

Decreasing Stress Through Education for Caregivers of Community-Dwelling Individuals with
Dementia

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Abstract

People with dementia experience a decline in mental ability that interferes with daily life. The behavioral and psychological symptoms of dementia affect the majority of individuals suffering from dementia and cause negative health outcomes, contribute to caregiver stress, decrease quality of life, increase rate of institutionalization, and increase healthcare cost. The purpose of this evidence-based quality improvement project was to determine if providing resources and education on psychosocial interventions for management of the behavioral and psychological symptoms of dementia decreases stress, as measured by the Zarit Burden Interview questionnaire, among caregivers of community-dwelling individuals with dementia in the outpatient primary care setting. The project utilized a one group pretest and posttest design with a convenience sample of three participants. The small project sample size did not allow for comparison data analysis, and the limited results were varied in the burden scores with two of the three participants showing lower caregiver stress scores after the educational intervention. Assessing and alleviating stress by involving caregivers in the management of behavioral and psychological symptoms of dementia has the potential to ensure the health of the caregiver and the care recipient and decrease the rates of institutionalization rates of individuals with dementia.

Keywords: dementia, behavioral and psychological symptoms of dementia (BPSD), caregiver stress, caregiver intervention

Decreasing Stress Through Education for Caregivers of Community-Dwelling Individuals with Dementia

Dementia is a serious disorder that impacts over five million people in the United States with 110,000 of these individuals living in Missouri (Alzheimer's Association, 2016).

Alzheimer's disease is the sixth leading cause of death in the United States and individuals with dementia are projected to cost the healthcare system approximately \$277 billion in 2018 alone (Alzheimer's Association, 2018). People with dementia experience a decline in cognition that interferes with their quality of lives and up to 90 percent of these individuals are affected by behavioral and psychological symptoms of dementia (BPSD; Chen, et al., 2014). BPSD cause negative health outcomes for the individual, contribute to caregiver stress, decrease the patient's quality of life, increase the rates of institutionalization, and increase healthcare costs (Brodaty & Arasaratnam, 2012; Chen, et al., 2014; Mitchell, et al., 2015; Rocca, et al., 2010).

Nonpharmacological interventions have been shown to be more effective in managing BPSD with few reported negative effects on the individual with dementia (Kales, Gitlin, & Lyketsos, 2014).

Local Issue

The total number of caregivers in Missouri in 2016 was 314,000, and they provided an estimated total of 357,000,000 hours of unpaid care (Alzheimer's Association, 2016). Caregiver burden has become an increasing problem with 32 percent of caregivers reporting high levels of burden and 19 percent reporting moderate levels of burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). As a result of BPSD, these caregivers are experiencing higher levels of stress (Adelman, et al., 2014). It is estimated that 30 to 40 percent of dementia caregivers will experience high levels of stress, burnout, or depression (Robinson, Wayne, & Segal, 2016).

Caregiver stress stems from factors such as having difficulty dedicating time to themselves, struggling to manage the emotional and physical stress of caregiving, and being unable to balance family and work responsibilities with the responsibilities of caregiving (Centers for Disease Control and Prevention, 2011). Caregivers often take the individual with dementia to health care appointments and the focus of the visit is only on the care recipient (Riedel, Klotsche, & Wittchen, 2016). Failure to acknowledge the caregiver at primary care appointments can leave the caregiver with feelings of abandonment and inadequate support (Adelman, et al., 2014).

Diversity Considerations

The diagnosis and impact of dementia are influenced by ethnic diversity. Elderly African-Americans and Hispanics have a higher incidence rate of dementia than elderly Caucasians (Alzheimer's Association, 2018; Chin, Negash, & Hamilton, 2011). The higher rates of dementia among minority populations are thought to be attributed to lower education levels, higher poverty rates, and higher rates of comorbidities which increase dementia incidence, such as cardiovascular disease and diabetes (Alzheimer's Association, 2018). There is also evidence that ethnic minorities with dementia often present with greater cognitive impairments, receive diagnosis later, and obtain insufficient treatment (Chin, Negash, & Hamilton, 2011). The delay in diagnosis and care of minority individuals with dementia is influenced by cultural factors including variations in perceptions regarding the aging process, insufficient access to medical care, and the mistrust of medical establishments (Chin, Negash, & Hamilton, 2011). Geographically, Hispanics and African-Americans are more likely to live in the community, while Caucasians are more likely to reside in a skilled nursing or assisted living facility (Chin, Negash, & Hamilton, 2011).

The literature recommends healthcare providers recognize the important role of the caregiver, ask the caregiver about their experiences, perform caregiver assessments, and provide information regarding the management of BPSD (Adelman, et al., 2014; McCabe, You, & Tatangelo, 2016). It is imperative that caregiver stress is recognized so that the healthcare provider can intervene to ensure the health of the caregiver and the patient. The current evidence-based quality improvement project focused on mediation of stress through caregiver support and education (see Appendix A for Definition of Terms).

Problem & Purpose

BPSD are present in the majority of people with dementia and contribute to high levels of caregiver stress (Adelman, et al. 2014; Chen, et al. 2014). In current practice, pharmacological interventions are being utilized as first line treatment for BPSD. Numerous studies have shown little evidence that pharmacological interventions influence BPSD, and adverse effects are common and detrimental to the patient's health (Brodaty & Arasaratnam; 2012; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Mitchell, et al., 2015; O'Neil, et al., 2011). Nonpharmacological interventions have little reported negative effects on the patient and could potentially be more beneficial in managing the BPSD. The purpose of this evidence-based practice Doctor of Nursing Practice (DNP) project was to determine if providing resources and education on psychosocial interventions for management of BPSD decreases stress in caregivers of community-dwelling individuals with dementia in the outpatient primary care setting.

Facilitators & Barriers

Facilitators for this evidence-based practice project include executive support, availability of necessary resources and time within the project setting, self-efficacy of the caregivers in implementing interventions and utilizing resources, and resource accessibility within the

community. Barriers to consider include recruitment of the specific caregiver population, issues with scheduled follow up appointments or phone calls, time limitations for the education, previously defined organizational culture, the caregivers' utilization of interventions and resources, and the cost of utilizing the community resources such as the adult day cares. Direct costs to implement this project were minimal and included the printed resources and assessment tools to be completed by the caregivers. Factors promoting sustainability of the intervention will be the student investigator and clinical preceptor. A factor inhibiting sustainability during the project is caregivers not attending follow up appointments or answering follow up phone calls.

Review of the Evidence

Inquiry

The question is: In caregivers of community-dwelling people with dementia, does providing resources and education on psychosocial interventions for management of BPSD decrease caregiver stress within three months in the outpatient setting?

Search Strategies

A review of the literature examined the empirical research concerning caregivers of people with dementia, caregiver stress, and interventions to address support of caregivers. The University of Missouri-Kansas City Health Sciences Library was used to search databases including CINAHL, Medline, PubMed, the Cochrane Library, and the National Guideline Clearinghouse. The keywords entered into these databases include *dementia*, *nonpharmacological*, *caregiver stress*, *caregiver burden*, and *interventions*. The articles were examined based on their title and abstract and those that met the inclusion criteria were retrieved from the database and included in this paper. Inclusion criteria included articles written in English that were published after 2005, a study population of individuals with dementia of any

type and their informal caregivers, involved nonpharmacological interventions, and an outcome measure of the effects on BPSD or caregiver stress. The exclusion criteria included articles in which professional care was provided or informal care was given to older adults with memory loss or impaired cognitive functioning unrelated to dementia.

Twenty-six studies were included in the synthesis of evidence. These articles include eight quantitative systematic reviews, one qualitative systematic review, three clinical practice guidelines, two randomized controlled trials, two mixed-methods studies, six quantitative studies, one concept analysis, two expert opinion articles, and one published evidence-based practice project (see Appendix B for evidence table). The levels of evidence represented by these articles are eleven level one studies, two level two studies, one level three study, five level four studies, one level five study, one level six study, two level seven studies, and one mixed-method study which included level 1 and level 4 evidence (see Appendix C for hierarchy of evidence table).

Synthesis of Evidence

This review of the literature explored the current research outcomes of nonpharmacological interventions and healthcare providers properly addressing caregiver stress. Five topics were found to be essential to support the implementation of the evidence-based practice project: effects of nonpharmacological interventions on BPSD, effects of BPSD on caregivers, caregiver stress, caregiver assessment, and caregiver interventions. Three studies discussed effects of BPSD on caregivers, nine studies supported the use of nonpharmacological interventions for BPSD, five studies defined and classified caregiver stress, three studies advocated for the use of caregiver assessments, and six articles encouraged implementing caregiver interventions.

Effects of nonpharmacological interventions on BPSD. BPSD occurs in the majority of people with dementia, can be disturbing, and have negative effects on both the individual and the caregiver (Ayalon, Gum, Feliciano, & Arian, 2006; Brodaty & Arasaratnam, 2012; Chen, et al., 2014; Mitchell, et al., 2015; O'Neil, et al., 2011). Current practice utilizes pharmaceuticals that are not an approved treatment by the Food and Drug Administration for the use in the elderly population, show little evidence of effectiveness, and have common adverse effects (Ayalon, et al., 2006; Brodaty & Arasaratnam, 2012; Chen, et al., 2014; Gitlin, et al., 2010; Kales, et al., 2014; Kong, Evans, & Guevara, 2009; Mitchell, et al., 2015; O'Neil, et al., 2011). Clinical practice guidelines recommend BPSD be managed by recognizing and avoiding triggers to symptoms, classifying the symptoms, and utilizing interventions known to decrease or diminish the symptoms (National Guideline Clearinghouse, 2016; National Guideline Clearinghouse, 2012). The literature also recommends utilizing nonpharmacological interventions; which have few reported negative effects on the patient, are more effective in managing BPSD than medications, and potentially delay long-term care placement (Gitlin, et al., 2010; Kong, et al., 2009; Kales, et al., 2014; Mitchell, et al., 2015; O'Neil, et al., 2011; Spijker, et al., 2008). Inconsistencies have been identified in the literature on the effectiveness of nonpharmacological interventions on BPSD, and many interventions lack quality evidence (Kong, et al., 2009; O'Neil, et al., 2011). Research that utilized individualized nonpharmacological intervention care plans and involved the caregivers were effective at alleviating BPSD and significantly lower the risk of harm to the individual with dementia (Ayalon, et al., 2006; O'Neil, et al., 2011).

Effects of BPSD. BPSD have been researched extensively and are concluded to be more challenging to manage and cause more stress and burden on caregivers than cognitive, physical, or functional deficits (Brodaty & Arasaratnam, 2012; Fonareva & Oken, 2014; Kales, et al.,

2014; Rocca, et al., 2010). Research has also shown that caregivers of individuals with dementia have higher rates of unmet needs and decreased rates of service utilization, which lead to caregiver stress (Fonareva & Oken, 2014; McCabe, et al., 2016). Compared to non-caregiving peers, caregivers of individuals with dementia struggle with their physical and psychological health which leads to high rates of hospitalizations, increased prescription usage, and greater mortality (Dang, Badiye, & Kelkar, 2008; Fonareva & Oken, 2014). Caregivers are also more likely to develop dementia than the general population and exhibit negative effects on blood pressure, cardiovascular disease markers, blood glucose, coagulant activity, cortisol levels, immune function, and cellular aging (Dang, et al., 2008; Fonareva & Oken, 2014). BPSD is also associated with increased healthcare costs and institutionalization (Afram, et al., 2015; Ayalon, et al., 2006; Dang, et al., 2008; Gitlin, et al., 2010; O'Neil, et al., 2011; Spijker, et al., 2008). Because BPSD is a main source of caregiver stress and predispose the individual with dementia to increased risk of institutionalization, interventions are needed to prevent negative health consequences and avoid admission to nursing facilities (Afram, et al., 2015; Brodaty & Arasaratnam, 2012; Collins & Swartz, 2011; Fonareva & Oken, 2014; Kales, et al., 2014; Oken, et al., 2010).

