RELIEVING THE BURDEN FROM CAREGIVERS OF PATIENTS WITH
DEMENTIA

By

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Abstract

A predominant concern in nursing is the immense burden that can be felt by those who care for dementia patients, whether it is hospital staff, family members, or care home staff. The thesis will take the form of a research-based paper, and the research will be obtained from multiple databases as needed, such as CINAHL and PubMed. After having extensively researched and obtained background on the topic in general, this research will differ from previous research because of the comprehensive nature of it. While other authors have touched on particular aspects of caregiver burden, none have developed complete best-practice guidelines to be implemented by health care professionals. This thesis will discuss background and purpose in the first chapter, search method and review of literature in the second chapter, best practice recommendations in the third chapter, and methods of implementation in the fourth chapter. Overall, the thesis will address what caregiver burden is, the causes and factors impacting it, negative outcomes from it, and potential interventions to implement in the clinical setting.
Chapter One: Introduction

Cognitive deficits, like those seen in patients with dementia, are very frustrating for patients and their caregiver. A predominant concern in nursing is the burden experienced by caregivers for cognitively impaired patients, whom can be hospital staff, family members, or care home staff. The concern is crucial to address through interventions developed to prevent and reduce the burden in caregivers. The purpose of this honors thesis is to explore interventions to reduce burden in caregivers for cognitively impaired patients, particularly informal caregivers.

Background of the Problem

Alzheimer’s disease (AD) is the most common cause of dementia, which is a decline in memory, language, problem solving, and other cognitive skills. AD impacts daily activities caused by damage to the neurons in the areas of brain responsible for cognitive function, specifically the cerebral cortex, entorhinal cortex, and the hippocampus. The disease is the result of the accumulation of beta-amyloid plaques outside of neurons and tau tangles of protein inside neurons that causes damage to the synapses and eventually causes neuron death (Alzheimer’s Association, 2016, p. 463). Other causes of dementias are vascular dementia, dementia with Lewy bodies, mixed dementia, frontotemporal lobar degeneration, Parkinson’s disease dementia, Creutzfeldt-Jakob disease, and normal pressure hydrocephalus. Many of the risk factors for developing AD include age, family history, the presence of genetic biomarkers, physical activity, diet, cardiovascular disease, education, social and cognitive engagement, or Traumatic Brain Injury (TBI). Currently, 5.5 million people have dementia in America (Alzheimer’s Association, 2016). The prevalence of only AD related dementia across the country is predicted to increase to 13.8 million in 2050 because of the increase of people living older than 65 years. In turn,
Caregivers are markedly impacted, along with families and health care systems (Alzheimer’s Association, 2016).

**Caregivers**

A caregiver is someone who cares for another person and tends to their health needs, and they may assist with activities of daily living (ADLs), like bathing and dressing, and instrumental activities of daily living (IADLs), like shopping, driving, and paying bills (Alzheimer’s Association, 2016). Alzheimer’s disease (AD) and related dementias are very frustrating diseases not only for the patient, also for the caregiver. The caregiver burden associated with the frustrating aspect of AD is of large concern.

Approximately 15 million caregivers provided unpaid care for a person with dementia (PWD) over 2 years, and the value of informal care provided by unpaid caregivers was almost equal to that of medical and long-term care by formal caregivers for dementia patients (Alzheimer’s Association, 2016). The Alzheimer’s Association values informal care for a patient with dementia in the United States at $234 billion in 2019, while the cost for formal care in the United States in 2019 was estimated to be $290 billion (Alzheimer’s Association, 2020). In 2020, it is predicted that 16 million people will provide unpaid, informal care to a person with dementia. The Alzheimer’s Association (2020) estimates that 18.6 billion hours of care will be provided by informal caregivers in 2020, and the Association also estimates that this time is going to value at about $244 billion. Informal, unpaid caregivers are the main source of care for many communities, contributing 60%-90% of care in the home, and they are usually family or friends of their patient (Pauley, Chang, Wotjak, Seddon, & Hirdes, 2018). Overall, caregivers are frequently older than 65, in a long-term relationship of some sort with the patient, non-Hispanic white females, living with the patient. Among caregivers, 23% are not only caring for
an older parent, but are also caring for their own children under 18, which is called a “sandwich generation” (Alzheimer’s Association, 2016, p. 475). Per the Alzheimer’s Association (2016), the main reasons for someone deciding to be a caregiver for a patient include a desire to keep the family member at home, be in close proximity to the patient, or a feeling of obligation to their spouse. Overall, despite the caregivers feelings of closeness to their patient, they report feeling stressed with the care they provide (Alzheimer’s Association, 2016). The stress caregivers experience includes financial, emotional, and physical stress, and some of the impacts were depression, decreased quality of life, difficulties performing other tasks or caring for children, poor eating habits, and a feeling of obligation to caring for the patient (Alzheimer’s Association, 2016). Caregivers for PWD experience stress in all areas of their life, and the burden effects their ability to care for themselves as a caregiver or their own children. Prior studies have shown a positive relationship between the cognitive function of PWD and caregiver anxiety, depression, and the overall experience of burden (Wang, et al., 2018). As the PWD cognitively worsens, caregiver burden also worsens.

Although paid caregivers would seem to experience less burden, they are still greatly impacted. Paid caregivers in settings like nursing homes and long term care facilities may feel that they lack sufficient training and staff, and they tend to feel overwhelmed, which can contribute to the high turnover rate. The burden not only affects the caregiver, but also affects the quality of care the patients with dementia receive (Alzheimer’s Association, 2016).

Significance to Nursing

Caregiver burden is relevant to the field of nursing because of the 5.5 million people with dementia related to AD or other conditions who require the care of professional nurses and other nursing support staff. Professional caregivers can also experience burden, and acknowledgement
of the potential for stress is important. Professional nurses can also experience secondary burden when working with caregivers of PWD because of the empathetic aspect of nursing. Resources for caregivers experiencing burden are essential to help caregivers understand why they feel burdened and how they can cope with or prevent burden.

**Purpose**

The PICOT(S) question guiding the evidence search is: Among informal caregivers for a patient with dementia, what interventions will prevent or reduce caregiver burden? The purpose of the thesis is to explore interventions for informal caregivers to experience less burden. For the purposes of this paper, the population of interest is informal caregivers, and their patient with diagnosed dementia, and burden is any physical, emotional, social, or financial problems that result from their role as a caregiver. Other objectives include review and report on evidence-based causes, factors, impacts, and prevention of caregiver burden from the research literature.

**Summary**

Caregivers are central to the well-being and care of many people in the world, and caregivers are especially crucial to the support and safety of those with dementia. As people begin to live longer with the advances of technology, the demand for caregivers has increased. The caregiver role may result in a great amount of stress among caregivers, whether they are paid or unpaid. Nursing professionals assume the role of caregivers when patients with AD are housed in health care settings, where they have the responsibility of caring for the patient’s entire health, including physical, mental, and psychosocial health. The burden caregivers experience can be detrimental to the effectiveness of their care and to their own health, and there is a need to explore and implement interventions to better their health and, subsequently, the health of their patients.
Chapter Two: Review of Literature

Chapter two addresses a review of research literature on the challenges of caregiving, methods of assessing the sense of burden experienced by caregivers, and potential interventions for caregiver burden. The databases used to find the research articles were PubMed and CINAHL, both of which had a date filter set for studies only from 2013-2018. In PubMed, the student filtered to only show nursing journals. Search words used were “caregiver burden,” “caregiver burden recommendations,” “Alzheimer’s Disease,” and “caregiver burden in Alzheimer’s Disease.”

