

Increasing Education to Decrease Caregiver Burden of the Alzheimer's Disease Patient

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Abstract

People living with Alzheimer's disease face a progressive disease which causes decreased abilities to perform activities of daily living and increased care provisions by caregivers. In Alzheimer's disease, patients lose their independence and autonomy. Limited caregiver knowledge is associated with increased caregiver burden. The purpose of this quasi-experimental, single group, pre and post-test study was to determine if increased caregiver education decreases caregiver burden in individuals caring for people with Alzheimer's disease. This study used the Zarit Caregiver Burden Scale to assess caregiver burden in caregivers over four months in a primary care setting. While the project was unsuccessful due to low participants, the results were positive with a decrease in caregiver burden. This research study encouraged providers to enhance education to caregivers to limit the burden. Increasing the education to the caregiver of the disease process, symptoms, and progression of Alzheimer's disease decreased caregiver burden associated with anxiety, stress, and fatigue which are factors that can negatively impact the patient with Alzheimer's disease.

Keywords: Alzheimer's disease, caregiver, education, caregiver burden

Increasing Education to Decrease Caregiver Burden of the Alzheimer's Disease Patient

Alzheimer's disease (AD) is a progressive, non-curable disease that affects much of the aging population with 7.7 million diagnoses per year (Du & Hu, 2016). Currently, 5.8 million Americans are living with AD (Alzheimer's Association, 2019). That number is only expected to rise to 14 million by 2050 (Alzheimer's Association, 2019). Alzheimer's disease is characterized by increased cognitive impairments, a decrease in activities of daily living (ADLs), and behavioral and emotional changes that affects a patient's quality of life in several ways (Alzheimer's Association, 2019). Due to the decrease in function, patients become unable to care for themselves independently. The need for a caregiver becomes necessary as their daily needs are unable to be met without one. The increasing demands of care needed can cause an increased burden on the patient and their caregiver (Liu et al., 2016). With the increased weight of caring for a patient with AD, a caregiver is necessary to fulfill the daily needs of a patient (Liu et al., 2016).

Family members have increasingly become the primary caregivers in the United States (Bialon, & Coke, 2012). Sometimes that family member can be a spouse or a child. If the caregiver is a child, the adult daughter is often the one caregiving (Day, Anderson, & Davis, 2014). Nearly 66% of these caregivers live with the person they are caring for (Alzheimer's Association, 2019). Furthermore, a fourth of these caregivers are in the sandwich generation where they are caring for their own families while caring for a parent as well (Alzheimer's Association, 2019). While patients are living longer, family members are devoting more time to be their caregiver (Bialon, & Coke, 2012). These caregivers amount to over 15.5 million caregivers for those with AD (Alzheimer's Association, 2019). 83% of the help given to older adults is from family members, friends, or other unpaid caregivers in the United States while half

of these caregivers are helping those with Alzheimer's disease (Alzheimer's Association, 2019). According to the Alzheimer's Association (2019), caring is costing \$4.5 billion in the United States. This unpaid care values up to \$4,568,000,000 which is mostly done by the family where 70% of these expenses are out of pocket (Alzheimer's Association, 2019).

Significance

Unfortunately, AD can affect anyone. While patients are living longer, their quality of life through caring should be maximized as many of their functional and mental abilities will decrease over some time. When caregivers are burdened, there is an increased risk that the caregiver could ultimately become a patient as well. Caregivers are those most affected with a burden when caring for a loved one. Increased caregiver education proves effective in decreasing caregiver burden. Furthermore, educating the caregiver helps prepare for many of the side effects that arise with this progressing disease.

Local Issue

According to the Alzheimer's Association (2019), over 110,000 Missourians are living with AD. With that being said, the costs of caregiving increase as the number of those diagnosed with AD increases. In Missouri alone, per capita, \$22,425 in Medicare and \$923 million in Medicaid costs are spent caring for those with AD (Alzheimer's Association, 2019). Additionally, 317,000 caregivers are caring for a loved one in Missouri for a total of 361,000,000 total hours of unpaid caregiving time (Alzheimer's Association, 2019).

Diversity Considerations

The participants of this study were chosen in a nondiscriminatory manner of those who access the primary care clinics in a mid-Missouri hospital-affiliated clinic. With the diverse population in this mid-Missouri town seeking healthcare, this study was inclusive to all persons.

Roughly 42,000 residents where the majority are white, non-Hispanic at 74% (US Census Bureau, 2018). The bulk of the patients are primarily English speaking, therefore this study focused on those who were English speaking as the education was geared towards them.

