.

We are conducting this systematic review to show the need for more research in the United States. Seventy-five percent of the articles were reviewed were conducted in a country other than the United States. Additionally, we are conducting this systematic review because previous research has focused on the well-being and QOL of clients with dementia. However, we are now seeing the importance of addressing caregiver burden. This can be correlated to the aging population in our society. Caregiver education can enhance psychosocial interventions for healthcare providers because it can help to provide effective care.

Methods for Conducting the Systematic Review

We conducted this systematic review using databases including: EBSCO, PsychINFO, and Proquest to search for articles to appraise. We screened all databases using identified search terms, which were from commonly created lists. Our previously learned knowledge on the subject matter contributed to our search methods.

Inclusion and Exclusion Criteria

We critically reviewed each article by establishing inclusion and exclusion criteria to help determine if the research articles were applicable for examination. We initially expected that this review would be limited to research studies providing evidence about the effectiveness of community-based psychosocial interventions in any setting, such as: nursing homes, long-term care facilities, hospitals, or homes. Due to the enormous amount of research we found regarding psychosocial interventions, we narrowed the search. We excluded all settings except the home setting; this exclusion criteria narrowed the search too much. We then incorporated settings that included home and LTC when we were searching for relevant articles to help answer our research question.

The inclusion criteria for selection included the following: (1) research must incorporate family caregivers for persons with dementia in the intervention; (2) research must conduct a psychosocial intervention within community-based settings only within the home or LTC; (3) articles were published between 2008 and 2013; (4) the subjects of the research, or family caregivers were of any age, gender or ethnicity; (5) only English studies were considered; (6) all geographic locations were considered; (7) articles were peer-reviewed; (8) the methodological quality of the study was reviewed at a level 1-4, based on the threshold approach (Costa, 2013).

The exclusion criteria for selection included the following: (1) research was excluded when it was not centered around a family caregiver for a person with dementia (2) we excluded research when not centered on a community-based (home and LTC) psychosocial intervention (3) articles were older than 2008; (4) research was not English; (5) research had a methodological quality reviewed below a level 4 study, based on the threshold approach (Costa, 2013).

Article Identification and Collection

We conducted a literature search to identify publications pertaining to psychosocial interventions, specifically addressing home-health and LTC facilities. The electronic databases we used to search for evidence-based articles for this systematic review were EBSCO, PsychINFO, and Proquest. We developed search terms related to the focus of this review in conjunction with Dr. Costa, who teaches occupational therapy research at Touro University Nevada. We conducted all searches using the term *caregivers for persons with dementia*. In addition, we used keyword combinations such as: *psychosocial intervention* yielding 22 articles, *occupational therapy and quality of life* yielding four articles, *occupational therapy and well-being* yielding three articles, *occupational therapy and QOL* yielding seven articles, and *quality of life* yielding 145 articles. We used only the EBSCO, PsychINFO, and Proquest databases.

Approach to Appraisal of Articles to be Included in the Review and Peer Review Process

We identified a total of 27 publications relevant to psychosocial interventions for caregivers for persons with dementia that decrease caregiver burden in this literature search. We obtained copies of all articles as PDF files and reviewed them thoroughly. Of these research studies, we identified 18 using the inclusion and exclusion criteria. We excluded three articles from this review because they were systematic reviews. We excluded another article because it was a protocol. In addition, we excluded two articles because the psychosocial intervention was designed for the client with dementia and not intended for the caregiver. We appraised and ranked the remaining 12 studies according to the level of evidence provided. All articles were critically appraised using the McMasters University Guidelines and Appraisal Forms for Critical Review (Law et al., 1998). We divided the articles evenly between us for critical appraisal. Each of us critically appraised six articles. We added the information from all 12 critical review forms to the AOTA Evidence Table after peer review. It was important to take into account the quality of evidence when interpreting the findings in the articles.

Results

Twelve reports of the 27 studies met our inclusion criteria (Table 1). The publications described a variety of psychosocial interventions for caregivers. All interventions varied in intensity, frequency, duration, and outcome measures. Nearly half of the studies are randomized controlled trials (RCT). Significant effects can be defined as $p<0.05$, where the intervention group showed statistical differences from the control group. The studies were appropriate for our review because they provided stronger levels of evidence and pertained to research criteria.

Outcome Measures and Strengths

The findings of the 12 included studies were classified into outcome categories with respect to psychosocial interventions: education (3 studies), effective intervention (3 studies), caregiver increased QOL (4 studies), caregiver decreased burden (4 studies), and increased QOL for client with dementia due to effective intervention (4 studies).