The Effects of Burden on the Caregiver’s Health

The first study was a phenomenological qualitative study focusing on the experience of unpaid caregivers for family members with dementia or AD. The study is specifically a hermeneutic phenomenological design with 10 participants (8 women and 2 men) that were purposefully recruited from a randomized trial performed by the Project Advancing Caregiver Training (ACT) database (Czekanski, 2017). The participants all chose to interview in their home, and their ages ranged from 37 to 84 years old in caregivers and 58 to 92 years old in patients. Two audiotaped and participant-guided interview sessions were conducted with each participant individually, the first interview gathering information about their experiences and the second confirming the information (Czekanski, 2017). The study found seven themes among caregivers throughout their interviews: something is wrong, the ambiguity and negative emotions along their journey to diagnosis, losses and challenges in the shifting roles and relationships, solutions and frustrations in seeking knowledge and support, finding a purpose in the adaptation to the topsy-turvy world of caregiving, preserving self without guilt, and finding a way out. Another very surprising finding was that none of the participants referred to nurses at any point.
in time during their interviews, which comes to show that they lack support necessary to perform the activities that a nurse would provide in a facility (Czekanski, 2017). The findings are significant because they exhibit the lack of support, access, and services that should be present for the caregivers to adequately take care of themselves and the recipient of their care. A strength of the study is the use of interviewing to obtain specific, subjective data on a very emotional topic regarding caregiver burden. The study successfully met data saturation as well, which is an indication that the themes developed are an accurate representation of the target population (Czekanski, 2017). One weakness of the study, despite meeting data saturation, is that the sample size was very small. Additionally, the study notes that the participants were asked to recall events and information from the past, which could lead to an inaccurate account or perception of details. The study also only has one researcher, which may lead to the presence of bias (Czekanski, 2017).

Another study investigated four research questions: Do caregiver reactions to dementia symptoms of care recipients affect their coping repertoire?, Is the caregiver’s coping repertoire affected differently by their reactions to specific sets of dementia symptoms?, Do caregiver reactions to dementia symptoms of care recipients affect their mental health?, and Is the caregiver’s mental health affected differently by their reactions to specific sets of dementia symptoms? The study is a descriptive secondary analysis of data from a community convenience sample of 138 female caregivers (Zauszniewski, Lekhak, & Musil, 2018). The researchers performed face-to-face interviews to determine caregiver reactions, spiritual practices, resourcefulness, perceived stress, and depressive symptoms (Zauszniewski et al., 2018). Depressive symptoms of a family member with dementia were found to have a negative impact on the caregivers’ coping strategies. Additionally, disruptive symptoms of family members with
dementia were found to be associated with more stress, less resourcefulness, and more
depression in caregivers (Zauszniewski et al., 2018). Finally, memory-loss symptoms were not
found to be associated with a caregiver mental health and repertoire. The findings are significant
because of the statistical strength demonstrating the association between the perceived symptoms
of the PWD and the caregiver’s ability to cope, and they are useful clinically because they are
relevant to mental health nurses working with caregivers for people with dementia
(Zauszniewski et al., 2018). A strength of the study is the use of standardized instruments for
measuring to ensure the validity of the intended measured variables. However, the study is weak
because of the cross-sectional nature that prevents the development of a causal relationship, the
use of self-report in the participants, and the use of only one gender in the sample.

The next study aimed to examine subjective burden and strain in caregivers for dementia
patients. The study was a cross-sectional descriptive study that selected and analyzed data from
2015-2016 in China. A total of 212 caregivers for patients with dementia completed a survey
over a personal interview in their homes, and the patient and caregiver were interviewed
separately by a Registered Nurse (Zhang, Chang, Gao, & Porock, 2018). The study found that
higher burden and strain is present in children and spouses of dementia patients. Lower income
and education played a role in increasing burden and strain, and familial or prolonged caregiving
appeared to increase caregiver strain and burden (Zhang et al., 2018). Burden was also found to
be associated with change in plans, time, and emotional state of caregiver. Overall, Chinese
caregivers of patients with dementia were found to have a moderate burden and high strain level.
The results are significant because of the associations that were developed as a result of the
strong relationships between the variables, and they also addressed different factors and
situations in life that other articles failed to. The study was effective in avoiding bias in
caregiver and patient self-report by interviewing them separately. The study was weak in their recruitment because the participants all volunteered to participate, which may mean that they came into the study with strong feelings to caregiver burden. The study was also a cross-sectional analysis (Zhang et al., 2018).

**Assessment of Caregiver Burden**

The first study had three different objectives: determine the prevalence of AD symptoms relating to disturbed sleep, examine what symptoms affect the quality of life and predict burden of the caregiver, and compare how sleep disturbance symptoms compare to other symptoms of AD in terms of their effect on the caregiver. The study was a cross-sectional, secondary data analysis of surveyed data from 130 caregivers of patients at home who met criteria for possible or probable AD (Gehrman et al., 2018). Variables that were measured in caregivers’ situations were demographics, burden, quality of life, physical and mental status, depressive symptoms, patient’s ability to perform basics activities of daily living (BADLs) and instrumental activities of daily living (IADLs), and the patient’s sleep. The survey was presented at the Penn Memory Center of the University of Pennsylvania’s Alzheimer Disease Center, where patients met the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer Disease and Related Disorders Association criteria (Gehrman et al., 2018). Among the participants in the sample, 60% of the patients with AD experienced disturbances in their sleep, such as wandering, snoring, awakening, and sleeping during the day. The findings are statistically significant because of a strong relationship between caregiver burden and sleep disturbances in the patient. Overall, the main finding was that caregiver burden and mental and physical statuses were predictors of caregiver quality of life, which means that burden on caregivers for AD patients can be predicted by the symptoms of sleep disturbance (Gehrman et al., 2018). A strength of the
study is the use of exclusion criteria and measurement of many different variables to acknowledge and eliminate the influence of extraneous variables. Two major weaknesses of the study are the use of self-report to determine sleep symptoms and the cross-sectional nature that prevents the assessment of causality (Gehrman et al., 2018).

The next study aimed to examine predicting factors of distress in caregivers providing in-home care. The objectives of the study are to identify factors of newly developed caregiver distress and factors influencing a decrease in caregiver distress. The researchers created separate multivariate logistic regression models to demonstrate onset of distress and improvement of distress in caregivers based on the statistics from the Ontario Association of Community Care Access Centre providing home care for 323,409 clients from 2002 to 2015 (Pauley et al., 2018). The data was collected using two Resident Assessment Instrument-Home Care (RAI-HC) assessments. The RAI-HC identifies distressed caregivers based on two parts: ability to continue care and self-report of distress or depression (Pauley et al., 2018). Characteristics of the clients that were examined in the study were their gender, age, marital status, living situation, recovery chances, extent of care needed, presence of an interpreter, health characteristics, Method for Assigning Priority Levels (MAPLe) scores, Cognitive Performance Scale (CPS) scores, and Activities of Daily Living Hierarchy (ADLH) scores (Pauley et al., 2018). The study found that factors influencing the onset of caregiver distress were the caregiver feels that they lack support and the client lives with caregiver. The study also found that factors with the most influence on a decrease in caregiver stress were the client is now living with other persons and the client has good prospects for recovery (Pauley et al., 2018). The findings are clinically and statistically significant because they allow a strong relationship to be seen between the care required by the client and the caregiver well-being and quality of life, and the results encourage the
consideration of healthcare professionals to always assess both the client and caregiver in their care because the two influence each other greatly (Pauley et al., 2018). The strengths of the study are the analysis of several variables to acknowledge as many aspects of the clients care that could possibly impact the caregiver and the analysis of a large sample size. The most notable weakness in the study is the use of the RAI-HC, which is designed for the client and may not be a valid measurement of caregiver burden (Pauley et al., 2018).