Purpose

Problem Statement

Caregivers who lack knowledge about AD are susceptible to burnout and fatigue. As caregiver demands increase, so too does stress and exhaustion. This burden leads to negative consequences for the caregiver who may ignore their own health care needs, whereby creating a new patient which only intensifies the issue.

Intended Improvement

The purpose of this AD caregiver education project was to determine if the evidence-based caregiver education interventions decrease caregiver burden in AD caregivers in the primary care setting. By educating the caregiver on the disease process and how to care for their loved ones, a decrease in caregiver burden was achieved. Decreasing this burden helps ensure that the loved one is properly cared for and limits the adverse health sequelae related to the stress of caregiving. Furthermore, increased education and awareness of the disease process helps prepare for the future with this progressive disease.

Facilitators and Barriers

The positive aspect of this project is the ability for sustainability after the student nurse investigator conducts the study. This project focused on recommendations to local support groups, local Alzheimer's Association chapters, and online resources from the Alzheimer's Association webpage for education. This allowed the provider to implement this project in his or her daily work when a caregiver of a patient with AD is identified.

There were few barriers to this study that were apparent. First, the number of caregivers available in this time frame did not surpass the amount necessary for this study. Also, patients who are experiencing memory changes are often referred to a neurologist and would not be diagnosed in the primary care clinic setting. These barriers were met when finding participants to fulfill the appropriate sample size for this study.

Another barrier to this study was the amount of additional time at clinic appointments this study required. Clinic appointment times were slightly adjusted to allow the appropriate time allotment to accommodate the caregiver appropriately. While the Zarit Caregiver Burden scale took minimal time to complete, the discussion of referral to outside resources did take away some time from clinic appointment times of caregivers who were there for unrelated reasons. Additionally, the willingness to participate in such a study was a hindrance as well. Some participants were not agreeable with the idea of being involved in a study even though the study had no impact on the subject.

This project is sustainable after the student investigator has educated staff on how to administer the Zarit Caregiver Burden Scale. The ability to educate the staff on its use and how to perform the test easily allows this project to be sustainable as a new method of testing caregiver burden is done in the primary care clinics.

Inquiry

In caregivers of AD patients, does increased education decrease caregiver burden as measured by the Zarit Caregiver Burden Scale, within four months at a mid-Missouri primary care clinic?

Search Strategies

Databases used in this project were CINAHL, Medline, PubMed, PsychINFO, Cochran Library, and Google Scholar. After previous research, the terms caregiver, burden, Alzheimer's disease, education, family, and fatigue were used. While performing these searches, the word family was removed, and caregiver was used as a higher quality of evidence was found. The term family, as it relates to AD caregivers, was too narrow and did not capture all those providing care to AD patients. Caregivers can be those not blood related, therefore, not technically considered family in terms of research definitions. Also, distinguishing between certain types of caregivers reveals who AD caregivers are. Spouses and children as caregivers were reported differently as the relationship dynamic had now changed. Moreover, the term caregiver provided further valuable evidence for the use of this project.

For this project, most of the research came from clinical randomized controlled trials or systematic reviews. Qualitative research helped guide this study throughout the remainder of the project, providing insight into the nature of this phenomenon and its impact on patients and caregivers. Case studies directed this project, demonstrating the efficacy of proper education for AD caregivers. For the subtopics of caregiver burden, education, and caregiver types, there were multiple levels of evidence. For caregiver burden: one qualitative, Level VI, one cross-sectional, Level II, one cohort, Level I, one quantitative, Level VI, two systematic review, Level I, and one cross-sectional, non-experimental, Level IV. For education: one quasi-experimental, Level IV, one randomized control trial, Level I, one experimental, Level IV, and one qualitative, Level IV. For types of caregivers: two mixed cross-sectional, Level IV, and VI, two four cross-sectional, Level II, two qualitative, Level VI, one concept analysis, Level I, one systematic review, Level I, and one internal review, Level I (see Appendix A and Appendix B).

Evidence by Themes

The themes for this project are related to caregivers who are caring for a loved one with AD. These themes are caregiver education of the AD patient, caregiver burden, and caregiver type. The themes all encompass the barriers and challenges in caring for a person with AD.

Caregiver Education of the Alzheimer's Disease Patient

Education remains an important aspect when caring for a patient, especially one with a complex disease like AD. Caregivers often have very little knowledge and are unsure of how to properly care for their loved ones. This leads the caregiver to have limitations in knowledge and self-care.

Knowledge deficits.