There were three studies that provided education for the caregivers during the psychosocial interventions within the study (Andren & Elmstahl, 2008; Bramble & Shum, 2011; & Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). There were four studies that measured QOL for caregivers for persons with dementia (Chien & Lee, 2011; Dias et al., 2008; Tschanz et al., 2013; & Taka, Takahashi, Iwamitsu, Oishi, & Miyaokai, 2011). Two of these studies used the World Health Measurement.

Several studies reported decreased symptoms and QOL of the client with dementia due to effective interventions for caregivers (Chien & Lee, 2011; Dias et al., 2008; Tschanz et al., 2013; & Taka, Takahashi, Iwamitsu, Oishi, & Miyaokai, 2011). Psychosocial interventions are statistically significant if we look at interventions given to caregivers for patients with mild forms of dementia (Andren & Elmstahl, 2008: Tschanz et al., 2013; & Takai et al., 2011). Decreased caregiver burden was reported as a result of the intervention (Chien & Lee, 2011; Andren & Elmstahl, 2008; Whitebird et al., 2012). Psychosocial interventions have also been identified as low-cost, making it a feasible intervention for caregivers (Whitebird et al., 2012).

A strength we found in our study is that caregiver QOL is more associated with negative psychological affects and caregiver burnout when patients are in the earlier stages of dementia. This highlights the need as to why psychosocial interventions are important for the caregiver to use from the onset of a family member being diagnosed with dementia.

Table 1

EVIDENCE TABLE TOPIC Psychosocial Interventions for Caregivers of Person's with Dementia

Author/ Year	Study Objectives	Level/Design/Subjects	Intervention and Outcome Measures	Results
Chien, W. T., &. Lee, I. Y.M. (2011).	Examined effectiveness of 6 month dementia care program for Chinese families caring for a relative with dementia compared to routine family support services.	RCT	- Psychosocial intervention, 6, 12 & 18 month follow-up - Each participant was assigned one case manager, who conducted weekly home visits Measures used: 1.Family Caregiver Burden Inventory 2.The World Health Organization Quality of Life Measure- Brief Version 3.Six-item Social Support Questionnaire 4.Family Support Services Index 5.Neuropsychiatric Inventory Questionnaire	Results at 18-month follow-up reported significantly greater improvements in: 1. Clients' symptoms 2. Institutionalization rates 3. Caregivers' QOL & burden Statistically significant differences between groups on improvement in caregivers' burden
Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010).	Test non-pharmacologic interventions (COPE program) realigning environmental demands with patient capabilities to reduce dependence, improve quality of life, and enhance engagement in activities.	RCT	- Baseline, 4, & 9 month follow-up - Treatment elements: assessments, caregiver education, & caregiver training to address caregiver concerns to help reduce stress. - 10 sessions over 4 months with occupational therapists, 1 face-to-face session, and 1 telephone. Measures used: 1.FIM 2.Quality of l Life-Alzheimer Disease Scale 3.Validated 5-item scale 4.Agitated in Behavior in Dementia Scale 5.Perceived Change Index 6. Investigator-developed items 7.11-item survey	At 4 months, COPE group demonstrated less functional dependence (p=.02). Measure outcomes: 1. FIM scores for IADLs (p=.007), 2. Improved engagement (p=.03), 3. Caregiver well-being (p=.002), 4. Confidence using activities (p=.002). No significant differences found between groups at 9 months. However, this could be due to large number of drop-outs.
Whitebird, R., Kreitzer, M., Crain, L., Lewis, B., Hanson, L., & Enstad, C. (2012)	Purpose of the Balance Study was to compare a mindfulness-based stress reduction (MBSR) intervention to a community caregiver education & support (CCES) intervention for family caregivers of people with dementia.	RCT	-Randomly assigned 78 family caregivers to MBSR or CCES intervention, matched for time and attention. Study participants attended 8 weekly intervention sessions & participated in home-based practice. Survey assessed psychosocial & caregiver burden at baseline, post-intervention, & 6 months. Outcome areas: 1. Stress, 2. Mental health (depression & anxiety), 3. Caregiver burden & 4. Social support. Measures used: 1. Perceived Stress Scale (PSS); 2. Center for Epidemiologic Studies Depression Scale (CES-D) & State-Trait Anxiety Inventory (STAI); 3. Montgomery Borgatta Caregiver; 4. Burden Scale Medical Outcomes Study Social Support Survey	MBSR was more effective at improving overall mental health, reducing stress, & decreasing depression than CCES. Both interventions improved caregiver mental health & were similarly effective at improving anxiety, social support, & burden.
Andren S, & Elmstahl S. (2008).	Evaluate efficacy of psychosocial intervention on family caregivers level of burden, satisfaction, and possible influence of caregiver's relationship, health, and patient's severity of the disease on the effects of intervention	RCT	Measures used: MMSE, Burger Scale, Katz Index -5 week program, met 2 hours once a wk. - Educated caregiver & assisted in development of coping skills -Sessions included advice about effective ways of responding to changes to their own quality of life. - Pre and post intervention (6 and 12 months) used to evaluate effectiveness of intervention & nonintervention on caregiver's outcome. Outcome areas: Caregiver's improved psychological well-being and/or social well-being.	- When caregivers received intervention, it had significant effects on outcomes. -The areas most affected were total burden after 6 months, and isolation & disappointment after 12 months. - Statistical significance when looking at intervention given to caregivers of patients with low severity of dementia.
Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, et al. (2008).	Develop & evaluate effectiveness of home based intervention in reducing caregiver burden, promoting caregiver mental health & reducing behavioral problems in persons with dementia.	RCT	Each community team had two Home Care Advisors (HCAs), a part-time local psychiatrist from public health services, and a part-time lay counselor (who was shared by both teams). Participants received intensive training for a week through role play & interactive training methods. Measures used: 1.) Socio demographic characteristics of the person with dementia and the caregiver 2.)Everyday Abilities Scale for India (EASI) 3.)Neuro-Psychiatric Inventory (NPI) Questionnaire 4.)Zarit Burden scale (ZBS) 5.)General Health Questionnaire (GHQ)	Treatment lowered risk of death during the 6 month period. However, reduction was not statistically significant. No significant difference in the baseline characteristics of those who died or were alive until the end of the trial (p.> 0.05 for GHQ, NPI-S, NPI-D, EASI, ZBS scores).