Another study examined the frequency of the assessment of caregiver needs in a sample of persons with dementia (PWDs) and their caregivers to determine if caregivers were assessed and if overall documentation increased with an increase of reported relationship problems and burden resulting from their responsibility as caregiver. The study consisted of a total of 211 PWDs and their caregivers drawn from a previous randomized controlled trial at the Michael E. DeBakey VA Medical Center, Houston, TX that tested a psychosocial intervention for preventing aggression in PWDs (Huang et al., 2015). A cross-sectional design was used to extract data from a 12-month period of an electronic medical record (EMR) review, specifically the baseline research assessments performed using Burden Interview and Mutuality Scale. Data was compiled using a tool created by the authors to assess documentation of information considered important to caregiver assessment in clinical guidelines, like caregiver needs, caregiver well-being, and caregiving context (Huang et al., 2015). The method of data collection allowed the researchers to identify documentation of key factors in clinical guidelines. Caregivers were identified, whether they were present or absent, approximately 89% of the time. Of the 177 EMRs with caregiver identification, caregiver well-being was documented only 27% of the time, and 78% of those cases had caregiver support or referrals documented (Huang et al., 2015). 100% of the 73 EMRs documenting caregiver needs also documented that support or referrals
were provided. Lower mutuality scores were associated with more documentation of assessment of the caregiver's needs perceived by the veteran and referrals to the Alzheimer’s Association (AA). Unexpectedly, caregiver burden was not associated with any documentation variables, and mutuality or caregiver burden were not associated with the assessment of caregiver well-being (Huang et al., 2015). Overall, caregiver well-being is either not assessed or not documented nearly as much as is necessary. However, when caregiver burden was assessed properly, the caregiver was determined to need more support, action was taken, and support was provided. An unusual finding was that caregiver burden was minimally associated with any part of the documentation analysis. A potential explanation is that the expression of relationship problems through low mutuality scores initiated further caregiver documentation and assessment in the area of relationships more than caregiver burden. Providers may also have determined that relationship problems are more problematic than caregiver burden, and they may not assess caregiver burden or document on their assessment. Finally, there is a possibility that caregivers are already involved with the AA. A strength of the study was the large sample size to increase the reliability of the results, as well as the objective and factual use of the EMR to reach results based on the immediate and hopefully accurate documentation by the physician. On the other hand, limitations of the study have to do with the documentation, bias, and population. Whether the physicians did not assess caregivers or did not document the assessment is unknown, which can create a lack of data available. The bias may have resulted from the recruitment process because physicians referred their patients and caregivers to the study, so the physicians may have been more invested in the care of the dyad and the patient and caregiver outcomes were better as a result (Huang et al., 2015). The trial is also very specific to the Veteran population, and
previous research found that only 1/3 of caregivers in the general population have been assessed (Huang et al., 2015).

**Interventions for Caregiver Burden**

The goal of the following study was to determine if social support for caregivers played a role in the relationship between patient factors and negative outcomes for caregivers of AD patients. Another goal was to see if positive aspects of caregiving also played a role in this relationship. The study was a cross-sectional study on 210 AD patients and their caregivers in 2 hospitals and 3 communities in Taiyuan, China who volunteered for the study (Wang et al., 2018). Caregiver negative effects were assessed using the Caregiver Burden Inventory (CBI), Self-rating Anxiety Scale (SAS), and the Self-rating Depression Scale (SDS). Caregiver positive effects were assessed using the Social Support Rating Scale (SSRS) and Positive Aspects of Caregiving (PAC) scale. Patients were assessed using the Montreal Cognitive Assessment (MoCA) (Wang et al., 2018). The study found that caregivers experienced heavy burden. Some factors playing a role in their experience, as well as in depression and anxiety, were found to be gender, age, educational level, employment status, and family size. The duration of caregiving was not found to affect the caregiver, but a decrease in patient cognitive function and increase in patient depression were both found to increase caregiver burden (Wang et al., 2018). Social support was found to mediate caregiver burden but not caregiver anxiety and depression. Positive experiences of caregivers were found to be mediators between the factors negatively impacting caregiver burden, anxiety, and depression (Wang et al., 2018). The study results are significant despite their small mediating and moderating effects because they acknowledge the relationship between social support and caregiver burden, prompting the acknowledgement of this relationship in health care professionals assessing patients and caregivers regarding their
social support. The study has the strength of involving an intervention group to demonstrate more specific factors that may play a role in caregiver burden, anxiety, and depression in caring for a person with AD. The researchers also utilized multiple settings and locations to study, which allows for more generalizability to the population of caregivers for AD patients. A weakness of the study is the use of a cross-sectional analysis, which prevented changes in variables and conclusive causative relationships between the variables in the mediation group (Wang et al., 2018).

The aim of the next study was to develop an intervention program for coping strategies and investigate whether the intervention program is able to improve coping strategies and subsequently reduce caregiver burden. Using a RCT, the study evaluated the effectiveness of coping strategy interventions for 46 dementia caregivers (Chen, Huang, Yeh, Huang, & Chen, 2014). Participants were recruited from a university-associated outpatient memory clinic. Participants were at least 18 years old, living with a PWD, and providing at least one-third of their time at home in the past month (Chen et al., 2014). The PWD had to be at least 65 years old and not have any outside, uncontrolled, terminal medical condition. There were two parallel groups: experimental and control. In the experimental group, the participants were provided an intervention to improve coping, and, in the control, the caregivers receive usual clinical care (Chen et al., 2014). The intervention was six sessions over three months, preceded and followed by a questionnaire to assess their current coping strategies and burden and the change in them following the intervention or lack of intervention (Chen et al., 2014). Instruments used were Revised Memory and Behavior Problems Checklist (RMBPC), Chinese version of the Caregiver Burden Inventory (CBI), and Revised Ways of Coping Checklist (WCCL-R). The first session was based mostly on educating the patient to ensure there were no misunderstandings of the
patient’s condition (Chen et al., 2014). The second session provided the participant with resources regarding support, and the third and fourth sessions brainstormed techniques to improve management of behavioral symptoms of dementia (BSD) that caused the caregiver the most burden and stress. The fifth session provided the caregiver with self-care skills, and the final session created a system of self-support for immediate access to help with problem solving (Chen et al., 2014). The results from the CBI in the experimental group expressed a decrease in the score on the CBI, indicating less caregiver burden. The scores from the WCCL-R demonstrated an increase in the problem-focused and seeking social support scores in the experimental group and a decrease in scores in the control group (Chen et al., 2014). Other factors measured in the tests were blaming self, wishful thinking, and avoidance, but there were no statistical significances or differences among the groups (Chen et al., 2014). Evidently, caregivers reported a decrease in their burden, which resulted from psychosocial interventions, education, and problem-focused and social support coping strategies (Chen et al., 2014). The interventions did not necessarily provide sources that were given to the caregiver as a one-time intervention; rather, interventions seemed to provide the caregiver with long-term strategies for coping and awareness of self that allow them to be adaptable to changes in their PWD’s condition. The intervention did help to improve positive coping strategies, but the authors did notice that there was not a method to help decrease negative coping strategies, so there might be a need for further research in the area of negative coping strategies (Chen et al., 2014). A potential limitation of the study was the small sample size and the single study site used. Overall, strengths of the study was the identification of several factors in caregiver burden and use of many forms of measurement to provide evidence of an improvement in burden. The study can also be generalized to an extent to informal caregivers at home, and the study can also be
individualized to different caregivers because each person received a unique intervention depending on their situation (Chen et al., 2014).