Caring for a patient with AD is not an easy task. Caregivers are often unsure of how to address the needs of their loved ones. This lack of knowledge can greatly affect the patient. Education focusing on AD is important to promote a healthy lifestyle (Du & Hu, 2014). When educational opportunities are available to caregivers, subjective comfort levels increase. Bartfay & Bartfay (2013) theorized that community-based interventions such as support groups increased AD patient's quality of life. Additionally, with the implementation of community-based interventions, caregiver knowledge is improved. Studies have shown improvement in the quality of life of caregivers after utilizing support group programs focusing on reducing caregiver strain and lowering stress (Bartfay, & Bartfay, 2013).

Caregivers who lack formal education of AD can develop caregiver burden. The caregiver burden can directly affect the quality of life for a patient with AD. Due to the increasing caregiver demands and nature of the AD, caregiver burden is an inherent part of the illness. Increased physical and mental support required by the patient leads to increased stress, anxiety, and depression among caregivers. Increasing caregiver education can reduce the stress

and anxiety of the caregiver. Evidence-based recommendations include increasing caregiver education and community-based services for those who care for patients with AD. Also, providing coping strategies, and programs to train caregivers on their caregiving role helped improve the overall quality of care provided (Liu et al., 2016).

Education and therapeutic interventions for caregivers can lead to a better understanding of the disease and ultimately help cope with the struggles of caring for a patient with AD. There was a correlation between improved functional status and less caregiver burden (Heller, Gibbons, & Fisher, 2015). Therefore, the correlation of the presence of caregiver burden was reliant on the functional status of the patient.

Self-care education for caregivers.

Myhre, Bjornstad Tonga, Ulstein, Hoyer, & Kvaal, (2018) noted that increasing the awareness of coping strategies helped to decrease the caregiving burden. When caregivers are aware of the potential effects of caring, the burden can be lessened (Myhre, Bjornstad Tonga, Ulstein, Hoyer, & Kvaal, 2018). Du & Hu (2016), also reported that education to the caregiver helped increase the knowledge and therefore decrease the burden while caring for a patient with AD.

Caregiver Burden

Caregiver burden is a growing concept that is rarely discussed. With the current push for adults to age at home and longer life expectancies, caregivers feel obligated to care for their loved ones at home (Johnson, 2014). Caregiver burden happens when a caregiver has been physically, emotionally, or mentally depleted from caring for another person (Lilly, Robinson, Holtzman, & Bottorff, 2012). This depletion causes stress and fatigue in the caregiver. Caregiver burden has also been defined when the caregiver fails to recognize their own health concerns

(Johnson, 2014). The caregiver can be a family member, spouse, friend or neighbor. All of whom have increased risk for caregiver fatigue when caring for a loved one. With caregiver burden, the caregiver may ignore their health status and focus solely on the one whom they are caring for. This in turn causes greater harm to the caregiver. Fatigue and stress are negative aspects often associated with caring for a loved one (Choi et al., 2014). Those with chronic health conditions are forced to rely on these individuals to help care for them when they are unable. When taking care of a loved one for an extended amount of time, the caregiver may feel the increased amount of stress and fatigue mounting with the increasing demands (Choi, Wu, & Hsiao, 2015).

Caregivers are often engrossed in their caregiver role that they are unable to relinquish that control to others (Lilly, Robinson, Holtzman, & Bottorff, 2012). They do not want to burden others with the caregiving duties and are hesitant to give up those responsibilities (Lilly, Robinson, Holtzman, & Bottorff, 2012). Additionally, their pride or perceived stigma can contribute to one's inability to ask for help (Lilly, Robinson, Holtzman, & Bottorff, 2012). Caregivers often feel forgotten and abandoned to the care for their loved ones as their only focus has been on the caregiver role and associated responsibilities. The caregiver can become so fixated on caring for their loved one that their health is ignored. Caregivers often feel so responsible for their loved one that the added burden of self-care is too much. As a result of self-neglect, caregivers experience a decline in their health, which can dramatically affect the loved one making it difficult to continue care (Lilly, Robinson, Holtzman, & Bottorff, 2012).

According to randomized trials, there were a few identifiable factors that help promote decreased caregiver burden. Yu, Wang, He, Liang, & Zhou (2015) identified that assistance with patient factors such as decreasing the burden of caregiving to help promote caregiver self-care. Ensuring the caregiver is healthy and able-bodied to care for the loved one is important. When

the caregiver's health is starting to decline, the one being cared for also suffers (Yu, Wang, He, Liang, & Zhou, 2015). Furthermore, ensuring the caregiver is not burdened will help to confirm the patient with AD is properly cared for. Eliminating this burden allows the caregiver to care for themselves as well (Yu, Wang, He, Liang, & Zhou, 2015). As identified by Boltz, Chippendale, Resnick, & Galvin, (2015), the increasing demands on the caregiver and the decreased functionality of the patient causes increased caregiver anxiety. This is evident in multiple sources, however, the further the disease progresses, the amount of burden increases.