Caregiver stress. Caregiver stress has been widely explained as the burden caregivers endure when tending to a care recipient with a chronic illness, such as dementia (Adelman, et al., 2014; Pearlin, Mullan, Semple, & Skaff 1990; Zarit & Zarit, 1990). There are two components to caregiver stress: subjective stress which includes the caregiver's emotional and cognitive reactions to the situation and objective stress which includes the physical tasks that must be completed by the caregiver for the loved one (Llanque, Savage, Rosenburg, & Caserta, 2016). The main factors contributing to caregiver burden in this population include severity of

dementia, degree of personality change, and BPSD (Brodaty & Arasaratnam, 2012; Chiao, Wu, & Hsiao, 2015; Fonareva & Oken, 2014). Some of the challenges associated with increased caregiver stress include devastating disease progression, fatigue, exhaustion as demands increase, isolation and loneliness as independence disappears, and financial struggles as cost of care rises and hours spent working decrease (Brodaty & Arasaratnam, 2012; Dang, et al., 2008; Robinson, et al., 2016). Caregiving also leads to decreased time for personal care, physical illness, poor sleep quality, poor cognitive functioning, anxiety, depression, and physiological stress as the individual with dementia declines mentally and functionally (Bailes, Kelly, & Parker, 2016; Dang, et al., 2008; Fonareva & Oken, 2014; McCabe, et al., 2016; Svendsboe, et al., 2016). Caregiver stress has a negative impact on caregivers of individuals with dementia, and research findings such as these should empower healthcare providers to intervene promptly.

Caregiver assessment. Currently, caregiver needs are not being met by healthcare providers, which is contributing to high levels of stress (Dang, et al., 2008; McCabe, et al., 2016; Riedel, et al., 2016). Knowledge deficits regarding a dementia diagnosis and how to manage BPSD are not being addressed in the primary care setting (Collins & Swartz, 2011; Dang, et al., 2008; McCabe, et al., 2016; Riedel, et al., 2016; Svendsboe, et al., 2016). Purposeful caregiver assessment is a process in which information is gathered about the care recipient-caregiver relationship, their needs and strengths, and the resources being utilized (Collins & Swartz, 2011; Dang, et al., 2008). Caregiver assessments should include two main areas. One area includes identifying factors that contribute to caregiver stress such as physical demands, role conflicts, psychological effects, and financial strain, while another area includes evaluation of caregiver perceptions involving their health, challenges and benefits to caregiving, knowledge of care management, confidence in caregiving skills, and additional support systems that may be needed

(Adelman, et al., 2014; Collins & Swartz, 2011; National Guideline Clearinghouse, 2016).

Encouraging healthcare providers to screen for stress during a routine clinic visit can identify caregivers who are struggling and assist the provider in intervening to ensure the health of the caregiver and care receiver (Adelman, et al., 2014; Dang, et al., 2008; Riedel, et al., 2016).

Caregiver interventions. Providing support to the caregiver of a community-dwelling individual with dementia has been shown to be a factor in decreasing stress (Adelman, et al., 2014; Collins & Swartz, 2011; Dang, et al., 2008; Fonareva & Oken, 2014; McCabe, et al., 2016). Primary care providers are typically in regular contact with the individual with dementia and the caregiver, but frequently role stress is overlooked (Riedel, et al., 2016). It is imperative for healthcare professionals to use a collaborative approach in the patient-provider relationship and provide caregiver support to prevent negative outcomes (Adelman, et al., 2014; Collins & Swartz, 2011; Dang, et al., 2008). Supporting caregivers can occur in several ways including encouraging self-care (taking breaks, healthy diet, exercise, mindfulness meditation), identifying coping strategies, addressing unmet educational needs, and providing available resources such as support groups and respite care (Collins & Swartz, 2011; Dang, et al., 2008; McCabe, et al., 2016; Oken, et al., 2010; Robinson, et al., 2016).

Research has recognized that services such as counseling, care management, support groups, respite care, and adult day care services are beneficial to caregivers with high stress levels (Bailes, et al., 2016; Dang, et al., 2008). Routine communication between the caregiver and the healthcare provider regarding care management and necessary community resources is needed to provide support and reassurance to the caregiver (Dang, et al., 2008; McCabe, et al., 2016; National Guideline Clearinghouse, 2016; National Guideline Clearinghouse, 2012).

Psychosocial educational intervention programs focused on increasing knowledge of the disease,

self-care, patient care, and advance care planning are also recommended to combat stress (Adelman, et al., 2014; Collins & Swartz, 2011; Dang, et al., 2008; Svendsboe, et al., 2016; Tang & Chan, 2016).

A few specific approaches regarding caregiver interventions include RECAPS (Reminders, Environment, Consistent Routines, Attention, Practice, Simple Steps) and MESSAGE (Maximize attention, watch your Expression and body language, keep it Simple, Support their conversation, Assist with visual aids, Get their message, Encourage and engage in communication) programs to provide caregiver education in regard to optimizing residual memory and communication abilities which could reduce burden (Smith, et al., 2011). Another approach called DICE (Describe, Investigate, Create, and Evaluate) allows the healthcare provider to have a conversation regarding the BPSD the patient may be experiencing and increase the knowledge-base of the caregiver in utilizing nonpharmacological interventions (Kales, et al., 2014). Effective support programs integrating caregiver involvement, community resources, and psychosocial intervention choices allow more freedom, personal control, satisfaction, and better adherence to the care plan (Brodaty & Arasaratnam, 2012; National Guideline Clearinghouse, 2016).

Theory

Pao-Feng Tsai's Theory of Caregiver Stress (TCS) was utilized to guide this evidence-based practice project (see Appendix D for Theory to Application Diagram). Tsai's (2003) purpose in creating the TCS was to predict caregiver stress and outcomes from input factors including internal and external stimuli such as objective burden, stressful life events, social support, social roles, and demographic characteristics. The coping mechanisms, perceived caregiver stress and depression, act as mediating variables between the input factors and the

output factors (Tsai, 2003). The caregiver's adaptive modes, or output factors, are the caregiver's responses to perceived caregiver stress and include physical function, self-esteem, mastery, role enjoyment, and marital satisfaction (Tsai, 2003). The TSC facilitates intervening in the caregiver-care recipient relationship to prevent caregiver stress from occurring. Implementing an educational program encompassing psychosocial interventions and community resources will impact the caregiver's objective burden and social support input factors with the goal of decreasing overall caregiver stress. The TCS has been cited by articles regarding caregivers of individuals with dementia and cancer (Awasthi & Pandey, 2017; Lewis, 2014).

Methods

Institutional Review Board and Site Approval

The primary Institutional Review Board (IRB) was the University of Missouri-Kansas City (See Appendix E for Institutional Review Board Approval Letter). A Federally Qualified Health Center (FQHC) in northwest Missouri granted approval for this project. This project is considered non-human subjects research or evidence-based quality improvement. Because the focus of this project was on improving the care of caregivers through education and resources, there was minimal risk to the participants.

Ethical Issues and Funding

Vulnerability, protection, autonomy, privacy, and confidentiality are all ethical concepts that were acknowledged for this project. People with dementia are considered a vulnerable population, and although the planned intervention was directed towards the caregiver, the care receiver could potentially be affected (Alzheimer Europe, 2014). This project was designed to provide the most protection to the care receiver while impacting current practice to increase the quality of life of the caregiver and the care receiver. Autonomy of the caregiver and the

individual with dementia was encouraged through choosing the interventions and resources that would be beneficial and conducive to their current situation. By utilizing the Zarit Burden Interview, privacy regarding specific symptoms and situations were maintained. This tool uses a Likert scale to measure caregiver stress which allows the caregiver to keep specific details private (Zarit & Zarit, 1990). This student investigator ensured the confidentiality of all data by coding the questionnaires so no personal information was included and the data analysis was completed through secure methods. No conflicts of interest are present regarding this project. Limited funding was required for this project as the only direct cost was for the paper and ink required to print the education and resource handouts and the Zarit Burden Interview questionnaires (See Appendix F for Cost Table). This student investigator self-funded the project.

Setting and Participants

This project took place in a FQHC in northwest Missouri. This is a non-profit community health center that provides care to low income and medically underserved individuals. A convenience sampling method was used to recruit participants for this study. Inclusion criteria included informal caregivers of an individual with a diagnosis of dementia of any stage who spend at least an average of 2 hours a day caring for the individual. These caregivers were not required to be patients of the clinic since many times the caregivers bring the individual with dementia to their appointments. The estimated sample size was 15 participants. Caregivers were excluded if they were compensated caregivers, if the care receiver did not have a diagnosis of dementia, or if the caregiver spent less than 2 hours a day caring for the individual with dementia.

Evidence-based Practice Project

Recruitment. Convenience sampling was utilized to recruit patients attending their primary care appointments. Patients known by the project facilitator to be caregivers of an individual with dementia, and meet the inclusion criteria, were asked to participate in this project. The Information Technology (IT) department also assisted in the recruitment process by running a search of patients with an ICD 10 code of dementia and compiled a list of potential participants. This list was then reviewed by the project facilitator and other supporting providers to narrow to patients who reside in the community with the help of a caregiver. Eligible caregivers did not have to be patients at the clinic but attended the appointment with the individual who has dementia.

Intervention. The evidence-based interventions for this project included performing a caregiver stress assessment and providing resources and educational materials on managing BPSD. The project focused on how to mediate caregiver stress through education on nonpharmacological psychosocial interventions the caregiver could implement and available resources in the community (see Appendix G for Intervention Materials). This was accomplished by providing the caregivers with support and creating an atmosphere where the caregiver was able to ask for assistance when struggling with high levels of stress. Providing this support has been shown to be a factor in decreasing caregiver stress (Adelman, et al., 2014; Collins & Swartz, 2011). An underlying intention of this project was to equip the caregiver with other nonpharmacologic intervention options when dealing with BPSD to increase the caregiver's self-efficacy. This increase in self-efficacy has been shown to mediate the effects of caregiver stress (Tang & Chan, 2016).