The next study aimed to estimate the efficacy of technology-based interventions for informal caregivers of people with dementia (PWD). Using PubMed, PsychoINFO, and Cochrane Library, the authors identified 33 randomized controlled trials (RCTs) that researched technology based interventions for informal caregivers (Deeken, Rezo, Hinz, Discher, & Rapp, 2019). The articles were selected based on whether they were an RCT, participants were unpaid and living in their own home, the interventions were aimed mostly at the caregiver, the intervention was technology based, and the study was quantitative in at least one way (Deeken et al., 2019). A meta-analysis was then performed based on outcome measures of depression and burden in caregivers, and a subgroup analysis looked at whether the intervention was via the computer, telephone, or both, or via DVD. Many of the interventions were sessions allowing the caregiver to receive education, group support, problem-solving tips, individualized support, coping skills, self-care, and strategies for BSD (Deeken et al., 2019). The overall analysis of the change in depression showed a small amount of improvement, with the highest impact in the combined group, followed by telephone, computer, and then DVD. As with depression, the overall improvement in burden among caregivers remained small, and the highest effect came from the combined interventions and computer-based interventions. The results of the analysis remain significant despite their small effect (Deeken et al., 2019). Overall depression and caregiver burden improved; however, caregiver burden improvement was not determined to be significant enough to use the analysis as evidence for technology-based interventions. The authors note that burden in caregivers is very multidimensional, often without definition and clarity (Deeken et al., 2019). Additionally, the disease of dementia is very progressive and
terminal, so although the interventions are often seen as helpful, dementia usually cannot be cured, so caregivers will always experience burden and grief with the terminal aspect of dementia. Another note from the author is further research should focus on the effect of interventions geared toward improving the symptoms of the PWD on the caregiver’s sense of burden and depression (Deeken et al., 2019). A notable strength of the study was the aspect of flexibility due to the technological factor. The interventions of the analyzed RCTs were able to reach many different populations, cultures, and lifestyles, allowing for the study to be more generalized to all caregivers for PWD (Deeken et al., 2019). On the other hand, the interventions may have all been vastly different in terms of their “dose” given to the participants and the content of their intervention, so the generalizability may be negatively impacted if the doses and content of interventions were vastly different among studies. The sample overall was obviously large, but the sizes of each individual study was relatively small, so size may have also presented a limitation in terms of the reliability of the results (Deeken et al., 2019).

The purpose of the study was to evaluate the efficacy of a modified New York University Caregiver Intervention (NYUCI), called Families Access to Memory Impairment and Loss Information, Engagement, and Supports (FAMILIES), provided to spousal and non-spousal caregivers of PWDs from a variety of etiologies in a limited number of sessions (Sperling et al., 2019). There were 122 primary caregivers for PWD living in rural and urban communities in Virginia involved. The participants were recruited based on clinician referral of caregivers with high level of distress from caregiving (Sperling et al., 2019). The methods of research and analysis used were descriptive analysis of demographics and descriptive statistics with a thematic analysis approach to analyze caregiver response to Caregiver Satisfaction Surveys (CSS) (Sperling et al., 2019). The FAMILIES intervention consisted of 6 sessions: 2 individual
and 4 group sessions in-person all with a counselor/social worker. The first session assessed the caregiver’s needs on a physical, emotional, social, and basic level, as well as the caregiver’s current level of support, environment of care, their patient’s BSD, and goals for their involvement. The four group sessions addressed the needs of the caregiver, like positive coping mechanisms, caregiving strategies, communication and support, and overall emotional support. The final session identified changes in the caregiver from the initial session (Sperling et al., 2019). The intervention resulted in an improvement in caregiver reaction to BSD, dysphoria, sleep, concentration, worthlessness, and agitation. A decrease caregiver burden and depressive symptoms was seen. In fact, there was a decrease in the number of caregivers considered clinically depressed, and the risk for becoming clinically depressed decreased (Sperling et al., 2019). The majority of caregivers, 98.1%, found the intervention to be helpful and 84.9% believed that the caregiver and PWD’s mood were impacted positively (Sperling et al., 2019).

Four themes found among caregivers when asked what they found to be most helpful: ability to express how caregivers feel about their situation, sense of being heard and validated, practical benefits from education on the disease and resources, and strengthening of support network (Sperling et al., 2019). The intervention targeted several aspects of caregiver burden. A caregiver’s ability to cope with BSD, knowledge of community support, sense of caregiver burden, and of depression all tie into each and can negatively and positively impact each other. By assessing the person holistically and targeting their individual needs, FAMILIES was ability to help a caregiver improve upon their overall well-being and even the well-being of the PWD. The improvement seen demonstrates the crucial impact that caregivers feeling supported and in a state of well-being can have on the care, health, and mood of a PWD because of the caregiver’s ability to appropriately and effectively care for their PWD (Sperling et al., 2019).
An important note is that people found support and feeling heard to be most helpful from the intervention, which can bring to light that the caregivers simply need someone to be there for them and listen to them. A strength of the study are the large sample size to increase reliability of the results. The analysis also took into consideration of every aspect of the caregiver and PWD to ensure that all possible and key variables are involved. The results proved consistent with other very similar randomized control trials that used the NYUCI. A potential limitation is that the study did not use a control group because of their desire to meet the needs of a broad population of caregivers (Sperling et al., 2019).

**Summary**

Research evidence reviewed in this thesis strongly supports the experience of burden among caregivers of individuals with dementia. In addition, research studies have identified variables that are associated with caregiver burden, such as the symptoms exhibited by the PWD, the level of cognitive function of the PWD, education and employment of caregiver, and caregiver age and gender (Wang et al., 2018). There is a need for studies that focus on how to decrease caregiver burden and what resources are necessary to preserve caregiver’s mental health while also preserving the health of a patient with dementia. Overall, the research suggests exploration into potential interventions to eliminate the burden on caregivers, such as education on the disease, self-care strategies, problem solving skills, and methods of caring for BSD (Chen et al., 2014). Implications for education and nursing professionals is especially important. Nursing students must learn and nursing professionals need to know the resources available to informal caregivers and to be more involved in the care of not only patients with dementia, but also in the care and preservation of the mental health of their family and friends.
Chapter 3: Recommendations for Practice

The purpose of this thesis is to design a set of best practices for decreasing caregiver burden in those caring informally for PWD. There is a common theme among the research addressed in Chapter Two, which is that there is no cure for caregiver burden because there is no cure for dementia. Dementia is a chronic, debilitating, and progressive disease that involves deterioration of neurons involved in cognitive function (Deeken et al., 2019). However, there is always room for improvement of caregiver burden, and that is the focus of the recommendations addressed in Chapter 3. Another note found in the research is the solution for caregiver burden does not originate from correcting the PWD’s disruptive symptoms; rather, the best interventions for decreasing caregiver burden were those that helped strengthen the caregiver (Chen et al., 2014). Overall, the desired outcome from the interventions is to decrease caregiver burden. Table 1 summarizes the recommendations drawn from the research review in Chapter Two.