Interventions to help limit the caregiver burden were explored. Abdollahpour, Nedjat, & Salimi (2018), noted there was a positive side caregiving associated with identifying burden early to decrease the occurrence. Also, it was suggested a need for interventions with educational programs helped to decrease burden (Abdollahpour, Nedjat, & Salimi, 2018).

Heller, Gibbons, & Fisher (2015) found that improved mental health, increased knowledge, and a decrease in caregiver burden showed an increase in patient happiness and quality of life. To decrease caregiver burden, engaging patients in ADLs and increasing functionality were proven beneficial (Heller, Gibbons, & Fisher, 2015).

Caregiver mood and acceptance of the disease process were positively impacted when caregiver education was present (Jackson, Roberts, Wu, Ford, & Doyle, 2015). Furthermore, caregiver education has been proven to reduce stress, caregiver burden, and depression. Overall studies have proven that caregiver education and support have positive results on caregivers and their loved ones (Jackson, Roberts, Wu, Ford, & Doyle, 2015).

Caregiver Types

Day, Anderson, & Davis (2016) addressed that there are often thoughts of uncertainty, doubt, attachment and strain concerning caregiving. The types of caregivers that are caring for

the patient with AD are ever-changing. While a family may seem the most typical, oftentimes, the caregiver is not necessarily blood-related. Caregivers may include family or non-blood related individuals providing the care. Caregivers are those identified as holding the responsibility of assisting the patient with their routine ADLs (Conde-Sala, Turrio-Garriga, Garre-Olmo, Vilalta-Franch, & Lopez-Pousa, 2014). Moreover, Alzheimer's disease is frequently identified as the family disease simply because the disease encompasses the entire family (Svendsboe, Terum, Testad, Aarsland, Ulstein, Corbett, & Rongve, 2016). The demands placed upon the caregivers cause burden differently in the diverse caregiver types. Svendsboe, Terum, Testad, Aarsland, Ulstein, Corbett, & Rongve (2016), noted there was moderate to high caregiving burden in family caregivers caring for patients with AD. This proved similar in other studies. Families experience a higher burden when the physical functions were lower requiring more strains (Boltz, Chippendale, Resnick, & Galvin, 2015).

When females are the caregivers, the stigma to care for their parent or spouse was expected (Day, Anderson, & Davis, 2014). There were increased expectations placed on the female to care for her loved one, increasing the burden (Werner, Mittelman, Goldstein, & Heinik, 2011). Day, Anderson, & Davis (2014) also discussed the increased burden on the adult daughter caring for her parents. While the adult daughter may have her own family to care for, she now has to care for her parents which increases the load. However, the male caregiver also experienced the same symptoms of caregiver burden over time (Geiger, Wilks, Lovelace, Chen, & Spivey, 2015). Sallim, Sayampanathan, Cuttilan, & Ho (2015) discussed that female caregivers are at the highest risk for depression compared to their male counterparts. Spouses were also at risk for depression which was 2.51 times higher when they were the caregiver (Sallim, Sayampanathan, Cuttilan, & Ho, 2015). When the caregiver is the family member, as in

most cases, interventions must be in place to help decrease the burden symptoms of anxiety and depression (Richardson, Lee, Berg-Weger, & Grossberg, 2013).

A few studies identified how the burden is different for spouses. When a spouse is now expected to care for their partner, the dynamic of the relationship changes (Myhre, Bjornstad Tonga, Ulstein, Hoyer, & Kvaal, 2018). Spousal caregiver burden was prevalent in a few studies as well. Myhre, Bjornstad Tonga, Ulstein, Hoyer, & Kvaal (2018), explored how the everyday life of the relationship now changes when the spouse has taken on the caregiving role. While this study was performed in Norway, the idea of the increased awareness of coping strategies is still prevalent. Milbury, Badr, Fossella, Pisters, & Carmack (2013) reported there had been reports of distress, schedule disruptions, and financial stress on the spouse who was now not only the caregiver but the sole provider of the household. The patients who exhibit a better quality of life are less depressed, male gender, and show less apathy (Conde-Sala, Turrio-Garriga, Garre-Olmo, Vilalta-Franch, & Lopez-Pousa, 2014). These changes in the roles also proved to increase the burden.

Theory

The theory of caring is consistent with the caregiver of the AD patient. Kristen Swanson developed five major concepts related to caring. This theory involves knowing, being with, doing for, enabling, and maintaining belief all to be important concepts for a nurse when caring (Alligood, 2014). This study closely aligns this project as the caregiver must have the ability to obtain all five facets of the theory of caring.