Implementation. Prior to the implementation of this project, the student investigator obtained IRB approval and gathered all the educational materials and resources to create a

bundle to guide the educational intervention. Educational materials were requested from the local chapter of the Alzheimer's Association and this student investigator created a document listing local resources for caregivers of people with dementia, including adult day cares, respite care, and support groups, that could potentially relieve caregiver stress. The first step in implementing this project was the recruitment of caregivers. The second step was to evaluate caregiver eligibility for inclusion in the project. Caregivers were deemed eligible if they provided informal care at least two hours per day to an individual with dementia. The third step was verbal consent of the participants. Recruitment, eligibility, and informed consent were completed by the student investigator and clinic staff for approximately two months. The fourth step was pre-intervention screening. The eligible caregiver was asked to complete a form for demographic characteristics and a Zarit Burden Interview questionnaire. The pre-intervention screening took approximately five to ten minutes for the caregiver to complete. The fifth step was education provided by the student investigator on local resources and psychosocial interventions shown to manage BPSD. The caregiver was provided written materials and verbal education lasting approximately ten minutes. After the appointment, the caregiver was asked to provide their phone number. Follow-up phone calls were completed at one and two months. A post-intervention Zarit Burden Interview questionnaire was completed by the caregiver at the two month follow-up appointment. The student investigator also asked the caregiver about the utilization of local resources and psychosocial interventions within the two month time frame. Once all the project data was collected, the student investigator compared the pre-intervention and post-intervention scores to determine the educational intervention effect on perceived caregiver stress (see Appendix H for Project Timeline Flow Graphic and Appendix I for Intervention Flow Diagram).

Change Process and Evidence-based Practice Model

This project was implemented following the Awareness, Desire, Knowledge, Ability, and Reinforcement (ADKAR) change process model and the Academic Center for Evidence-Based Practice (ACE) star model. The ADKAR model focuses on each individual person's ability to change, therefore promoting organizational change (Connelly, 2015). The ADKAR model was utilized because antipsychotic medications have become the norm to manage BPSD and changing that thought at the individual level can then promote a culture change within the setting. Connelly (2015) states the five actions of individual change include awareness of the need for change, desire to contribute to and support the change, knowledge of the process to change, ability to implement required skills and behaviors, and reinforcement to sustain the change. The ACE star model focuses on knowledge transformation through five major stages: Discovery, Evidence Summary, Translation to Guidelines, Practice Integration, and Evaluation (Stevens, 2004). The ACE star model depicts the cyclical pattern of the knowledge transformation into practice (Stevens, 2004). The ACE star model was utilized for this project because it supports the use of multiple forms of research knowledge to form clinical decisions and ultimately implement evidence-based practice (Stevens, 2004).

Sustainability of caregiver assessment and intervention is likely because the clinical preceptor and support staff were involved in the change process and witnessed benefits to the caregivers. This investigator has assisted the clinic site in obtaining permission to use the Zarit Burden Interview questionnaire beyond the project implementation timeframe to promote the continued assessment of caregiver stress. Extra Alzheimer's Association brochures and educational materials were provided to the clinic upon completing the project to promote sustainability.

Study Design

This evidence-based practice project was intended to be a quasi-experimental study with a one group pretest and posttest design. Caregivers of community-dwelling individuals with dementia were given education and resources on psychosocial interventions that could be utilized to alleviate BPSD in the care receiver. A goal convenience sample of 15 patients was attempted from a primary care clinic setting. The outcome measure was caregiver stress using the Zarit Burden Interview questionnaire, and the results were to be analyzed utilizing a Wilcoxon Signed-ranks test (See Appendix J for Logic Model).

Validity

Within the design of this project, several threats to internal validity exist. One major threat was the convenience sampling method because the impact on caregiver stress could potentially not be caused by the educational intervention. Another threat to internal validity in this project was the length of time from pretest to posttest. Within two months, caregivers participated in monthly follow-up phone calls to complete post-intervention evaluation, but this time frame was lengthy and caused high attrition rates. A further threat to this project was the self-report pre-posttest study design. When the same questionnaires are utilized both before and after the intervention, the participants are sensitized to the questionnaire when taking the post-intervention surveys (Polit & Tatano Beck, 2012). Another threat was having a small sample size; in which it was difficult to draw accurate conclusions on the effects of the intervention.

The extent to which the findings from this project can be generalized is limited. Findings from this project can only be generalizable to a similar population of caregivers of community-dwelling individuals with dementia. The project sample was not representative of the general population because it was obtained by convenience from one primary care setting. Although the

results cannot be widely generalized, this study could easily be replicated in multiple settings to provide increased generalizability.

Outcome and Measurement Instrument

The primary outcome in this project is caregiver stress. The intended goal of the project was to decrease caregiver stress by providing resources and educational materials on managing BPSD. Caregiver stress was measured utilizing the Zarit Burden Interview questionnaire (Zarit, Reever, & Beck-Peterson, 1980). This tool is a 22 item self-report questionnaire and each question on the survey is scored on a Likert scale ranging from never to nearly always (see Appendix K for Zarit Burden Interview Measurement Tool). The total scores range from 0 (low burden) to 88 (high burden; Zarit, Orr, & Zarit, 1985). The Zarit Burden Interview has good construct validity and internal consistency with a Cronbach's alpha of 0.93 and a test-retest reliability of 0.89 (Seng, et al., 2010). For pre-intervention screening, this measurement tool was delivered in a written format to the caregiver to complete by circling the numbers that best represent how they feel regarding each of the 22 questions. Post-intervention screening was delivered verbally over the phone by the student investigator or in written format if the patient had a follow-up within the allotted study timeframe. Permission to use the Zarit Burden Interview was obtained (see Appendix L for Permission for Tool).

Quality of Data

To ensure the quality of the data collection process, participation in the project remained confidential and identifying information was coded on questionnaires. To protect against bias, nurse and medical assistants within the clinic setting were recruited to obtain verbal consent from caregivers. The caregiver was provided resources and education materials and completed the questionnaire within the examination room to promote privacy. The student investigator

delivered the education, explained the data collection methods, and provided ample time for the caregiver to complete the questionnaire. The Zarit Burden Interview questionnaire has been utilized throughout the literature to assess caregiver burden (Adelman, et al., 2014; Afram, et al., 2014; Chiao, Wu, & Hsiao, 2015). The data collected from this project can be compared to other published data regarding the impact of providing BPSD resources and education on caregiver stress (Chiao, Wu, & Hsiao, 2015; Collins & Swartz, 2011; Oken, et al., 2010; Smith, et al., 2011). For this project, a priori or post-hoc power calculation was not utilized to determine a sample size due to an expected small sample size. To protect against potential threats, the only person collecting and analyzing data to prevent transcription errors was the student investigator. Issues with attrition and missing data remained as some caregivers did not participate in follow-up phone calls or complete the post-intervention questionnaire.

Analysis Plan

The planned statistical analysis for this one group pretest posttest design evidence-based practice project was to be completed using IBM SPSS Statistics Version 24. Comparative testing was expected to be performed on the pre-intervention and post-intervention Zarit Burden Interview scale data by utilizing a Wilcoxon Signed-ranks test to determine the impact of providing resources and educational materials on caregiver stress. Demographic data collected included age, gender, ethnicity, relationship status, education level, employment status, and household income (See Appendix M for Data Collection Template).

Results

Setting & Participants

This project was conducted in a FQHC in northwest Missouri from December 2018 through March 2019. Many patients that are seen by providers within this non-profit community

health center are low income and medically underserved individuals. Three primary care nurse practitioners agreed to recruit caregivers in this project. The recruitment process revealed nine caregivers willing to participate. Most of these caregivers reported spending over 30 hours per week caring for a person with dementia. Only three of the nine caregivers were able to complete the project and provide post-intervention data within the project timeframe.

Intervention Course

The first step in implementing this project occurred in November 2018 when IT was asked to run a search for patients of the three nurse practitioners that had been documented as having a dementia ICD 10 code. This list was then narrowed to patients with caregivers who had an appointment within the next two months. The caregivers were then recruited between December 2018 and January 2019 at their family member's regularly scheduled appointment by having a member of the clinic staff ask for verbal consent to participate. By the end of January, nine caregivers had been recruited to participate, and demographic questionnaires and pre-intervention Zarit Burden Interview scores were collected. The first follow up phone call, which included education on local resources and psychosocial interventions shown to manage BPSD, was done between January 2019 and February 2019. During this step, one caregiver notified the student investigator that she was no longer a caregiver, one caregiver did not have time to complete the educational intervention, and one caregiver was unable to discuss her family member's diagnoses in front of her. At this time, three other caregivers were not answering phone calls or voicemails left by this student investigator; therefore, only three caregivers were given the educational intervention at the first follow-up call. The final interaction, where the post-intervention Zarit Burden Interview scores were obtained, was completed from February

2019 thru March 2019. One caregiver completed this step over the phone, while the other two were face-to-face at a clinic appointment.

Outcome Data

Because there were only three caregivers that completed this project, the data was analyzed by descriptive statistics. No missing data was found on the three participant questionnaires. Each of the three caregivers had different situations and ended the study with different results (See Appendix N for Outcome Data Table). The first caregiver to complete the project was a husband taking care of his wife without much assistance. His pre-intervention score was 22 (mild to moderate burden) and his post-intervention score was 20 (little to no burden). He told the student investigator that the education was beneficial but that he did not utilize any of the external resources provided.

The second caregiver to complete the study was a daughter caring for her mother who was residing in an assisted living facility. She reported spending approximately 10-20 hours per week caring for her mother by assisting with cooking, cleaning, and medication organization. Her pre-intervention score was 60 (moderate to severe burden) and her post-intervention score was 54 (moderate to severe burden). This caregiver was worried about the need to decide to increase the level of care her mother required due to safety concerns. She expressed concerns regarding the financial aspect of transferring the patient to a long-term care facility. This caregiver also told the student investigator that the education and support provided was beneficial, but she too did not utilize the external resources provided within the study timeframe.

The last caregiver to complete the study was a wife taking care of her husband with the assistance of a part-time in-home formal caregiver. She reported caring for her husband for greater than 30 hours per week. Her pre-intervention score was 26 (mild to moderate) and her

post-intervention score was 33 (mild to moderate). This caregiver reported to the student investigator at the post-intervention interaction that her paid in-home caregiver had stopped coming on a regular basis. This project participant utilized the formal caregiver as a relief so she could complete her errands and other tasks. For her, an external factor caused her burden score to increase by the post-intervention data collection (See Appendix N for Statistics Table).

Discussion

Successes

The success of this project is uncertain due to the limited number of caregivers that were able to complete the project. Two out of the three participants had lower caregiver stress scores after the educational intervention. The recruitment of the caregivers went smoothly, but the project suffered when caregivers were not returning calls or external factors did not allow completion of the intervention. Although the sample size was limited, this project laid the foundation for the practical implementation of an educational intervention for caregivers of an individual with dementia in the primary care setting. A positive outcome reported by all three caregivers who finished the study was that the education was helpful, and they would potentially use some of the techniques provided when caring for their loved one. Further studies are needed to assess the impact of providing education and support to caregivers of an individual with dementia.

Study Strengths

The FQHC where this project took place values providing quality care to all patients regardless of ability to pay. Support for this project was provided by people in different roles throughout the organization. The IT department assisted in finding patients with dementia by formulating a list of people who had been coded with a dementia ICD 10 code. The care

managers and behavioral health counselor recommended a few patients with caregivers that they had been following. The nurses and medical assistants obtained verbal consent from the caregivers and made phone calls to caregivers when the student investigator was unable to contact them. Finally, three nurse practitioners supported the implementation of this project by assisting with recruitment and allowing for time within their scheduled appointments to complete the baseline data collection and educational intervention.