Table 1

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### Caregiver education of patient symptoms

- Education and understanding of the patient symptoms by the caregiver helped decrease caregiver burden and symptoms of depression

### Caregiver education on strategies for management of behavioral symptoms of dementia (BSD)

- Caregivers experienced less burden when they were provided with more effective strategies for management of the unpredictable BSD in their patient
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In summary, caregiver burden is not something that can be completely resolved; rather the focus is on minimizing the impact on the caregiver’s health and ability to care. The first area of focus is on improving the caregiver’s overall wellbeing because this is one of the largest factors in their negative health outcomes like depression. The next recommendations involve educating the caregiver on the symptoms of dementia and providing them with strategies for managing difficult behaviors of their patient, and education will play a large role in improving their ability to care for their patient and their attitude toward their frustrating symptoms.

Telehealth is an important resource to have available so that every population and lifestyle can be reached and provided with all of the recommended support. The last recommendations of coping methods and self-support focus on facilitating caregiver self-support that can benefit the caregivers at any time and place or when there is not outside support available.
Chapter 4: Plan for Implementation

This chapter will provide and discuss a hypothetical implementation of an intervention to relieve caregiver burden based on the best practice recommendations from Chapter 3 with focus on the PICOT(S) question: Among informal caregivers for a patient with dementia, what interventions will prevent or reduce caregiver burden? After the literature review, the narrowed target population for the purposes of clarity in the implementation process are informal caregivers 65 years or older living with and caring for a family member with diagnosed dementia; however, the intervention can likely be used among almost all populations. The hypothetical intervention will be an online video chat utilizing Zoom between a caregiver-patient dyad and a health care professional with skill and knowledge in the area of caregiver burden and dementia. The reason for choosing the population of 65 years or older caring for a family member at home is because this group makes up a large portion of the informal caregivers (Alzheimer’s Association, 2016). The population will require a large amount of consideration when implementing the intervention because of the tendency for the age group of 65 years and older to be less savvy with technology. The intervention is chosen based on the research from Deeken et al. (2019), which provided evidence from a met-analysis of RCTs that utilized technological interventions that were either web-based, telephone-based, or a combination of both. In the study, Deeken et al. (2019) reported the combined intervention reduced caregiver depression and burden most significantly, and the authors noted that the intervention was very flexible to many different populations because of the ability to use it without having to travel to be face-to-face. Utilizing a video chat allows for a seemingly combined intervention of talking with a person in real time like one would over the phone, while also utilizing an online format of learning to create the most significant effect on caregiver burden. The intervention can be
personalized to individual dyads because the supportive professional can assess the situation via a telehealth route in real-time to provide individualized education on patient symptoms, patient behaviors and strategies for management of them, positive coping mechanisms for caregivers, and self-care methods and resources for the caregiver with the ultimate goal in mind to improve caregiver wellbeing to decrease caregiver burden.

The plan of implementation will be guided by the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) Planning and Evaluation framework (Glasgow et al., 2019). The reason for choosing RE-AIM is the comprehensive nature of the framework steps promotes the consideration of the impact among a broad population. This guided plan for implementation will be discussed in this chapter. Following the implementation plan, the evaluation of the outcomes and process of implementation will be described.

**Implementation**

The RE-AIM planning and evaluating framework will be utilized to guide the plan for implementation of an online video chat program providing caregivers for persons with dementia with the necessary support to improve their wellbeing and decrease caregiver burden.

**Reach**

In the Reach step of the RE-AIM framework, the following question must be answered: “How do I reach the targeted population with the intervention?” (Glasgow et al., 2019, Table 1). This includes describing the number of individuals who are willing to participate, a description of the target audience, and how the needs of the target audience will be met (Glasgow et al., 2019). For the implementation of a video chat program, the target audience will be informal caregivers aged 65 years or older caring a family member with diagnosed dementia at home. This population will be reached primarily through the caregiver via their patient’s primary care
physician because it is most often the caregiver that brings the patient to their appointments. Prompting the intervention through the patient’s physician might initiate more trust from the caregiver and enhance participation on their part, and it is also extremely convenient versus the dyad having to go to a support group or other more time-consuming activities. The physician will be given the contact information for the program via a brief in-service sharing the evidence supporting it, and they can provide the dyad with the contact information for the supportive professionals that the caregiver can then call and set up an appointment. The method of using a video chat from home is likely more well-accepted because the caregiver does not have to find care for their patient while they are gone and the caregiver does not have to welcome anyone else into their home and disturb the environment of the patient. Overall, it is expected that the caregivers may feel more inclined to participate in this intervention because it feels safer. The assumption that many of the individuals will be willing to participate is valid because much of the research demonstrated that caregivers would appreciate more support in their care (Sperling et al., 2019). In order to operationalize the willingness of caregivers to participate, the physician would be asked to provide the number of patients they referred to the program in order for the program to compare how many referrals there were to how many people actually participated.

The needs of this audience in regards to the technological aspect of the intervention will potentially necessitate more consideration than other populations, as previously mentioned. It is important that the video chat program utilized allows for ease of access and simplicity in use. The intended application for the video chat is Zoom because it allows the supportive professional to send a link to the caregiver via email, and the caregiver can click on the link from their phone, computer, tablet, etc., depending on what the caregiver feels most comfortable with and if they would like to move around the house with the supportive professional. The supportive
professional can provide the caregiver with a link to instructions for using zoom prior to their first meeting, and the caregiver can also be walked through the process while on the chat with the support professional. Overall, it can be predicted that the method of Zoom video chat can be adapted to this population with little to no complications.

**Effectiveness**

The question in need of answering in the Effectiveness step of the RE-AIM framework is: “How do I know my intervention is effective?” (Glasgow et al., 2019, Table 1). This section must address the outcomes of the intervention, such as the impact on the quality of life of the population, possible negative outcomes, and potential economic impacts. The heterogeneity of the effects must also be addressed (Glasgow et al., 2019). The intervention’s effectiveness will be determined largely by the evaluation of the outcomes, which will be addressed later in this chapter; however, the overarching goal is for caregivers to report increased wellbeing, improved quality of life, and reduced burden following the intervention. Potential negative outcomes may include further frustration from the caregiver with technology, interruption of caregiver daily activities with their patient, and a possible lack of reception of the intervention by the caregivers. Short term economic impacts are anticipated to be minimal because the service and necessary technology would be provided free of charge, but the long-term impacts may include less utilization of costs for the effects of caregiver burden, like depression and anxiety. In terms of the heterogeneity, this intervention is being provided to a specific age group of people who may or may not possess similar characteristics or values, so there is uncertainty surrounding whether or not the effects of this intervention will be the same for a different age group. Every dementia patient tends to have different behavioral symptoms and caregivers possess different styles of caring, which is why the intervention is developed to personalize to each dyad. In this sense,
there should be heterogeneity of effects because the supportive professionals adapt to each individual and provide support based on the needs of each caregiver.

**Adoption**

The Adoption phase of the RE-AIM framework must answer the question of: “How do I develop organizational support to deliver my intervention?” (Glasgow et al., 2019, Table 1). This must address the settings and the intervention agents and how they will adopt the intervention (Glasgow et al., 2019). The intended intervention will be applied within the caregiver’s home but there are several steps that need to happen in order to reach this point. First, the supportive health care professionals performing the intervention need to be recruited. This would be done via telephone calls to professionals in the area that specialize in caregivers for dementia experiencing burden, specifically a community resource local to Tucson called the Pima Council on Aging (2020), to first see if they are willing to participate. They must be up-to-date on evidence-based information for providing caregiver education on dementia, behavioral symptoms, coping strategies, and self-care strategies. Familiarity with Zoom is also necessary among the support persons. Once the supportive professionals have been recruited, the next necessary step is to contact primary care offices in the community to determine who provides care to dementia patients. Once the locations have been gathered, the next step is to request that they provide contact information for the caregivers (ensuring that they match the previously described criteria for the target population) to reach out to a supportive professional for support and strategies in their care. A brief discussion regarding the impacts of caregiver burden and the positive effects that this form of support has had on caregivers in the past with the physicians in the participating offices may be necessary to ensure that there is trust among the physicians and
the intended intervention. Ultimately, as mentioned previously, the intervention will be delivered to the participating caregiver’s home, or a setting of their choice.