Level and Design

The remaining 12 studies, 5 RCTs, two quasi-experimental, two cohort, two cross-sectional, and one qualitative were ranked according to the level of evidence provided. The five RTCs are level one, the two quasi-experimental studies are a level two, the two cohort and two cross-sectional studies are level three, and the qualitative study is a level four (Costa, 2013).

Study Limitations

Several limitations can be identified in our study due to limitations of the studies we reviewed. There were small sample sizes used by the majority of the studies, while only two studies appear to have a larger sample size (Vasse et al., 2012; Whitebird et al., 2012). Convenience samples were used within some studies. This represents a problem because participants might have been more motivated during the intervention. Participants were not randomly assigned into the control or intervention group, methodology was not very clear, and there was a lack in obtaining ethnically diverse participants (Haberstroh, Neumeyer, Krause, Franzmann, & Pantel, 2011; Whitebird et al., 2012). Inter-reliability between professionals was not measured, the home setting was not included in practicability, and discriminatory capacity was not examined across participating countries (Vesse et al., 2012). The demographic characteristics for dementia were not representative (Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011). The general measures used were not representative of the outcome measures (Dias et al., 2008; Garcia-Alberca et al., 2012). Therefore, several of the studies we assessed did not provide standardized protocols for administration; this made it difficult to accurately theme outcomes from all the studies. We only included one LTC study in our systematic review; consequently, our study could be strengthened by researching more studies within the LTC setting. Occupational therapists are qualified to administer psychosocial interventions; however, they did not execute the psychosocial interventions in our studies.

There are several biases in our study. Ten studies had selection bias since they did not randomly assign participants. This occurred because the participants were required to meet the criteria of being a caregiver for persons with dementia; therefore, not everyone in the population had an equal chance of being selected to participate in the research studies (Chien & Lee, 2011; Gitlin et al., 2010; Andren & Elmstahl, 2008; Haberstroh et al., 2011; Bramble & Shum; Tschanz et al., 2013;Vasse et al., 2012; Takai et. al., 2011;Garcia-Alberca et al., 2012; (Vernooij-Dassen, Joling, Hout, & Sherman, 2010). In addition, selection bias occurred because the recruitment process consisted of caregivers who volunteered to participate in the study (Gitlin et al., 2010). Two studies had performance bias because the intervention groups were informed about the outcomes of the intervention before results of the study were obtained (Garcia-Alberca et al., 2012; Dias et al., 2008). Attrition bias was described; however, not all studies indicated how many participants dropped out (Gitlin et al., 2010; Bramble & Shum, 2011).

Narrative Synthesis

The outcomes can be categorized into themes. Four articles provided evidence that psychosocial interventions were statistically significant when reducing caregiver burden. Caregiver QOL and burden were found to diverge in a statistically significant manner between the intervention and control group (Chien & Lee, 2011). TANDEM training increased effective communication strategies and caregiver's moods significantly (Haberstroh et al., 2011). Caregiver QOL is associated to negative psychiatric symptoms such depression, burnout, and anxiety when patients with dementia are in early stages (Takai et al., 2011). Mindfulness-based stress reduction interventions appear to improve overall mental health, reduce stress, and decrease depression (Whitebird et al., 2012). However, post-intervention outcomes only show short-term benefits on caregiver stress reduction and depression (Gitlin et al., 2010; Whitebird et al., 2012).