Swanson identified knowing as being empathetic to a patient's situation (Swanson, 1991). The caregiver must be knowledgeable about these certain situations to have care for the patient. Being with, concerning the theory of caring, involves being emotionally present with the

patient (Swanson, 1993). By being there for the patient, one can put their trust in the caregiver that their needs will be met. This allows the patient to feel comfort in knowing that what they are feeling is real. Being with a patient isn't just the act of physically "being with" the patient but being an advocate, a listener, or a shoulder to cry on. Many times, a caregiver is there to care for a patient when they are unable to do so for themselves. Swanson (1993) identified her theory of caring as not only being there for the patient but understanding their needs and making sure they are met. According to Swanson, enabling is not seen in a negative connotation regarding the theory of caring. Enabling is focused more on giving the patient information to make decisions for themselves. Enabling allows the nurse to empower the patient to make their own informed decision.

Maintaining belief shows that the nurse has faith in the patient. The nurse establishing trust and rapport with the patient shows that she/he maintains belief. By maintaining belief, the nurse can care for a patient during a difficult time and be empathetic to the patient and their situations (see Appendix C).

Methods

IRB and Site Approval

The approval for this project will be from the Institutional Review Board of the University of Missouri-Kansas City utilizing human subjects for the research study. Site approval has been obtained from the clinical manager. The location of this study will be primarily aimed at patients who utilize the local affiliated hospital's primary care clinics (see Appendix D, Appendix E).

Ethical Issues

To ensure this project is successful, one must maintain a belief for the caregiver. Also maintaining adequate and reliable information ensures these caregivers are properly educated. Furthermore, limiting bias is always necessary for the implementation of caregiver education. All information was kept private and confidential. Furthermore, the information obtained is kept following the Health Insurance Portability and Accountability Act. The participants are properly informed that a student investigator will be researching with all information being in full disclosure. Maintaining the ethical considerations of the participants by ensuring autonomy, justice, maleficence, and beneficence are upheld is imperative for the participants of this research study. Furthermore, confidentiality and informed consent was obtained to protect the participants and there was no conflict of interest.

Funding

The costs of this project are minimal. With the way this project is designed, the only costs will be printing costs. Printing will be of educational referral handouts with information to direct the caregiver to the appropriate resources. The total cost for this project was \$0.51 for printing costs (see Appendix F).

Setting and Participants

The participants of this study are patients in a primary care practice who are caregivers of those diagnosed with AD. The project was projected for 15 AD caregivers. This convenience sample of caregivers was English speaking and reside near Jefferson City, Missouri and use the local affiliated hospital primary care clinics. The capability in finding enough participants proved difficult.

These patients provided consent before the study and were informed of the intent of the project. The project will last approximately four months with an evaluation of the caregiver's

caregiver burden upon completion of the project. The data was then utilized to determine if increased caregiver education decreases caregiver burden.

EBP Intervention

With the implementation of this project, the decreased caregiver burden was predicted in caregivers of patients with AD. The caregiver received education through support groups or the Alzheimer's Association website on the disease process, stages of caregiving, expected behavioral changes, and how to limit caregiver burden. When caregiver burden is decreased, these referral opportunities can be used in patients who are AD caregivers.

Upon implementation, caregivers provided a higher quality of health care when they thoroughly understood the disease process. When implementing an educational program to caregivers, caregiver burden can be decreased. Additionally, the caregiver will have a greater understanding of what to expect with this progressive disease. This allows them to prepare for a drastic change in the abilities and personality of their loved one. There is no cure for the disease, only symptom management. When the caregiver is well prepared for the life changes ahead of time, then the quality of life of the patient can be maximized and the burden can be decreased.

This study was initiated and directed by the student nurse practitioner. The project started with the recruitment of study subjects when a caregiver has been identified by the providers at the project site. The expected number of participants was 15. This number seemed small enough to capture enough participants yet with the understanding that capturing that number of participants may be difficult. The caregiver of a patient with AD was acknowledged during a primary care clinic appointment. When the caregiver was identified, consent for the study was obtained along with information regarding the study. The caregiver completed the Zarit Caregiver Burden Scale and the initial level of burden was reviewed by the provider. The

caregiver was referred to community resources for AD and also to the Alzheimer's Association website for additional information. After the referral at a period of 4 months, the caregiver was reevaluated with the Zarit Caregiver Burden Scale at a follow-up appointment. The level of burden was evaluated from the pretest and the post-test scores with changes noted according to a paired t-test.