The educational intervention was implemented successfully within this primary care clinic setting. Once the student investigator contacted the local Alzheimer's Association and compiled packets of information for the caregivers, these were utilized to guide the educational intervention. The follow-up phone call component of the project did not proceed as planned. A majority of the caregivers did not answer the phone and did not respond to voicemails. This contributed to the small sample size because of the lack of post-intervention data. If this project was implemented again, the student investigator would ensure an adequate timeline and obtain post-intervention data at scheduled follow-up appointments.

Results Compared to Evidence in the Literature

Current literature recommends the utilization of more effective nonpharmacological interventions when managing BPSD (Gitlin, et al., 2010; Kong, et al., 2009; Kales, et al., 2014; Mitchell, et al., 2015; O'Neil, et al., 2011; Spijker, et al., 2008). To accomplish this, many researchers and specialists in this field are requesting that healthcare providers spend time educating and supporting caregivers of individuals with dementia to reduce caregiver stress (Adelman, et al., 2014; Brodaty & Arasaratnam, 2012; Collins & Swartz, 2011; Dang, et al., 2008; Kales, et al., 2014; O'Neil, et al., 2011; Svendsboe, et al., 2016; Tang & Chan, 2016). A study by Oken and colleagues (2010) showed that an educational intervention for caregivers of

people with dementia decreased self-perceived stress levels. The hope of this EBP was to reflect Oken and colleagues' (2010) findings, but because of the small sample size, no conclusions can be extracted from the data.

Limitations

Internal Validity Effects

Only three caregivers were able to complete the project within the allotted timeframe, which resulted in the inability to establish clinical or statistical significance. The small sample size was a predicted threat to internal validity at the beginning of this project, but the high rate of attrition caused this project to transition into a limited case study of three caregivers. Potential factors for the high attrition rate are the timeframe between baseline and post data collection and caregivers lacking the time to participate in the educational intervention. The collection of data via telephone communication negatively affected the study outcomes and resulted in the inability to draw inferences on the effects of the intervention.

External Validity Effects

As a result of the small sample size, the outcomes of this project are not able to be generalized. Although this project converted into a limited case study, the educational materials and Zarit Burden Interview questionnaires could be transferrable into other healthcare settings. Replication of this study in multiple locations with larger sample sizes would strengthen the validity and generalizability of this evidence-based educational intervention.

Sustainability of Effects and Plans to Maintain

The nurse practitioners that supported this project were not directly involved in the education of the caregivers, so the project sustainability is limited. This student investigator has given these providers extra Alzheimer's Association educational materials to use when working

with caregivers of individuals with dementia. Also, the student investigator has offered to assist the clinic site in obtaining permission to use the Zarit Burden Interview questionnaire beyond the project implementation timeframe to promote the continued assessment of caregiver stress.

Minimizing the Study Limitations

The primary limitation to this project was the attrition of caregivers from the project. An effort to minimize this limitation was to educate caregivers about what to expect at the beginning of the study. The student investigator provided this specific project information before continuing with the educational intervention. Unfortunately, unforeseen external factors mostly contributed to the high attrition rate. One participant reported at her first follow-up phone call that she was no longer a caregiver due to a change in family dynamics. Another participant reported at her first follow-up phone call that she was unable to speak to me in front of her loved one because she does not speak about her diagnosis of dementia. Another participant reported at her first follow-up phone call that she did not have the time to review and participate in the educational intervention. The student investigator was unable to contact the last three participants. The high attrition rate directly affected the ability to draw conclusions from this project.

Interpretation

Expected and Actual Outcomes

The expected result of this project was a significant decrease in caregiver stress after an education intervention was implemented. However, the student investigator was unable to draw conclusions from this project due to the limited number of participants. Two out of the three participants had lower caregiver stress scores after the educational intervention, but more participants are needed to show significance.

This student investigator underestimated the difficulty in recruitment and retention of caregivers in the project. It was noted during the recruitment phase of this project that there are many patients at the clinic with cognitive impairments that have not been formally diagnosed with dementia. The lack of formal diagnosis could be due to the high number of patients with limited finances or insurance coverage.

Intervention Effectiveness and Revision

The effectiveness of this educational intervention is unknown because of the lack of a significant sample size. Although two of the three caregivers did have a decrease in their Zarit Burden Interview questionnaire scores, a larger sample size is needed to show clinical significance. A longer project implementation timeframe could have allowed for more participants from which to draw conclusions on the educational intervention.

There are a few potentially beneficial revisions that could be made to this project. One modification to this project would be to conduct face to face follow-up at clinic appointments. This would allow for a predetermined time for the educational intervention and data collection process throughout the project. Another modification would be to recruit caregivers in advance instead of using a list generated by the IT department. This change could have yielded more dedicated and involved caregivers to participate in the study. The last modification would include caregivers of patients with significant cognitive impairment that have dementia specific symptoms. This modification could allow for a wider potential sample pool.

Impact to Health System, Costs, and Policy

High stress levels can have negative impacts on the caregiver's health and wellbeing. The caregiver's health directly affects their ability to care for their loved one. The complications related to high stress can cause caregivers to place the individual with dementia into a care

facility, which increases the overall cost of healthcare. At this time, this project did not demonstrate any benefit to the health system due to its insignificant sample size. Potential benefits could be determined through replication of this project with a larger sample size.

The anticipated cost of this project was minimal and was funded by the student investigator (See Appendix F for Cost Table for Project). The actual costs of implementing the project were less than the anticipated cost because the student investigator only made fifteen copies of both the educational materials and the questionnaires. This project economically could be easily sustainable because all the educational materials could be copied at the clinic setting. The only cost to the organization would potentially be to continue utilizing the Zarit Burden Interview questionnaire because it is not in the public domain.

Conclusion

Healthcare providers have a duty to recognize caregiver stress and provide support to caregivers to prevent negative outcomes (Llanque, et al., 2016). When stress is recognized and treated, the caregiver is able to maintain a positive attitude and their overall health and the individual with dementia will be able to continue receiving quality care, therefore maintaining their quality of life (Collins & Swartz, 2011; Llanque, et al., 2016). Throughout the literature, there is understanding of the importance of addressing caregiver stress through recognition, assessment, intervention, and follow-up care within the primary care setting (Adelman, et al., 2014; Collins & Swartz, 2011; Dang, et al., 2008; National Guideline Clearinghouse, 2016; Riedel, et al., 2016). Multicomponent interventions combining education, assistance with managing BPSD, psychosocial interventions, counseling, and support are most effective in mediating caregiver stress, reducing institutionalization rates, and decreasing healthcare service utilization (Adelman, et al., 2014; Collins & Swartz, 2011; Dang, et al., 2008; McCabe, et al.,

2016; Tang & Chan, 2016). Individualized plans are needed to address the unique care needs of individuals with dementia (National Guideline Clearinghouse, 2016).

The project aim was to provide resources and education on psychosocial interventions to determine the effect on caregiver stress. Overall, the goal of this project was to decrease stress among caregivers of individuals with dementia by providing education, support, and an atmosphere that invites the caregiver to share experiences. This project is practical to implement within the primary care setting because it can be completed within the patient's regularly scheduled appointment time. Further studies implementing an educational intervention with caregivers of community-dwelling people with dementia could include more in depth educational interventions and multiple educational sessions to promote knowledge retention. Additional studies could also be done on developing programs such as the RECAPS and MESSAGE program to address caregiver education on working with individuals with dementia (Smith, et al., 2011). Results of the project were disseminated through a poster presentation at the Advanced Practice Nurses of the Ozarks conference. Sharing the knowledge gained through completion of this project reinforced the need for healthcare providers to recognize the important role of the caregiver, ask the caregiver about their experiences, perform caregiver assessments, and intervene to prevent stress (Adelman, et al., 2014).

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Appendix A

Definition of Terms:

- Behavioral and psychological symptoms of dementia: symptoms common in a person with dementia that include agitation, hallucinations, delusions, anxiety, disinhibition, depression, euphoria, sleep disturbances, wandering, refusal of assistance with activities of daily living, and appetite changes (Ayalon, et al., 2006; Brodaty & Arasaratnam, 2012; Chen, et al., 2014; Mitchell, et al., 2015; O'Neil, et al., 2011).
- Caregiver: someone who is responsible of taking care of another person (Pearlin, et al., 1990)
- Caregiver stress: the burden caregivers endure when tending to a care recipient with a chronic illness, such as dementia. Symptoms of caregiver stress include depression, anxiety, anger, social withdrawal, exhaustion, irritability, cognitive disturbance, sleeplessness, poor health status, and role entrapment (Llanque, et al., 2016).
- Dementia: a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform every day activities (Alzheimer's Association, 2018)
- Psychosocial interventions: ways to support people to overcome challenges and maintain good mental health without the use of medication (Tang & Chan, 2016).

Appendix B

Table of Evidence

P: In caregivers of community-dwelling people with dementia
 I: Provide education and resources to manage behavioral and psychological symptoms of dementia
 C: Current practice
 O: Decreased caregiver stress
 T: Three months
 S: Outpatient setting

PICOT

In caregivers of community-dwelling people with dementia, does providing resources and education on psychosocial interventions for management of BPSD decrease caregiver stress within three months in the outpatient setting?

First author, year, title, Journal, & Purpose	Research Design, Evidence Level, & Variables	Sample & Sampling	Measures & Reliability (if reported)	Results & Analysis Used	Strengths & Limitations
Effects of BPSD					
Afram, B (2014). Predicting institutional long-term admission in dementia: A mixed-methods study of informal caregivers' report. <i>Journal of Advanced Nursing</i> . -Purpose: investigate the agreement between 1. expected and actual reasons for admission to long-term care of people with dementia 2. measurement scores prior to admission and actual reasons for admission	-mixed-methods -quazi-experimental -cohort study -convergent design -Level 4	- 126 dyad convenience sample; participants with diagnosed dementia were recruited from home-care organizations -informal caregivers eligible if they visited the patient at least twice a month	-data collected through interviews Patient Measurements: -Standardized Mini Mental State Examination -Neuropsychiatric Inventory Questionnaire (test-retest correlations 0.80 and 0.94) -Katz index of independence in ADLs (Cronbach's alphas 0.87-0.94) -Charlson Comorbidity Index (test-retest correlations 0.91) Caregiver Data: -Zarit Burden Interview (Cronbach's alpha 0.93) -Caregiver Reaction Assessment (Cronbach's alpha 0.62-0.83)	-informal caregivers can offer clues regarding causes of admission of patients with dementia to a long-term care center -verbal reports and measurement tool scores can indicate likelihood of admission of a patient with dementia to a long-term care center	-skewed distribution of sample being from France -short follow-up period led to a small sample size -inability to apply results to general population