The following articles have supported evidence on the benefits of psychosocial interventions. The COPE intervention by Gitlin, et al., (2010) demonstrated increased functional independence in IADLs, increased participation, caregiver well-being, and self-confidence. Caregiver burden was reduced while satisfaction with care increased (Andren & Elmstahl, 2008). The intervention proved that family knowledge about dementia was increased; however, caregiver satisfaction with staff was decreased while staff stress was increased (Bramble & Shum, 2011). The goal was to increase levels of satisfaction and decrease stress in the staff at LTC facility; however, the opposite effects of psychosocial interventions occurred. Quality indicators (QI) were defined based on selective strategies where 12 QIs were identified as key elements of psychosocial interventions that help to guide an effective program (Vasse et al., 2012). Evidence may be useful for designing treatment interventions that aim to modify the use of coping strategies and thus reduce caregiver anxiety and depression (Garcia-Alberca et al., 2012). Disengagement coping strategies were utilized and increased levels of anxiety, depression, and caregiver burden occurred. Therefore, disengagement coping strategies are not effective. If disengagement coping strategies are modified effectively, the opposite results will occur. Person-centered psychosocial interventions have been found to be more effective than standardized interventions, because there are greater improvements in satisfaction of life and function of the client, and personal needs of the caregiver are addressed (Vernooij-Dassen et al., 2010).

Psychosocial interventions employed by the caregiver have been found to benefit the client as well. Caregiver coping strategies decrease functional and cognitive decline in persons with dementia and when the caregiver employs effective coping strategies, it not only benefits their well-being, but the client’s as well (Tschanz et al., 2013). Another study showed significant improvements in QOL of clients with dementia when communication strategies were utilized by caregivers (Haberstroh et al., 2011). However the following articles the articles by Dias et al., (2008) and Haberstroh et al., (2011) were not found to demonstrate effective examples of psychosocial interventions for caregivers. One article reported that the intervention was not statistically significant in improving caregiver well-being (Dias et al., 2008). Another article reported that caregiver burden of the intervention group could not be significantly reduced (Haberstroh et al., 2011).

Discussion and Implications for Practice, Education and Research

In this systematic review we attempted to gain insight on the positive effects psychosocial interventions have on caregivers for persons with dementia to increase the caregiver’s well-being. We outlined 12 studies that reported on the effectiveness of psychosocial interventions for caregivers of persons with dementia. The severity of dementia impacted how well the psychosocial intervention decreased caregiver burden. Smits et al., (2007) emphasized that the psychosocial needs of people with dementia should be addressed; however, this review confirms the psychosocial needs of caregivers should be addressed as well. Factors such as anxiety or depression contributed to the caregiver’s well-being. Coping strategies, support groups, and counseling also improved well-being and QOL in the caregiver if employed in a positive manner. Moreover, in order to supply more efficient and effective care, the focus should be on individualized treatment for the caregiver and client dyad. The therapist should work towards creating a therapeutic alliance to meet their needs.

The findings of this review warrant further research. Our findings conclude that psychosocial interventions may not only reduce burden of care in the caregiver, but can also increase QOL in the individual with dementia. In addition, home-based psychosocial interventions have been shown to be more useful for increasing well-being for caregivers caring for the individual with dementia if they are in early stages. The goal of healthcare providers should be to keep people in their home for as long as possible. The intervention will promote aging in place, where an individual can age not only in their home, but in the community as well. This will delay institutionalization of the client (i.e. LTC). Psychosocial interventions help reduce and prevent severe mental health issues, other diseases, and co-morbidities. However, more research needs to be conducted on the effectiveness of individualized interventions tailored to the needs of the caregiver for a person with dementia to increase their well-being. Also, research should be conducted to find an effective intervention in LTC since psychosocial interventions are not found to be as effective for caregivers of persons with dementia. Long-term benefits of psychosocial interventions need to be established. To eliminate bias in future studies that incorporate psychosocial interventions for caregivers of persons with dementia researchers should: (1) randomize participants within the study, (2) thoroughly explain why attrition occurred, and (3) participants should be double-blinded in the study. In future systematic reviews, we recommend incorporating more psychosocial interventions within the LTC setting, to give a more accurate account of results. In future evidenced-based articles we recommend that methods to measure outcomes should be standardized and incorporate OTs in administration of the interventions to help increase caregiver well-being. Overall, psychosocial interventions are a low-cost approach to help caregivers develop coping strategies that reduce stress. In addition, they provide access to social and educational supports in the community.

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