The implementation of educating the caregiver through referral is made to promote change. The effectiveness of the intervention was analyzed, and if effective, the goal of referral to education will become the standard of care in the clinical setting (see Appendix G, Appendix H, and Appendix I).

Change Process

This study utilized Lewin's change theory. This closely aligns with the project as it changes practice from what it once was to something different. It requires a practice of unfreezing, changing and refreezing (Nelson-Brantley, & Ford, 2017). This allows for old processes to be thrown away and new processes to be implemented. This is beneficial for an educational intervention as the old processes of no intervention will be removed and new processes of educational interventions will be implemented. Furthermore, these new processes of implementation are an educational referral to support groups and online education for caregivers to increase their knowledge and decrease the burden.

EBP Model

Since this project was designed for change, the Iowa Model was used. This EBP Model helped guide the project as it was to show solutions for change on a certain process (Titler, Kleiber, Steelman, Rakel, Budreau, Everett, ... & Goode, 2001). That process was how

caregivers are educated on their loved one's disease process. This process also allowed the users (the clinic staff) to give feedback to the student investigator as needed.

Study Design

The study uses a quasi-experimental, one group, pre-post design. Caregiver degree of knowledge associated with burden was analyzed in caregivers who have little to no education of the disease and/or disease process. The study will determine how effective caregiver education programs are at helping decrease caregiver burden.

This study is sustainable after the implementation by the student investigator. Education of initiating the use of the Zarit Caregiver Burden form was used at the clinic. Also ensuring there was adequate knowledge on how to refer the caregiver to educational resources was imperative. This education process and assessment tool can be used on future patients who are caregivers as well to assess burden; however, for this project, the form was isolated to AD caregivers. Sustainability was noted as this is a free service to caregivers when seeking education on their loved one's disease process.

Validity

With this study, it was expected a participant group of 15 caregivers. These participants are those caring for AD patients to accurately determine prior knowledge and to determine their knowledge levels of the disease process and symptoms. The preexisting knowledge of the caregiver was taken into consideration as fostered by their education. Other confounding factors include, familial or social support which provides education to the caregiver in some cases. Also, the degree of illness when identified can hinder the success of a burden decrease. Moreover, access to educational resources must be taken into account. Some caregivers may not have the ability to attend these support groups or access the internet access. When that issue has been

identified, those caregivers will be excluded from this study. The willingness to participate was imperative as some caregivers seem like this additional duty is a burden. Finding willing participants can hinder the participant number in the study. Increased clinic appointment times were necessary to provide additional information to caregivers. The student investigator was the primary education source for these patients. Following the completion of this study, revisions were made to utilize additional caregiver educational programs.

Outcomes

The primary outcome of this project was to increase caregiver education to decrease caregiver burden in caregivers of those with AD. If caregivers are well educated on the disease, improvements are seen with a decreased burden on the caregiver. By using the Zarit Caregiver Burden Scale, the student investigator identifies increasing educational support referrals and education to a caregiver limits their burden. This education is designed to increase awareness, knowledge, and comfort with the increasing demands of this progressive disease to assist them in properly caring for their loved ones. If the caregiver is aware of the expectations, the burden of the caring process can be lessened.

Measurement Instrument

The outcomes were evaluated using the Zarit Caregiver Burden Scale as designed by Steven Zarit (Zarit, Reever, & Bach-Peterson, 1980). This 22 item scale is on a 5 point Likert scale of 0-4 of never, rarely, sometimes, frequently, or always respectively (Shaw, Hall, Lovato, Alli, Clarke, Villalba, & Sink, 2013). This test determines the severity of a caregiver's burden with a score range of 0-88 (Zarit, Reever, & Bach-Peterson, 1980). This scale is the most used in dementia caregiving research (Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001). The Cronbach's alpha for this scale was 0.93 for assessing caregiver burden (Yap, 2010).

The scale also showed an internal consistency range of 0.85-0.94 (Lu, Wang, Yang, & Feng, 2009). The intraclass correlation coefficient for the test and retest reliability of the test scored at 0.89 (Yap, 2010). The negative aspect of this test was the length of time to conduct the test. With the 22 question test, this can take time from the clinic appointment times. Therefore, a shorter version may be just as efficient if this becomes an issue revealing the same results (Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001). For the future, a shorter version of the test will be used to help decrease time. It should be noted that the term relative used in the Zarit Caregiver Burden Scale is used as a blanket term for those caring for a loved one (Zarit, Reever, & Bach-Peterson, 1980).