<p>Fonareva, I (2014). Physiological and functional consequences of caregiving for relatives with dementia. <i>International Psychogeriatrics</i> -Purpose: summarize physiological and functional changes in caregivers due to chronic dementia caregiver stress</p>	<p>-systematic review -Level 1</p>	<p>-37 studies including 4,145 participants</p>	<p>-outcome measures included markers of dyscoagulation, inflammation, and cell aging</p>	<p>-persistent caregiver stress increases the caregiver's susceptibility to disease and reduces the quality of the care they provide</p>	<p>Weakness: only English articles, observational nature of data collection, most included studies recruited female participants</p>
<p>Rocca, P (2010). Neuropsychiatric symptoms underlying caregiver stress and insight in alzheimer's disease. <i>Dementia and Geriatric Cognitive Disorders</i> -Purpose: determine the validity of cluster analysis on caregiver burden, lack of insight, and cognitive impairment and to examine the impact of neuropsychiatric profiles on these factors</p>	<p>-cluster analysis -cross-sectional study -Level 4</p>	<p>-195 outpatients with dementia diagnosis</p>	<p>Measurements: Neuropsychiatric Inventory Questionnaire, Mini-Mental State Exam, Clinical Insight Rating Scale, Caregiver Burden Inventory -two-step cluster analysis used to identify meaningful subgroups - ANOVA and the χ^2 test were utilized for categorical variables -linear regression used to test relationship between measurement scores within clusters</p>	<p>-three clusters identified: behavioral/psychotic, depressive, and minimally symptomatic -greater levels of caregiver burden were associated with the psychotic/behavioral cluster -each cluster demonstrated a relationship between behavioral disturbances and caregiver burden</p>	<p>Strengths: used widely accepted clinical criteria to diagnose dementia, used comprehensive tools to assess the feature of dementia Weakness: cross-sectional design</p>
<p>Benefits of Nonpharmacological Interventions on BPSD</p>					
<p>Mitchell, Ann M (2015). Nonpharmacological therapeutic techniques to decrease agitation in geriatric psychiatric patients with dementia. <i>Journal of Gerontological Nursing</i></p>	<p>Quantitative, Quasi-Experimental Nonequivalent Control Group Pretest-Posttest Design -Level 3 -IV: multisensory room -DV: agitation scores</p>	<p>-13 geriatric-psychiatric inpatients, convenience</p>	<p>-Pittsburgh Agitation Scale -interclass correlation coefficients between 0.60 and 0.77</p>	<p>-Significant decrease in PAS scores after intervention -significant decrease in agitation scores for vocalizations, motor agitation, and resistance to care, but not aggressiveness</p>	<p>Weakness: small convenience sample; time spent in the multisensory room was not recorded; staff instructed to escort patient to room for 15 to 30 minutes</p>

<p>-Purpose: quality improvement projects to examine the effectiveness of a multisensory room on agitation</p>					
<p>Chen, R (2014) Non-pharmacological treatment reducing not only behavioral symptoms, but also psychotic symptoms of older adults with dementia: A prospective cohort study in Taiwan. <i>Geriatrics & Gerontology International</i>.</p> <p>-Purpose: investigate the effectiveness of a structured nonpharmacological intervention program on BPSD</p>	<p>Quantitative -Prospective Cohort Study -Level 4</p>	<p>-104 older men with dementia living in two veterans homes in Taiwan (51 in intervention group and 53 in reference group)</p>	<p>-neuropsychiatric inventory (NPI), defined daily dose of psychotropic drug use, Barthel Index, Instrumental Activities of Daily Living, Mini-Mental State Examination, Geriatric Depression Scale, Tinetti balance and gait scores</p>	<p>- program was effective in managing BPSD -no decrease in antipsychotic medication use related to intervention</p>	<p>Weakness: -all male participants -increased interaction with patient by staff may have lessened the therapeutic effects</p>
<p>Kales, H. (2014). Management of neuropsychiatric symptoms of dementia in clinical settings: Recommendations from a multidisciplinary expert panel. <i>Journal of the American Geriatrics Society</i>.</p> <p>-Purpose: to define critical elements of care</p>	<p>-expert opinion -Level 7</p>	<p>Multidisciplinary panel took place in Detroit, Michigan in fall 2011 -Included University of Michigan Program for Positive Aging, Johns Hopkins Alzheimer’s Disease Research Center, and Center for Innovative Care in Aging</p>	<p>-No analysis preformed -DICE Approach developed to help clinicians balance the roles of nonpharmacological, medical, and pharmacological treatments when dealing with patients with dementia -Describe -Investigate -Create -Evaluate</p>	<p>-DICE approach approved by CMS and included in their toolkit to promote nonpharmacological approaches to dementia management</p>	<p>Weakness: grant support could have contributed to a conflict of interest</p>

<p>for NPS in dementia, construct an approach in managing NPS, and discuss how to implement the approach into clinical care</p>					
<p>Brodady, H (2012). Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. <i>The American Journal of Psychiatry</i></p> <p>-Purpose: to review the effectiveness of informal caregiver interventions in the management of BPSD of people living in the community</p>	<p>-meta-analysis -Level 1</p>	<p>-23 articles met review criteria -interventions studied had to involve the caregiver</p>	<p>-a second reviewer independently rated the methodological quality of 15 studies according to the National Health and Medical Research Council criteria for rating studies -meta-analysis performed by Review Manager -interventions categorized by consensus</p>	<p>- caregiver interventions can significantly reduce BPSD and their personal negative reactions to these symptoms</p>	<p>Limitations: multiple strategies vs. single interventions; not all interventions targeted behaviors; caregivers' variability; studies enrolled patients with fewer severe behaviors; rely on reported behaviors</p>
<p>O'Neil, M E (2011). A systematic review of non-pharmacological interventions for behavioral symptoms of dementia. <i>Department of Veterans Affairs</i></p> <p>-Purpose: review the literature on nonpharmacological interventions for BPSD</p>	<p>-systematic review -Level 1</p>	<p>-21 single studies and 7 systematic reviews included</p>	<p>-two reviewers evaluated articles -peer reviewed by technical advisory panel</p>	<p>-researchers studied how non-pharmacological treatments compare in effectiveness, safety, and cost - evidence for psychosocial interventions is varied and needs further investigation</p>	<p>Weakness: majority of articles are single studies</p>
<p>Gitlin, L N (2010) Targeting and managing behavioral symptoms in individuals with dementia: A randomized</p>	<p>-randomized trial -Level 2</p>	<p>participants were stratified according to relationship and randomized</p>	<p>-Advanced Caregiver Training (ACT) helps caregivers identify and modify potential triggers to</p>	<p>-ACT program has immediate positive effects on problematic behaviors, caregiver upset, and</p>	<p>Weakness: problem behaviors selected by caregivers; multiple treatment component; sample more</p>

<p>trial of a nonpharmacological intervention. <i>Journal of the American Geriatrics Society</i></p> <p>-Purpose: test the effects of Advancing Caregiver Training (ACT) on the management of distressing behaviors in community-dwelling people with dementia</p>		<p>-272 caregivers and people with dementia</p>	<p>eliminate, reduce, or prevent targeted problem behaviors -ACT involved 16-week active phase -chi-square and Wilcoxon rank-sum tests used to compare intervention and control group participants -Mantel-Haenszel chi-square used to determine ACT program effect -ANCOVA used to determine effects on caregiver upset and confidence in managing behaviors</p>	<p>confidence in managing behaviors - caregivers are less depressed, feel less burden, have better wellbeing, and enhanced skills with managing symptoms</p>	<p>motivated to learn because of voluntary participation</p>
<p>Kong, E (2009) Nonpharmacological intervention for agitation in dementia: a systematic review and meta-analysis. <i>Aging and Mental Health</i></p> <p>-Purpose: review the evidence regarding effectiveness of nonpharmacological interventions for agitation in people with dementia</p>	<p>-systematic review and meta-analysis -Level 1</p>	<p>-14 studies included -total sample size was 586</p>	<p>- 2 independent researchers evaluated the appropriateness of including each article (consensus achieved if disagreement) -2 individual researchers investigated potential sources of clinical and statistical heterogeneity of included studies -meta-analysis performed using Review Manager Software</p>	<p>-sensory interventions, such as aromatherapy, thermal bath, and calming music and hand massage, were found to be moderately effective in decreasing agitation -nonpharmacological interventions such as social contact, activities, environmental, caregiver training, combination therapy, and behavioral therapy were not found to influence agitation</p>	<p>Weakness: small sample sizes in respective studies; small number of studies; inconsistency in interventions and measurement tools; inconsistent definition of agitation</p>
<p>Spijker, A. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: A meta-analysis. <i>Journal of the American Geriatrics Society</i></p>	<p>-meta-analysis -Level 1</p>	<p>-13 studies included (1 study found utilizing snowball search; 10 articles randomized)</p>	<p>-two independent reviewers found and evaluated studies for inclusion and then assessed the methodological quality of the studies -disagreement between reviews was resolved by discussion</p>	<p>-nonpharmacological intervention programs can significantly reduce the rates of institutionalization and significantly lengthen the time to institutionalization</p>	<p>Weakness: cultural differences not considered; inconsistent severities of dementia, sample sizes, and follow-up periods</p>

<p>-Purpose: examine the effectiveness of nonpharmacological support programs on the institutionalization rates of the person with dementia</p>			<p>Cochrane Collaboration Group's Manager 4.2 was used to present findings</p>		
<p>Ayalon, L (2006). Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. <i>Arch Intern Med</i></p> <p>-Purpose: compare guidelines with existing evidence regarding nonpharmacological interventions for NPS to assist in making informed decisions about symptom management</p>	<p>-systematic review -Level 1</p>	<p>-3 RCTs and 6 single-case designs included</p>	<p>-literature searches were conducted by at least 2 independent investigators -articles reviewed by APA Task Force -extensive quality criteria had to be met for each article to be included in the study</p>	<p>-Not enough evidence to support individual nonpharmacological interventions in reducing NPS - Individualized approach is recommended by current evidence, focus on causes of symptoms and how to address them with behavioral techniques</p>	<p>Weakness: results relied primarily on SCD, most studies did not evaluate adverse effects</p>
<p>Caregiver Stress</p>					
<p>Bailes, C (2016). Caregiver burden and perceived health competence when caring for family members diagnosed with Alzheimer's disease and related dementia. <i>Journal of the</i></p>	<p>-quantitative descriptive study -Level 6 -IV: burden of care -DV: perceived health competence</p>	<p>- 64 total participants - convenience sampling -participants had to be informal caregivers, 18 years or older, and utilized services from the Alzheimer's Resource of Alaska (ARA)</p>	<p>-The Perceived Health Competence Scale with Cronbach's alpha of 0.93 -Modified Montgomery-Borgatta Caregiver Burden Scale which has three subscales with Cronbach's alpha of 0.91-0.95</p>	<p>- Spearman's rho correlation analysis determined a high negative correlation between perceived health competence and burden of care -independent t-test used to compare PHCS scores between males and</p>	<p>-Strengths: reliability of measurement tools was high, researchers performed multiple analyses of data to determine relationships Limitations: small number of</p>