**Implementation**

The RE-AIM framework step of Implementation must answer the following question: “How do I ensure the intervention is delivered properly?” (Glasgow et al., 2019, Table 1). This step must describe the fidelity of the intervention agents to the protocol of the intervention, the consistency of delivery, and time required; additionally, the adaptations that were made, costs of implementation, and individual use of the intervention by the participants must also be addressed (Glasgow et al., 2019). Because of the adaptability of the program to each individual dyad, the supportive professional will be allowed a wide range of adaptability in providing support for the dyad, but they will also be provided with a general outline of information to discuss during their video chat to ensure a degree of protocol and consistency of delivery. This will include facts about patient symptoms, facts about patient behaviors and tips for management of them, positive potential coping mechanisms for caregivers, and possible self-care methods and resources for the caregiver. Following the intervention, the supportive professionals will be asked to fill out a survey with 4 questions to address fidelity to protocol, adaptations made, consistency of delivery, and time spent: “How often did you utilize the outline provided?” (Rarely, Not often, Sometimes, Often, Almost always), “How often did you make changes to the information in the outline?” (Rarely, Not often, Sometimes, Often, Almost always), “To what extent did you change the intervention between participants?” (Rarely, Not often, Sometimes, Often, Almost always), and “How much time outside of the allotted hours did you spend on the intervention for technical issues, patient interruptions, etc.?” Caregivers and support professionals will be
provided with proper and necessary technology to ensure smooth usability of the intervention, so cost of implementation will be assessed after the purchasing of these materials is completed.

The intervention will include a total of five 1-hour sessions plus 15 extra minutes for questions and concerns, with one session per week, and with the same professional each week to ensure a level of consistency. The initial session will assess the needs of the caregiver, including their subjective sense of well-being, a measurement of their burden level using the CBI scale, and a measurement of their self-rated quality of life using the QOL-AD scale. Other things the supportive professional must ask or observe is the caregiver’s current knowledge on their patient’s symptoms and why they exist, caregiver’s strategies for managing their patient’s behaviors, caregiver’s current coping strategies, and caregiver’s current self-care strategies. The next appointment will be a session addressing the caregiver’s patient’s symptoms to educate the caregiver on why each one of their symptoms exists, with a basic set of facts provided on the on the standardized outline for the supportive professional. The third appointment will provide the caregiver with strategies for managing the behaviors of their patient, which can also be found on the outline for use by the supportive professional. The fourth appointment will provide the caregiver with additional methods of coping, which will be listed and described on the outline and may also be developed individualistically based on caregiver hobbies and desires. The final session will provide the caregiver with methods of self-care, either derived from caregiver preferences or new ideas from the outline and supportive professional. The final session will also assess post-intervention effects on the caregiver’s burden, using CBI, and quality of life, using QOL-AD, and the supportive person will ask the caregiver to describe their current subjective feelings of their well-being. The caregiver will also be asked to describe the knowledge they learned about patient symptoms, patient behaviors, and coping strategies and self-care methods
for the caregiver. Other logistical questions that will be asked to address participant use and participant implementation are: “How useful did you find the intervention?” (Not useful at all, Somewhat not useful, Neutral, Somewhat useful, Very Useful) and “To what extent have you implemented the information outside of your chats?” (Rarely, Not often, Sometimes, Often, Almost always). Another question that will be asked of both the intervention agents and the participants for the purpose of paying attention to improvement of the intervention is: “What do you feel would make this intervention better?”

**Maintenance**

The question in mind with this step of RE-AIM is: “How do I incorporate the intervention so that it is delivered over the long-term?” (Glasgow et al., 2019, Table 1). The Maintenance step of implementation aims to examine the extent to which the intended outcome is maintained at 6 or more months following the intervention and the extent to which a program becomes a part of the organization’s routine practices (Glasgow et al., 2019). To analyze the maintenance of the caregiver’s decreased burden following the intervention of Zoom chat sessions with supportive professionals, the caregivers will be followed-up with over the phone or email 6 months after the completion of the intervention. The caregiver will be asked to report their current burden, using CBI, and quality of life, using QOL-AD, and the supportive person will again ask the caregiver to describe their current subjective feelings of their well-being.

Another important aspect of maintenance is seeing whether the organization has implemented the program as part of its routine activities. In this case, the physician offices would be reached out to and asked to describe their current use of the referrals, including how many patients they referred to the program, what percentage of the patients they referred to the program, and whether it has become a part of their routine provision of resources for their patients’ caregivers.
Evaluation

The RE-AIM framework tends to evaluate at each step, but the most prominent steps for evaluation include the Effectiveness, Implementation, and Maintenance phases (Glasgow et al., 2019). At this point, it is necessary to again reiterate the PICOT(S) question in focus, which is as follows: Among informal caregivers for a patient with dementia, what interventions will prevent or reduce caregiver burden? The outcomes of the intervention are evaluated in the Effectiveness and Maintenance sections, and the evaluation of the implementation process is addressed in the Implementation step.

The overall desired outcome for this intervention is: Following five, 1-hour, weekly sessions via Zoom, caregivers who are 65 years or older and are informally caring for a family member with a diagnosed dementia at home will report a decrease in their score on the CBI scale of at least 15% from baseline score. Basically, the caregivers will report a decrease in burden by at least 15% per the CBI scale, which is the measure of evaluation, following the intervention. This number is based off a study by Chen et al. (2014), who found that their in-person sessions decreased caregiver burden per the CBI from 46.8 to 39.6, which is a 16.2% decrease. The percentage seems like a better value to utilize in this case because every caregiver starts off at different level of burden and thus may decrease more or less depending on how much they start with. This addresses the Effectiveness step of the RE-AIM because this is determining how effective the intervention was for the outcomes desired, which is decreasing burden. Another outcome to meet the requirements for the Maintenance step would be: Six months after an intervention consisting of five, 1-hour, weekly sessions via Zoom, caregivers who are 65 years or older and are informally caring for a family member with a diagnosed dementia at home will report a CBI score that has not increased from their post-intervention CBI score. This would
indicate that the intervention helped the caregiver to still feel less burdened than they did before the intervention.

The desired outcome for the process of the implementation is: The physicians for the patients will refer at least 75% of eligible patient-caregiver dyads to the program, and at least 75% of those referred will participate in the full five sessions with their supportive professional. In other words, the implementation will be deemed successful if at least three-quarters of the eligible dyads will be referred to the program and at least three-quarters of those patients referred actually participate in the entire program. This will be evaluated after determining how many eligible patients the physicians saw during the time of the implementation versus how many they actually referred, and evaluating how many of those referred completed all five sessions per the record of the supportive professional. This is part of the Implementation step of the RE-AIM framework.