The student investigator provided the paper and pencil questionnaire form to the patient and caregiver at the initial appointment. The questionnaire was given at the initial appointment and then again at least 4 months after the intervention. The prevalence and degree of caregiver burden will be assessed after the implementation of caregiver education after the study (see Appendix J, and Appendix K).

Quality of Data

Only valid sources of evidence were used to support the educational intervention. When increasing caregiver education, clinic appointment times need to be extended. Questionnaires were obtained in privacy, and data collection remained confidential. The questionnaire used was the Zarit Caregiver Burden Scale. These questionnaires were unbiased and at a 5th-grade reading level to capture accurate data. No coercion from health care staff or caregiver was placed upon the patient, as truthful answers were imperative to this study.

The participants of this study were patients and caregivers who are English speaking and residing near and use the affiliated hospital's clinics. These caregivers were those who are

established in a primary care clinic directly associated with the local hospital. The data collected identified if increasing caregiver education helps decrease caregiver burden. The Zarit Caregiver Burden Scale was used to determine if the caregiver had any change in burden levels from pretest at or near the time of diagnosis to posttest after the educational intervention. The measurements used were the pretest analysis of the burden via a mean score. The post-test results were analyzed in the same manner as the pretest. The results from the two were identified to determine if there was a change in burden at the end of the testing period. According to multiple sources, caregiver burden did decrease after an educational interventions.

Analysis Plan

The purpose of this project is to decrease caregiver burden. This decrease in burden helps to ensure that the patient is properly cared for along with the caregiver. Ensuring the caregiver is also taking care of themselves helps make them be a better caregiver. This project began in August 2019 and ended in March 2020. Analyzing the scores at posttest evaluated the effectiveness of the intervention. While the timeframe for the project is four months, extending the time frame to capture participants was necessary.

With this project, the two burden scores via the pretest and posttest were evaluated using a paired t-test score. This allowed for an analysis of changes within the groups. Since the Zarit Caregiver Burden Scale utilizes a score with little or no burden, mild to moderate burden, moderate to severe burden, and severe burden, a mean of the scores will be taken to determine where the caregiver's burden is at pretest and then where their burden is at posttest. This study utilized a Wilcoxon Signed-rank test when determining the outcomes from the testing period. The expected outcome for this project was a decrease in caregiver burden according to the scale.

However, it must be noted that the outcome was not to eliminate the caregiver burden as this is unattainable with this current project (see Appendix L).

Results

Setting & Participants

This project was conducted in a primary care clinic and was scheduled to be from August 2019 until December 2019 for a timeframe of four months. While conducting the research and finding it difficult to find participants, the timeframe was extended until March 2020 to try to capture more participants. However, the post-tests were completed at least four months after the intervention.

There was a total of five participants for this project. However, three participants completed the project with a pretest and posttest. Two participants did not return for their visit and were unable to be captured for the final posttest data. While there was an expectation of 15 participants, only three were captured to finalize this project. With that small sample size, the project was not necessarily incomplete but was too small to show an accurate trend.

Actual Intervention Course

After IRB approval was obtained through the University of Missouri-Kansas City, this project was started. The caregiver of a patient with AD was acknowledged during a primary care clinic visit. When the caregiver was identified, consent for the study was obtained along with information regarding the study. The caregiver filled out the Zarit Caregiver Burden Scale and the initial level of burden was obtained. This was part of the pretest burden level. The caregiver was directed to community resources, support groups, and the Alzheimer's Association website for information on how to care for a loved one with AD. After these recommendations to educational resources were made, the caregiver was reevaluated with the Zarit Caregiver Burden

Scale after four-months at a follow-up appointment. The level of burden was analyzed between the pretest and post-test.

There was a total of five participants who partook in the study for the pretest. Each caregiver was given the Zarit Caregiver Burden Scale as a pretest to assess their initial burden level. After these participants were referred to outside educational resources, the caregiver was to be followed up with after four months of educational opportunities. This was to allow enough time for the caregiver to attend support groups, access online educational information and obtain their information regarding AD. The caregivers were to be retested to determine their burden post-intervention. Only three participants were able to be retested and therefore, only three participants were able to be acknowledged for this study (see Appendix M).

Outcome Data by Subtopic

The mean scores of the pretest were noted at 41. This was in the range of moderate to severe burden. The five scores were analyzed, and the mean score was achieved. The last two participants were removed as they did not contribute to the final project numbers and the pretest mean scores were reevaluated at 44 which did show moderate to severe burden.

For the three participants on the post-test, the mean score was noted at 25. Though only three scores were obtained, the numbers were still evaluated. This score of 25 showed mild to moderate burden. This difference in the pretest and posttest scores did show that there was a decrease in burden after the intervention. The paired sample mean score was 19 between the pre and post burden. Therefore, the intervention was successful but the lack of participants leading to a small sample size proved this study was not as effective.