<p><i>American Association of Nurse Practitioners.</i></p> <p>Purpose: determine if there is a relationship between perceived health competence and caregiver burden</p>		<p>-surveys sent through email or in paper version</p>		<p>females; no statistical significance found -one-way ANOVA used to see if years of care impact perceived health competence; found no statistically significant difference</p>	<p>participants, mostly Caucasian population, did not consider extent of assistance needed by person with dementia</p>
<p>Llanque, S. (2016). Concept analysis: Alzheimer’s caregiver stress. <i>Nursing Forum.</i></p>	<p>-concept analysis</p>	<p>-types of articles in analysis included qualitative, quantitative, and mixed-method studies</p>	<p>-Wilson’s (1963) concept analysis procedure utilized -search terms included Alzheimer’s disease, caregiver stress, and nursing -no data analysis preformed</p>	<p>-caregiver stress defined as the burden caregivers endure which results in perceived tension and fatigue -understanding this concept is essential for nurses to intervene when caregiver stress is present</p>	<p>Weakness: Excluded dementia as keyword</p>
<p>Svendsboe, E. (2016). Caregiver burden in family carers of people with dementia with lewy bodies and alzheimer’s disease. <i>International Journal of Geriatric Psychiatry.</i></p> <p>-Purpose: characterize the differences in caregiver distress between those caring for people with DLB vs. AD</p>	<p>-cross-sectional cohort study - Level 4</p>	<p>-sample included 100 caregivers and people diagnoses with AD and 86 with DLB</p>	<p>-used Relative Stress Scale to measure caregiver distress -also collected data on neuropsychiatric symptoms, comorbidity, and ADL scores -linear regression and descriptive analysis completed</p>	<p>-high rates of caregiver distress and increased risk of developing psychiatric disorders among caregivers of people with mild dementia</p>	<p>-Strength: large cohort can provide robust data -Weakness: Done in Norway</p>
<p>Chiao, C. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. <i>International Nursing Review.</i></p>	<p>-systematic review -Level 1</p>	<p>-21 total studies included</p>	<p>-articles discovered by primary reviewer -two independent reviewers assessed the quality of the articles -review included: -16 cross-sectional</p>	<p>-severity of dementia, behavioral disturbances, extent of personality change, and psychiatric symptoms are determined to be the main patient</p>	<p>-Strengths: -thorough literature search -included 3 separate investigation to avoid bias Weakness:</p>

<p>-Purpose: identify factors of caregiver burden among informal caregivers of community-dwelling people with dementia</p>			<p>-3 longitudinal -1 cross-sectional longitudinal -1 retrospective record review -articles sorted into 3 themes -no comprehensive analysis performed</p>	<p>factors contributing to caregiver stress -main caregiver factors affecting caregiver stress included socio-demographic and psychological characteristics</p>	<p>-caregiver 'burden' not always clearly defined in included studies</p>
<p>Adelman, R. (2014). Caregiver burden: A clinical review. <i>Journal of the American Medical Association</i></p> <p>-Purpose: examine current evidence regarding caregiver burden (epidemiology, diagnoses, assessment, and interventions)</p>	<p>-cohort studies regarding the risk factors and negative outcomes of caregiver burden -systematic reviews and meta-analyses summarize the effectiveness of interventions -Level 4 and Level 1 -IV: psychosocial and pharmacological interventions DV: effect on caregiver burden</p>	<p>-32 cohort studies -5 meta-analyses -3 systematic reviews</p>	<p>-no analysis was completed on the cohort studies -8 studies met inclusion criteria for the systematic review -results were consistent among the studies and effect sizes were determined by aggregating the data from all these studies</p>	<p>-interventions to alleviate caregiver burden showed mild efficacy with psychosocial interventions with an effect size of 0.09-0.23 (95% CI) and pharmacologic interventions with an effect size of 0.18-0.27 (95%)</p>	<p>Strengths: used high level studies for systematic review Limitations: no analysis done on cohort studies; article only address physicians</p>
<p>Caregiver Assessment</p>					
<p>Riedel, O. (2016). Overlooking informal dementia caregivers' burden. <i>Research in Gerontological Nursing</i>.</p>	<p>-quantitative cohort study -Level 4 -IV: caregiver assessments -DV: the caregiver's levels of burden, morbidity, and need for support</p>	<p>-stage one included 403 caregiver-patient dyads -stage two included 237 caregivers</p>	<p>-continuous variables reported as means and SDs -categorical variables reported as absolute and relative frequencies -differences in means tested using univariate analysis and Mann-Whitney U test</p>	<p>-caregivers have high rates of physical and mental comorbidities -there is a considerable difference between caregivers' condition and physicians' appraisals -caregivers lack information about Alzheimer's</p>	<p>Weakness: only included mild-moderate dementia -high withdrawal rate from research -lack of measuring social cognition or social support</p>
<p>Collins, L. (2011). Caregiver care.</p>	<p>-clinical practice guideline -Level 1</p>	<p>-caregivers and care recipients</p>	<p>-includes evidence from 56 articles</p>	<p>-Evidence rating B: Therapeutic counseling, skills-training, and</p>	<p>Strengths: -outlines a caregiver assessment</p>

<p><i>American Family Physician.</i></p>				<p>psychoeducational interventions can decrease caregiver stress and increase quality of life for caregivers -Evidence rating C: In practice, providers should be offering caregiver assessments, meeting educational needs, providing resources, and encouraging caregiver self-care</p>	<p>-provides online resources for caregivers Weakness: -includes evidence of caregiver stress in relation to other diagnoses besides dementia</p>
<p>Dang, S (2008). The dementia caregiver- A primary care approach. <i>The Southern Medical Association.</i></p>	<p>-expert opinion -Level 7</p>	<p>-two victims of dementia: the patient and the caregiver</p>	<p>-no analysis used</p>	<p>-caregiver assessments are needed to identify caregiver stress -assessments can be performed in primary care office -education, support, and referral to community resources are strategies to combat caregiver stress</p>	<p>Weakness: low level of evidence</p>
<p>Caregiver Interventions</p>					
<p>McCabe, M. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. <i>The Gerontologist.</i></p> <p>-Purpose: understand the perceived needs of family caregivers of community-dwelling people with dementia</p>	<p>-systematic review of qualitative studies -Level 5</p>	<p>-12 qualitative studies included</p>	<p>-investigators searched using key terms dementia, family, care, needs, and qualitative - Critical Appraisal Skills Program tool used to assess study quality by two independent</p>	<p>-two major themes identified: caregiver needs related to managing care recipients and the personal needs of the caregiver</p>	<p>Strengths: rigorous literature search, use of CASP tool by two separate researchers Weaknesses: most articles included did not use theoretical framework or examine caregiver needs specifically</p>
<p>National Guideline Clearinghouse (2016) Delirium, dementia, and</p>	<p>-clinical practice guideline -Level 1</p>	<p>-162 studies and 9 guidelines reviewed</p>	<p>-guideline validation performed by internal and external peer review</p>	<p>Nurses caring for people with dementia should have knowledge regarding</p>	<p>Weakness: potential bias because funded by the Ontario</p>

<p>depression in older adults: Assessment and care. Agency for Healthcare Research and Quality.</p>			<p>-a rating system was utilized based on the levels of evidence to determine the quality/strength of evidence</p>	<p>nonpharmacological and pharmacological interventions for managing BPSD and be able to participate in shared-decision making and education with the caregiver</p>	<p>Ministry of Health and Long-Term Care</p>
<p>Tang, W. (2016). Effects of psychosocial interventions on self-efficacy of dementia caregivers: A literature review. <i>International Journal of Geriatric Psychiatry</i>.</p> <p>-Purpose: identify, summarize, and critically appraise current evidence on the psychosocial interventions used for enhancing the self-efficacy of dementia caregivers</p>	<p>-literature review -Level 1</p>	<p>-14 studies met the inclusion criteria -criteria included: RCT or quasi-experimental design, intervention directed towards caregivers of people with dementia with self-efficacy as an outcome measure</p>	<p>-no data analysis performed</p>	<p>-psychosocial interventions are effective in enhancing the self-efficacy of caregivers -group and individualized sessions on skill-building and information have been shown to be beneficial -it is beneficial for healthcare providers to have knowledge and professional experience in dementia caregiving</p>	<p>Weakness: no systematic comparison completed due to lack of effect sizes, only included studies in English, cultural differences no discussed</p>
<p>National Guideline Clearinghouse (NGC). Guideline summary: Recognition and management of dementia. In: Evidence-based geriatric nursing protocols for best practice. New York (NY): Agency for Healthcare Research and Quality (AHRQ); 2012.</p>	<p>-clinical practice guideline -Level 1</p>	<p>unidentified number of studies included - sample population: older adults with dementia</p>	<p>-guideline validation performed by internal and external peer review -articles were hand and electronically searched - a rating system was utilized based on the levels of evidence to determine the quality/strength of evidence</p>	<p>Management of person with dementia includes monitoring medications, avoiding restraints, addressing negative behaviors, use of cognitive-enhancement techniques, adequate rest, sleep, nutrition, and pain control, maximizing functional capacity, ensuring a safe and therapeutic environment, and providing caregivers education,</p>	<p>Weakness: does not tag levels of evidence to each recommendation; does not state they looked at unpublished literature; potential bias because developed/funded by Hartford Institute for Geriatric Nursing</p>

				support and community resources	
Smith, E. (2011). Memory and communication support in dementia: Research-based strategies for caregivers. <i>International Psychogeriatrics.</i>	-Evidence-based practice project (no implementation data in article)	-team of clinicians included researchers and educators in neuropsychology, psychogeriatrics, nursing and speech pathology -cited 43 references	-no data analysis performed -reviewed current evidence on strategies to increase memory and communication skills in people with dementia	-through literature review, these researchers created mnemonic "RECAPS" signifying memory strategies and "MESSAGE" for communication strategies -a DVD program for caregivers was created for caregivers to demonstrate these different techniques	Weakness: the DVD is 50 minutes long so could be difficult to implement in a fast-paced setting; no data analysis done in this article but states RCTs are being implemented
Oken , B (2010) Pilot controlled trial of mindfulness meditation and education for dementia caregivers. <i>Journal of Alternative and Complementary Medicine.</i> -Purpose: evaluate the effectiveness of a mindfulness meditation intervention with caregivers of dementia	-randomized control trial -Level 2 -IV: Mindfulness-Based Cognitive Therapy program -DV: caregiver perceived stress	-31 randomized caregivers who provide at least 12 hours per week of assistance to the person with dementia	Measurements: Memory and Behavior Problems Checklist, Caregiver Appraisal Tool, Perceived Stress Scale, Center for Epidemiologic Studies Depression Scale, General Perceived Self-Efficacy Scale -ANCOVA used	-program had a significant effect on caregiver stress when compared to the respite-only group -mindfulness and self-rated mood and stress scores were significantly correlated	Weakness: small sample size