**Strengths, Limitations, and Recommendations for Further Research**

A notable strength of this thesis is the abundance and variety of available research on burden among caregivers for dementia patients, including a detailed analysis of this information in the literature review section. Overall, the evidence-based findings were consistent with differing approaches and populations to improve heterogeneity and generalizability of the results. Another strength is that a hypothetical innovative intervention was created based on the research evidence reviewed. On the contrary, some of the limitations are the broad nature of the topic at hand and the difference of definitions of burden and criteria among the studies. Caregiver burden is very clearly defined at the beginning of the paper, and the evaluation of it with CBI is also clear, but the literature review has many differences in their definitions. This made it difficult to determine the consistency of the results across studies because of how many differences there
were among the methods of measurement of burden and the inclusion of other aspects into burden, like anxiety and depression.

An area for further research may need to include the benefit and usage of other telehealth methods for caregiver burden, like a cell phone application for example. Telehealth is increasingly becoming more useful to the world as technology advances and people find that they can reach many different professionals via telehealth versus traveling to see them in person. The literature reviewed in this paper only briefly touches on a method of telehealth and its impact on the caregivers, and it does not really touch on the details behind the implementation of the telehealth method. More research is necessary on the benefits of telehealth for informal caregiver burden, best methods for implementation, and the knowledge needed for nursing and other staff to participate in this intervention.

**Summary**

The purpose of the thesis is to evaluate interventions for informal caregivers to experience less burden, which includes evidence-based causes, factors, impacts, and prevention of caregiver burden from the research literature. It is clear that informal caregivers are about as essential as formal caregivers to the wellbeing of this world and the people living in it, especially when their patients are experiencing dementia and cannot function on their own. However, the number of people developing dementia is gradually increasing because the advanced world that humans live in allows people to live longer. As a result, both the informal and formal caregivers for these patients are experiencing a large amount of distress and burden, and the burden can lead to many long-term physical, mental, and emotional problems among caregivers. As caregivers themselves, nursing staff must take part in the exploration of research and participation in implementation of the evidence-based methods to decrease informal caregiver burden. This
thesis includes a literature review analyzing the current available research, a set of evidence-based best-practice recommendations, and a hypothetical evidence-based intervention to relieve some of the burden on the informal caregivers in the community. With that said, it is necessary to collect and analyze even more research, revise best-practice recommendations to be truly the best, and provide the highest level of evidence-based care and support to informal caregivers for dementia patients so that they can provide quality care to their patients.
References


Czekanski, K. (2017). The experience of transitioning to a caregiver role for a family member with Alzheimer’s Disease or related dementia. *American Journal of Nursing, 117*(9), 24-30. doi: 10.1097/01.NAJ.0000524517.60352.84


Appendix A: Table of Findings

<table>
<thead>
<tr>
<th>Author(s) and Date</th>
<th>Questions, variables, Objectives, hypothesis</th>
<th>Design, sample, setting</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
</table>
| Chen et al., 2014  | • Develop an intervention targeted towards improving coping strategies and to examine its effectiveness on reducing caregiver burden. | • Controlled study design  
  • Fifty-seven caregivers of dementia patients were enrolled, participants were randomly divided into two groups  
  • Intervention group was offered a series of five interventions in which problem-solving skills, knowledge of dementia, social resources, and emotional support were taught every 2 weeks, and the control group was telephoned every 2 weeks for the usual clinical management. | • No statistically significant differences were noted in the demographic data between the two groups.  
  • On the problem-focused coping subscale on the WCCL-R, the intervention group's mean score increased by 3.8 points, and the control group's decreased by 5.1 points ($F = 7.988, P = 0.007$).  
  • On the seeking social support coping subscale on the WCCL-R, the intervention group's mean score increased by 3.8 points, and the control group's decreased by 3.1 points ($F = 4.462, P = 0.04$).  
  • On the Caregiver Burden Inventory, the intervention group's mean score decreased by 7.2 points, and the | • Coping strategies were assessed with the Revised Ways of Coping Checklist (WCCL-R) and caregiver burden was assessed with the Chinese version of the Caregiver Burden Inventory.  
  • Two weeks after the end of the intervention, we again administered the WCCL-R and the Caregiver Burden Inventory. Two-way repeated-measure anova was used to evaluate the changes in coping strategies and caregiver burden. |
| Czekanski, 2017 | Phenomenological qualitative study on the experience of caregivers for family members with dementia or Alzheimer’s Disease (AD). | Hermeneutic phenomenological design with 10 participants (8 women and 2 men). Purposeful recruitment from a randomized trial performed by the Project Advancing Caregiver Training (ACT) database. Participants all chose to interview in their home. Ages of caregiver ranged from 37 to 84 years old and patients aged 58 to 92 years old. Two interview sessions were conducted with each participant individually. First interview gathered information about their control group's increased by 2.2 points ($F = 6.155, P = 0.017$). | Seven themes: 1. Something is wrong 2. The ambiguity and negative emotions along their journey to diagnosis 3. Losses and challenges in the shifting roles and relationships 4. Solutions and frustrations in seeking knowledge and support 5. Finding a purpose in the adaptation to the topsy-turvy world of caregiving 6. Preserving self without guilt 7. Finding a way out. | Data was analyzed using phenomenological methods initially developed by the Utrecht School of Phenomenology and adapted by Barritt and Cohen and their colleagues. Interviews were accurately transcribed, experiences were extracted, unimportant phrases were eliminated, and themes were developed. Data saturation was met. |
experiences, Second interview confirmed this information.

- The sessions were audiotaped and participant-guided.

<table>
<thead>
<tr>
<th>Deeken et al., 2019</th>
<th>The aim of this study was to estimate the efficacy of technology-based interventions for informal caregivers of people with dementia (PWD)</th>
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<tbody>
<tr>
<td></td>
<td>Meta-analyses for the outcome measures caregiver depression and caregiver burden were conducted with subgroup analyses according to mode of delivery (telephone, computer/web-based, combined interventions).</td>
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<td></td>
<td>To assess methodologic quality, the Cochrane risk-of-bias assessment was rated.</td>
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<td></td>
<td>Small but significant postintervention effect of technology-based interventions for caregiver depression and caregiver burden.</td>
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<td></td>
<td>Combined interventions showed the strongest effects.</td>
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<td></td>
<td>PubMed, PsycINFO, and Cochrane Library databases were searched in August 2018-no restrictions in language or publication date.</td>
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<tr>
<td></td>
<td>Two independent reviewers identified 33 eligible randomized controlled trials (RCTs) conducting a technology-based intervention for informal carers of PWD.</td>
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Gehrman et al., 2018

- 3 different objectives:
  1. Determine the prevalence of AD symptoms relating to disturbed sleep
  2. What symptoms affect the quality of life and predict burden of the caregiver?
  3. Compare how sleep disturbance symptoms compare to other symptoms of AD in terms of their effect on the caregiver.

- Cross-sectional, secondary data analysis of surveyed data
  - 130 caregivers of patients at home who met criteria for possible or probable AD
  - Variables of caregiver were demographics, burden, quality of life, physical and mental status, depressive symptoms

- Variables of patient were ability to perform basics activities of daily living (BADLs), instrumental activities of daily living (IADLs), and sleep
  - The survey was presented at the Penn Memory Center of the University of Pennsylvania’s Alzheimer Disease Center, where patients met the National Institute of Neurological and Communicative Disorders and

- The burden and mental and physical status were predictors of caregiver quality of life
  - Burden on caregivers for AD patients can be predicted by the symptoms of sleep disturbance.

- Descriptive Statistics were used to characterize sleep patterns in persons with AD. Univariate linear regression models were used to examine caregiver burden associated with sleep symptoms of their recipients of care. Multiple comparisons were corrected using conservative Bonferroni correction. Statistical analysis was performed using SPSS v24.
| Huang et al., 2015 | Determine the factors related to PWD- and caregiver-rated QOL in dementia as well as factors related to the discrepancy in these ratings. | Cross-sectional study  
- Analyzed data from a convenience sample of 106 PWD-family caregiver dyads (58 community-dwelling dyads and 48 nursing-home dyads)  
- PWDs' data included socio-demographic variables, QOL (assessed by the Quality of Life-Alzheimer's Disease [QOL-AD] scale), cognition, dementia severity, depression, comorbidities, and quality of the dyadic relationship  
- Caregivers' data included socio-demographic variables, depressive symptoms, and mutuality of the dyadic relationship | QOL-AD scores were lower when rated by caregivers than by PWDs  
- The key factors positively related to both PWD- and caregiver-rated QOL for PWDs were fewer PWD depressive symptoms and higher quality of the PWD-caregiver relationship.  
- The key factors related to the discrepancy in PWD- and caregiver-rated QOL in dementia were PWD residence in a nursing home and lower dementia severity, as well as higher caregiver depression, being an adult child caregiver, and lower caregiver-PWD mutuality. | Caregiver-rated QOL for PWDs and the discrepancy in rated QOL were significantly associated with PWD residence.  
- Effect of residence of PWD should be taken into consideration.  
- Caregivers' depressive status and mutuality with PWD must be also carefully assessed. |
| Sperling et al., 2019 | • We evaluated the efficacy of a modified New York University Caregiver Intervention (NYUCI), named FAMILIES, delivered to spousal and non-spousal caregivers of PWDs from diverse etiologies in a reduced number of sessions. | • Participants were 122 primary caregivers for community dwelling PWDs in Virginia. • Intervention included two individual and four family/group counseling sessions that integrated dementia education, coping skills and behavioral management training, emotional support, and identification of family and community resources. | • Symptoms of depression ($p < .001$) and caregiver burden ($p = .001$) and caregivers' capacity to effectively manage their reactions to BSD ($p = .003$), significantly improved at the sixth session. Benefits were maintained at 6-month follow-up. • Being married and female predicted improvement in caregiver burden. • Being male and living in a rural area predicted reduced risk of depression. • Caregivers reported that the intervention was helpful and had a positive impact on the PWD. | • Assessment of depression, caregiver well-being and burden, and caregiver reactions to the behavioral symptoms of dementia (BSD) were completed at baseline, the sixth session, and 6-month follow-up. |
| Pauley et al., 2018 | • The study aimed to examine predicting factors of distress in caregivers providing in-home care. The objectives of the study are to identify factors of newly developed caregiver | • Separate multivariate logistic regression models were created to demonstrate onset of distress and improvement of distress in caregivers based on the statistics from the Ontario Association of | • Factors influencing the onset of caregiver distress were the caregiver feels that they lack support and client lives with caregiver. • Factors with the most influence on a decrease in caregiver stress were the client is now living with other persons and | • Descriptive statistics were the method of analysis. Any variable with $p < 0.05$ were included. |
distress and factors influencing a decrease in caregiver distress.

Community Care Access Centre providing home care for 323,409 clients from 2002 to 2015.

- Data was collected using two Resident Assessment Instrument-Home Care (RAI-HC) assessments, which identifies distressed caregivers based on two parts:
  1. ability to continue care
  2. self-report of distress or depression

- Characteristics of the clients that were examined in the study were:
  - Gender
  - Age
  - Marital status
  - Living situation
  - Recovery chances
  - Extent of care needed

the client has good prospects for recovery.
| Wang et al., 2018 | - Presence of an interpreter  
- Health characteristics  
- Method for Assigning Priority Levels (MAPLe) scores  
- Cognitive Performance Scale (CPS) scores  
- Activities of Daily Living Hierarchy (ADLH) scores.  

- Cross-sectional study on 210 AD patients and their caregivers in 2 hospitals and 3 communities in Taiyuan, China who volunteered for the study.  
- Caregiver negative effects were assessed using the Caregiver Burden Inventory (CBI), Self-rating Anxiety Scale (SAS), and the Self-  
- Caregivers felt heavy burden.  
- Factors in this, as well as depression and anxiety: Gender  
- Age  
- Educational level  
- Employment status  
- Family size.  
- Duration of caregiving did not affect the caregiver.  
- Decrease in patient cognitive function and increase in patient depression increase caregiver burden.  

- Data was entered into EpiData 3.1 software twice to ensure data accuracy.  
- SPSS 22.0 was used for univariate analysis and analysis of the relationship between caregiver burden, anxiety, and depression.  
- Spearman’s rank was used to determine the relationship between factors of the patient. |
| Zauszniewski et al., 2018 | Four research questions:  
1. Do caregiver reactions to dementia symptoms of care recipients affect their coping repertoire?  
2. Is the caregiver’s coping repertoire affected differently by their reactions to specific sets of dementia symptoms?  
3. Do caregiver reactions to dementia symptoms of care | Descriptive secondary analysis of data from a community convenience sample of 138 female caregivers  
- Face-to-face interviews to determine caregiver reactions, spiritual practices, resourcefulness, perceived stress, and depressive symptoms. | Descriptive symptoms of a family member with dementia had a negative impact on the caregivers’ coping strategies.  
- Disruptive symptoms of family members with dementia were associated with more stress, less resourcefulness, and more depression in caregivers.  
- Memory-loss symptoms were not found to be associated with a caregiver mental health and repertoire. | Instruments used to measure variables were  
- 24-item Revised Memory and Behavior Problems Checklist  
- 10-item Spiritual Perspectives Scale (SPS)  
- 28-item Resourcefulness Scale (RS)  
- 14-item Perceived Stress Scale (PSS)  
- 20-item Center for Epidemiological Studies – Depression Scale (CES-D). |
recipients affect their mental health?
4. Is the caregiver’s mental health affected differently by their reactions to specific sets of dementia symptoms?

<table>
<thead>
<tr>
<th>Zhang et al., 2018</th>
<th>Examine subjective burden and strain in caregivers for dementia patients.</th>
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<tbody>
<tr>
<td></td>
<td>Cross-sectional descriptive study that selected and analyzed data from 2015-2016 in China.</td>
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<td></td>
<td>212 caregivers for patients with dementia completed a survey over a personal interview in their homes</td>
</tr>
<tr>
<td></td>
<td>The patient and caregiver were interviewed separately by a Registered Nurse.</td>
</tr>
</tbody>
</table>

|                   | Higher burden and strain is present in children and spouses of dementia patients. |
|                   | Lower income and education played a role in increasing burden and strain |
|                   | Familial or prolonged caregiving appeared to increase caregiver strain and burden. |
|                   | Burden was associated with change in plans, time, and emotional state of caregiver. |
|                   | Overall, Chinese caregivers of patients with dementia had a moderate burden and high strain level. |

|                   | Linear and multiple regression were used to analyze the data. |
|                   | Caregiver burden was measured using the Chinese version of the Zarit Burden Interview (C-ZBI). |
|                   | Caregiver strain was measured using the Chinese version of the Modified Caregiver Strain Index (C-M-CSI). |
|                   | SPSS 15.0 was used to analyzed the data, and a chi-square test was also used for determining if there’s a relationship. |
References


Czekanski, K. (2017). The experience of transitioning to a caregiver role for a family member with Alzheimer’s Disease or related dementia. *American Journal of Nursing, 117*(9), 24-30. doi: 10.1097/01.NAJ.0000524517.60352.84