Appendix C

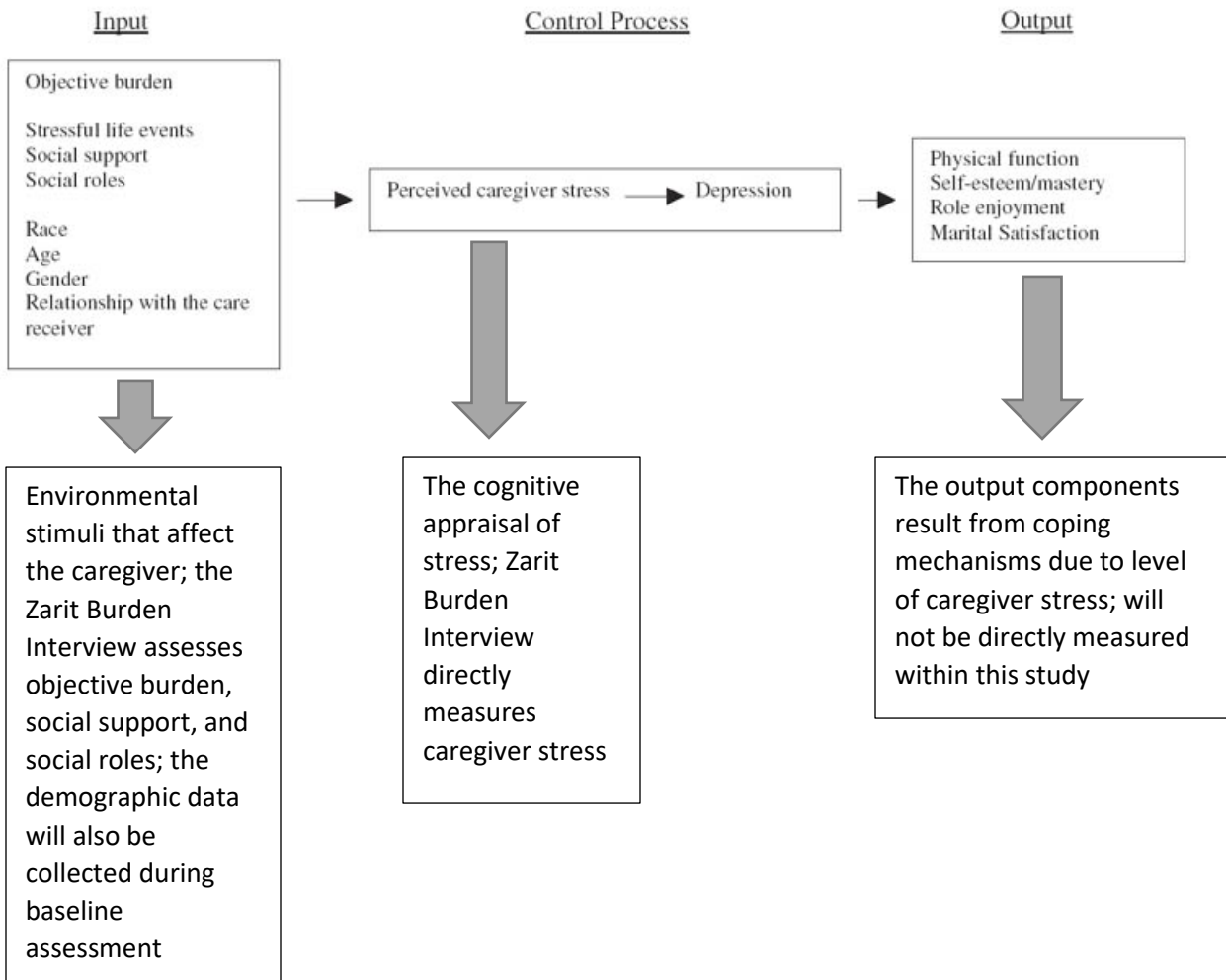
Rating System for the Hierarchy of Evidence For an Interventional Inquiry (Modification by Dr. Lindholm for course N5613)	
Level I	Evidence from a systematic review or meta-analysis of all relevant RCTs. <i>Evidence-based clinical practice guidelines based on systematic reviews of RCTs</i> .*
Level II	Evidence obtained from well-designed RCT. <i>Quantitative systematic review of well-designed controlled trial without randomization.</i>
Level III	Evidence obtained from well-designed controlled trial without randomization (<i>quasi-experimental</i>). <i>Quantitative systematic review of case-control, cohort, or correlational studies.</i>
Level IV	Evidence from well-designed case-control or cohort study (<i>or cross-sectional study</i>)
Level V	Evidence from systematic review of <i>quantitative</i> descriptive (<i>no relationships to examine</i>) or qualitative studies.
Level VI	Evidence from a single <i>quantitative</i> descriptive (<i>no relationships to examine in the study</i>) or qualitative study
Level VII	Evidence from the opinion of authorities and/or reports of expert committees

Melnyk, B.M.& Fineout-Overholt., E. (2015). *Evidence-based practice in nursing and healthcare*. Philadelphia Lippincott Williams & Wilkins,.

**Italics, appropriate in this category, modification by LL 2017 based on opinions from experts to place SR at one level higher than single study design level.*

Appendix D

Theory to Application Diagram



Note. From "A middle-range theory of caregiver stress," by P. F. Tsai, 2003, *Nursing Science Quarterly*, 16 (2), p. 137-145.

Appendix E

Institutional Review Board Approval Letter

From: UMKC IRB

Sent: Monday, August 27, 2018 9:52 AM

To: Lindholm, Lyla J. <lindholm1@umkc.edu>; Conant, Jessica N. (UMKC-Student)
<jnc9r6@mail.umkc.edu>

Subject: 18-204- Not Human Subjects Research Determination Notification

It has been determined that the protocol referenced below does not meet the definition of research with human subjects set forth in Federal Regulations at 45 CFR 46.102. Please go to <https://umkc.keyusa.net> and login to eProtocol to access the formal determination letter in the event history for this study.

Protocol ID: 18-204

Principal Investigator: Lyla Lindholm

Protocol Title: Decreasing Stress Through Education for Caregivers of Community-Dwelling
Individuals with Dementia

NHSR

If you have any questions about this determination, please contact the Research Compliance
Office (email: umkcirb@umkc.edu; phone: (816)235-5927).

Appendix F

Cost Table for Project

Item	Item Description	Quantity	Cost per Unit	Anticipated Cost
Project Costs				
DNP Student Investigator Time	Student investigator will not be compensated for data collection	165 hours	Donated	\$0.00
Zarit Burden Interview questionnaires	Paper copies of questionnaires for caregivers to fill out	60 copies	\$0.10	\$6.00
Educational Materials	Local resources will be printed for caregiver reference; preprinted educational materials will be requested from the Alzheimer's Association	30 lists of resources 30 brochures/other educational documents	\$0.10/ list Preprinted education will be no cost	\$3.00
Project Total				\$9.00
Dissemination of Project				
APNO Conference	Conference entrance fee	1 conference	\$75.00	\$75.00
Travel Expenses	Gas and hotel expenses	2 overnights and 1 tank of gas	\$140 per night \$40.00 for full gas tank	\$320.00
Poster Printing	Project poster for presentation	1 poster	\$100.00	\$100.00
Total				\$495.00

Appendix G

Intervention Materials

Links to Alzheimer's Association Education Materials

- <https://www.alz.org/media/Documents/alzheimers-dementia-activities-at-home-middle-late-b.pdf>
- <https://www.alz.org/media/Documents/alzheimers-dementia-unpredictable-behaviors-b.pdf>
- <https://www.alz.org/media/Documents/alzheimers-dementia-communication-all-stages-b.pdf>
- <https://www.alz.org/media/Documents/alzheimers-dementia-personal-care-middle-late-b.pdf>
- <https://www.alz.org/media/Documents/alzheimers-dementia-safety-ts.pdf>
- <https://www.alz.org/media/Documents/alzheimers-dementia-manage-caregiver-stress-b.pdf>

Two flyers for support group sessions offered once a month in St. Joseph

Information on facilities that offer respite care

Recommended Book List

- The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss by Nancy Mace and Pete Rabbins
- Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers by Jolene Brackey
- Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief by Pauline Boss

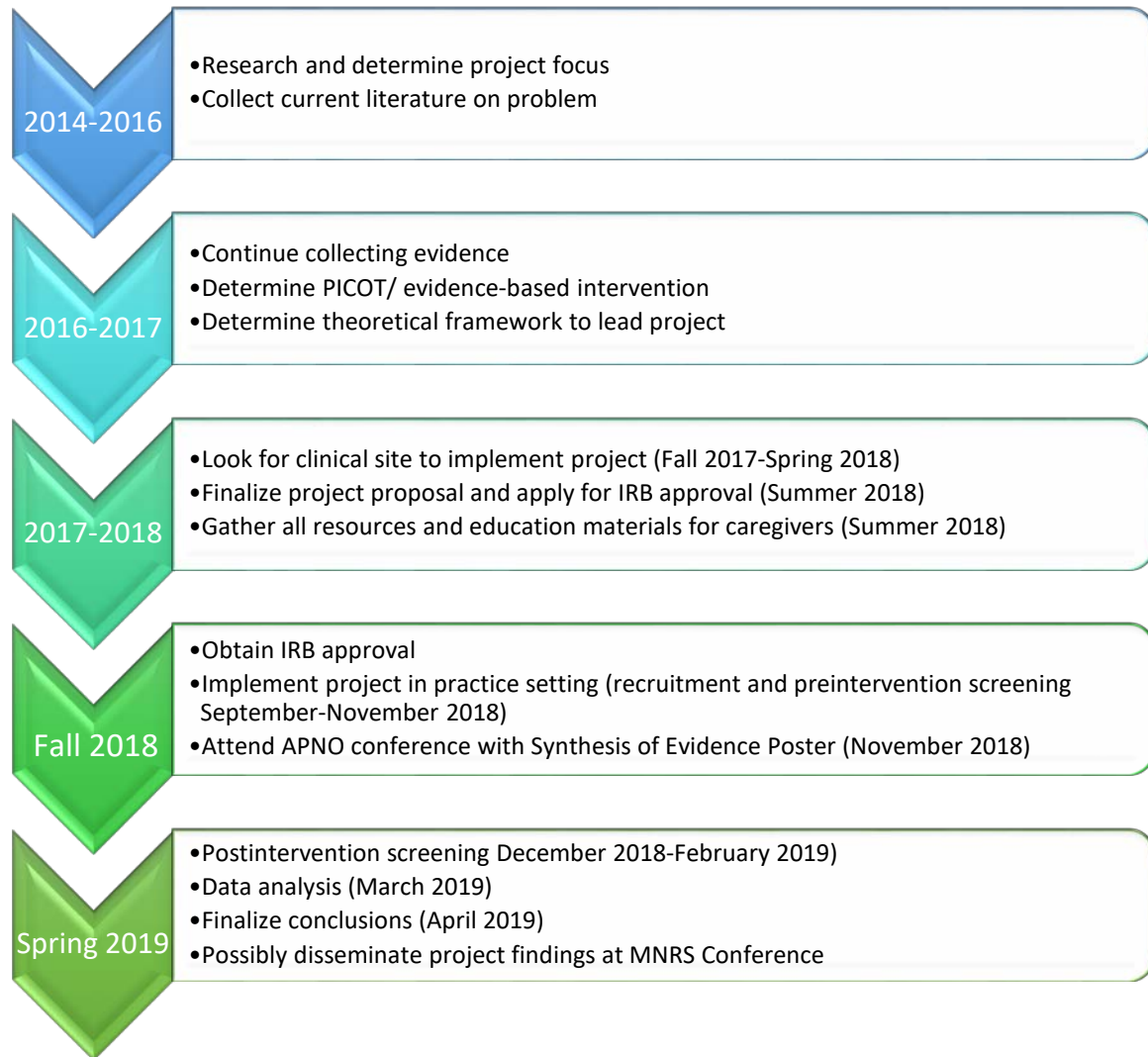
- Alzheimer's Care: The Caregiver's Guide to Understanding Alzheimer's Disease & Best Practices to Care for People with Alzheimer's & Dementia by Nancy Wiles
- Caring for a Loved One with Dementia: A Mindfulness-Based Guide for Reducing Stress and Making the Best of Your Journey Together by Marguerite Manteau-Rao
- Chicken Soup for the Soul: Living with Alzheimer's & Other Dementias: 101 Stories of Caregiving, Coping, and Compassion by Amy Newmark and Angela Timashenka Geiger
- Keeping Love Alive as Memories Fade: The 5 Love Languages and the Alzheimer's Journey by Debbie Bar, Edward Shaw, and Gary Chapman

Resources for Information and Support

- ADEAR (Alzheimer's Disease Education and Referral Center) 1-800-438-4380
www.alzheimers.org
- Alzheimer's Association 800-272-3900 www.alz.org
- American Association of Retired Persons 800-424-3410 www.aarp.org
- American Medical Association (AMA) 800-621-8335 www.ama-assn.org/
- Area Agencies on Aging (AAA) www.aoa.dhhs.gov
- Eldercare Locator 800-677-1116 <http://www.aoa.gov/naic/elderloc.html>
- Family Caregiver Alliance 415-434-3388 www.caregiver.org
- National Alliance for Caregiving (NAC) 301-718-8444 www.caregiving.org
- National Counsel on Aging 202-479-1200 www.ncoa.org
- National Family Caregivers Association 800-896-3650 <http://www.nfcacares.org>
- Rosalynn Carter Institute of Caregiving 229-928-1234 www.rosalynncarter.org

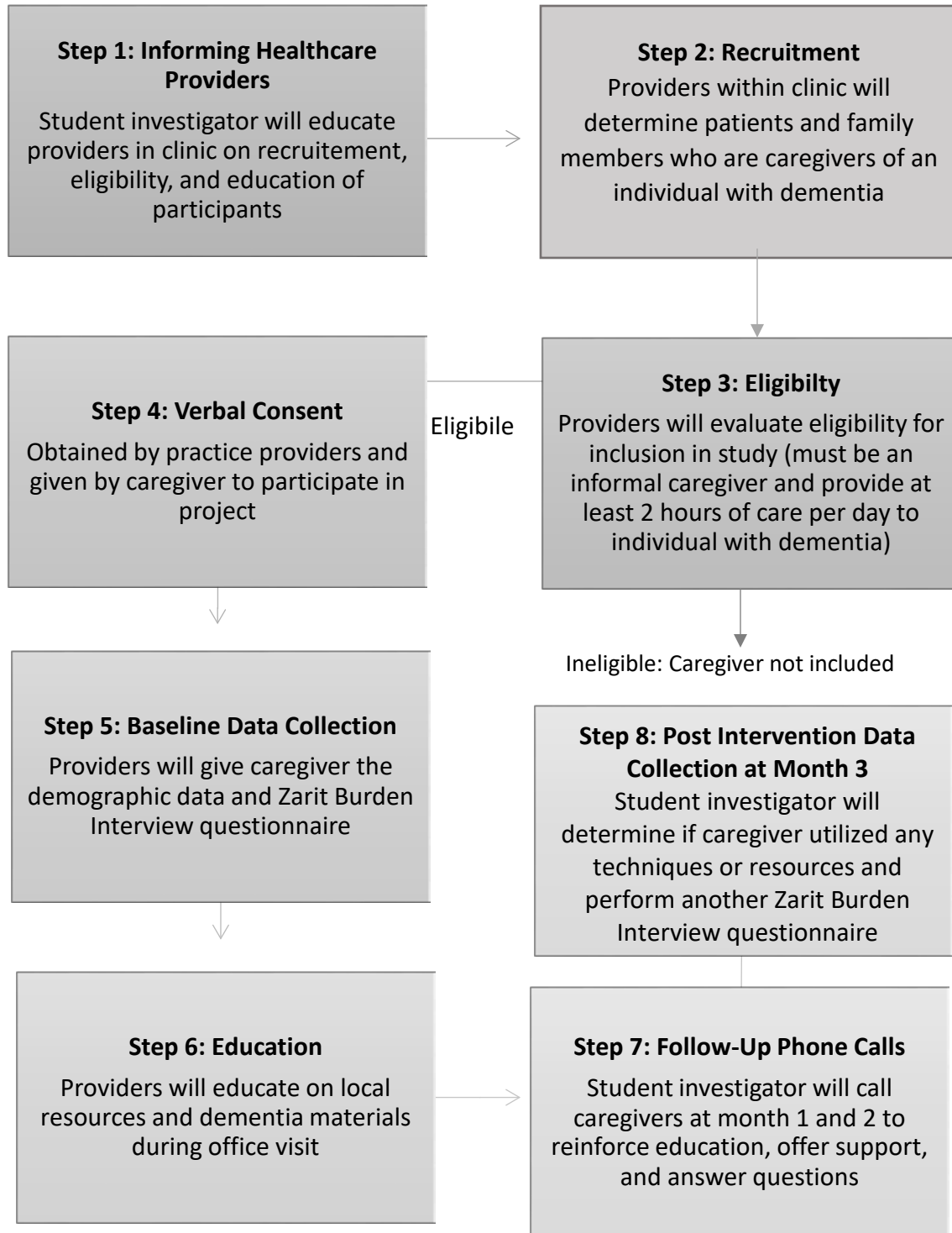
Appendix H

Project Timeline Flow Graphic



Appendix I

Intervention Flow Diagram



Appendix J
Logic Model for DNP Project

Inquiry, PICOTS: In caregivers of community-dwelling people with dementia, does providing resources and education on psychosocial interventions for management of BPSD decrease caregiver stress within three months in the outpatient setting?

Inputs	Intervention(s)		Outcomes -- Impact		
	Activities	Outputs Participation	Short	Medium	Long
<p>Evidence, sub-topics</p> <ol style="list-style-type: none"> 1. Benefits of nonpharmacologic interventions for BPSD 2. Effects of BPSD 3. Caregiver Stress 4. Caregiver Assessment 5. Caregiver Interventions <p>Major Facilitators or Contributors</p> <ol style="list-style-type: none"> 1. Executive Support 2. Self-efficacy of caregiver in implementing interventions 3. Resource accessibility in the community 4. Clinical guideline recommendations <p>Major Barriers or Challenges</p> <ol style="list-style-type: none"> 1. Limited time 2. Limited provider knowledge/training 3. Compliance to interventions 4. Cost of caregiver resources 	<p>EBP intervention which is supported by the evidence in the Input column (brief phrase)</p> <p>Provide caregivers with resources and education on interventions to mediate caregiver stress</p> <p>Major steps of the intervention (brief phrases)</p> <ol style="list-style-type: none"> 1. Screen patients for eligibility 2. Assess caregiver stress using Zarit Burden Interview tool 3. Provide resources and education 4. Follow up phone calls at month 5. Follow up in 2 months and assess use of interventions and complete Zarit Burden Interview tool again 	<p>The participants (subjects)</p> <p>N=15 Caregiver of community-dwelling individual with dementia</p> <p>Site</p> <p>Primary Care Clinic in Northwest Missouri</p> <p>Time Frame</p> <p>3 months</p> <p>Consent or assent Needed</p> <p>Verbal consent</p> <p>Other person(s) collecting data (yes,no)</p> <p>No</p> <p>Others directly involved in consent or data collection (yes/no)</p> <p>No</p>	<p>(Completed during DNP Project)</p> <p>Outcome(s) to be measured</p> <p>Primary: Caregiver stress</p> <p>Secondary, if applies: use of resources and/or interventions</p> <p>Measurement tool(s)</p> <ol style="list-style-type: none"> 1. Zarit Burden Interview 2. Descriptive data on use of resources/ interventions <p>Statistical analysis to be used</p> <ol style="list-style-type: none"> 1. Wilcoxon Test 	<p>(after student DNP)</p> <p>Outcomes to be measured</p> <p>Decrease caregiver stress over time by utilizing community resources and nonpharmacological interventions</p> <p>Increase caregiver self-efficacy in handling BPSD</p> <p>Increase the recognition and assessment of caregiver stress in the primary care setting</p>	<p>(after student DNP)</p> <p>Outcomes that are potentials</p> <p>Decrease institutionalization of community-dwelling people with dementia</p>

Appendix K

Zarit Burden Interview

Permission for tool obtained but not in public domain.

Appendix L

Permission for Tool

Dear Ms. Conant,

Thank you for your inquiry about the Zarit Burden Interview (ZBI).

You can request permission to use the ZBI on line by registering with eProvide and then searching for the Zarit Burden Interview on their website.

<https://eprovide.mapi-trust.org/instruments/zarit-burden-interview>

Information is also provided about available translations.

There is no fee for use of the ZBI in student or unfunded academic research, but you must register and request permission on the eProvide website.

Best wishes for a successful project.

Steve Zarit

Dear User,

Thank you for using our online distribution process on <https://eprovide.mapi-trust.org> for the use of this COA in your non-funded academic project!

Please find attached your completed user agreement.

Please remember that this COA is under specific conditions of use and copyright ownership (as detailed in the user agreement).

By accepting the terms of this agreement, you have acknowledged that you will respect these conditions, and especially:

- You will only use the COA in the context of use that you have indicated
- You will not modify the COA
- You will not translate the COA without obtaining the permission from Mapi Research Trust beforehand
- You will not distribute the COA to other third parties

Please refer to the user agreement for the complete information and for the specific conditions of use (use of the COA in a publication, on a website, on an electronic device...).

Thank you again for your interest in this COA!

Appendix M
Data Collection Template

Variable Values

Value		Label
Gender	1	Male
	2	Female
Ethnicity	1	American Indian or Alaskan Native
	2	Asian
	3	Black or African American
	4	Native Hawaiian or Other Pacific Islander
	5	Caucasian
Relationship	1	Single
	2	Married
	3	In Relationship, Unmarried
	4	Widowed
	5	Divorced
	6	Separated
Education	1	Less than High School Diploma
	2	High School Degrees or Equivalent
	3	Some College, No Degree
	4	Associate Degree
	5	Bachelor's Degree
	6	Master's Degree
	7	Doctorate Degree
Employment	1	Employed Full Time
	2	Employed Part Time
	3	Unemployed
	4	Student
	5	Retired
	6	Homemaker
	7	Self-Employed
Income	1	Less than \$20,000
	2	\$20,00 to \$34,999
	3	\$35,000 to \$49,999
	4	\$50,000 to \$74,999
	5	\$75,000 to \$99,999
	6	Over \$100,000

Appendix N

Outcome Data Table

Patient	Age	Gender	Ethnicity	Relationship Status	Educational Level	Employment Status	Income	Pre-intervention Score	Post-intervention Score
1	51-70 years	Male	Caucasian	Married	Some college	Retired	\$75,000-\$99,999	22	20
2	51-70 years	Female	Caucasian	Married	Some college	Homemaker	\$75,000-\$99,999	60	54
3	51-70 years	Female	Caucasian	Married	High School or Equivalent	Retired	Less than \$10,000	26	33

Appendix O



July 17, 2018

UMKC Institutional Review Board
Primary Project Site IRB
UMKC DNP Student

UMKC IRB, Primary Project Site IRB, and DNP Student

This letter serves to provide documentation regarding Jessica Conant's Doctor of Nursing Practice (DNP) Project proposal. Ms. Conant obtained approval for her project proposal, *Decreasing Stress Through Education for Caregivers of Community-Dwelling Individuals with Dementia*, from the School of Nursing and Health Studies DNP faculty on July 17, 2018.

If we can provide further information, please feel free to contact us.

Sincerely,

A handwritten signature in cursive script that reads "Dr. Cheri Barber".

Cheri Barber, DNP, RN, PPCNP-BC, FAANP
Clinical Assistant Professor
DNP Program Director
UMKC School of Nursing and Health Studies
barberch@umkc.edu

Lyla Lindholm, DNP, ACNS-BC
Clinical Assistant Professor
DNP Faculty

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