With the lack of participants, the smaller sample size was not able to show an accurate depiction of the study and its success. Since there were limited participants for this study, there

was a poor evaluation to show an accurate trend. Even though the intervention did prove positive in reducing caregiver burden and the evidence does support it, this project's small sample size cannot prove to show this as a successful project. The intervention did align with the evidence that increasing caregiver education can help decrease the burden placed upon them during this time.

Discussion

Successes

The main success of this project was education. Education of a particular topic can only come as a positive. Education in this project helped the caregiver plan for the unknown when caring for their loved ones. Education in any form provides a positive impact on the person with AD as their caregiver will be able to care for them well.

A second success with this project was the positive feedback received from the participants. The participants were thankful and happy with the project as it only helped them become a better caregiver. The participants were scared of the unknown and fearful as their duties of caring were changing. They were happy to have information at their fingertips that benefited both them and their loved ones.

Study Strengths

The location of this project was sufficient as the amount of geriatric and elderly patients being seen as high. The diverse patient load throughout the lifespan allows the providers to see patients of multiple ages. Also, the clinic was well known to see family members throughout the providers. The clinic is a close-knit family of sorts and sees multiple family members within the clinic. The clinic works well with the providers and the ancillary staff to communicate well. There is notable teamwork and making sure the patient is the number one priority.

This project did prove to be sustainable as the clinic staff was willing to help implement and conduct this study. The student investigator was notified when a potential participant was going to be seen in the clinic that week. The preceptor was available to help the student investigator recruit patients as seen fit. The clinic was available to help the student investigator when trying to implement this study. Furthermore, the office staff was also available to help the student investigator understand how the clinic worked and provide positive feedback for success in the future. The preceptor was also available for suggestions and worked at helping the student investigator succeed.

Results Compared to Evidence in the Literature

While this study lacked study participation of caregivers, the study results did the outline with the current research. Bartfay & Bartfay (2013) agreed that community-based interventions such as support groups help increase the quality of life of the AD patient. These support groups can help the caregiver increase their knowledge to be a better caregiver. Furthermore, these support groups can help the caregiver focus on ways to decrease stress and fatigue when caring for a loved one (Bartfay & Bartfay, 2013). This study directly correlated with the literature that supporting the caregivers helps increase the familiarity to decrease their burden levels. Liu et al., (2016), also agreed that providing coping strategies and ways to teach caregivers can help the caregiver in their new role. This project closely aligns with the literature in that way.

Evidence shown by Du & Hu (2016) also portrayed that education to the caregiver increased the knowledge and therefore helped lower their burden when caring for a loved one with AD. Abdollahpour, Nedjat, & Salimi (2018), also suggested a need for educational interventions to help decrease caregiver burden. Jackson, Roberts, Wu, Ford, & Doyle (2015), also agreed that caregiver mood and acceptance was positively impacted when caregiver

education was present. While this study was limited in the participant aspect, the results were similar to the literature.

Limitations

Internal Validity Effects

While all studies have some sort of limitations, this study proved that to be true. With the nature of the study, follow up is key for the future. This study was faced with some limitations as the number of patients being seen in the clinic was less than ideal. Also, the lack of follow up for some participants proved a hindrance.

This project was designed to make educating the caregiver easy. There were online resources and local community support groups available for the caregiver. It allowed them to be able to be at home or be out in public to receive an education. It was difficult to know where the learner went for their information and how accurate that information was. There was not a way to monitor that. While the student investigator gave educational referrals to the caregiver, it was not clear where they went for that information. If the caregiver went to do their research or used that provided was unknown and not able to be closely monitored. The participants who were willing to participate demonstrated a greater understanding of health and an eagerness to learn. While it was not discussed, having information from non-reputable sources could prove dangerous. Getting misinformed could hinder the caregiver's ability to care for their loved one. This could place bias in the study outcomes and not prove that the education the student investigator provided was useful.

External Validity Effects

While it was difficult to get patients to follow up or reach back out to them, this study captured its participants as best it could. For the future, following up via telephone or email

encounters could prove beneficial. It might be valuable to stretch the post-intervention posttest to 6 or even 12 months out. This could help eliminate the difficulty with follow-ups and capture more participants. The current follow up of four months seemed too short as these patients are rarely seen that soon in a primary care clinic, especially if they are rather healthy. Most insurances will not cover annual well visits that soon. Additionally, the location of this clinic setting might not have been ideal as previously determined.

Sustainability of Effects and Plans to Maintain Effects

Since this project was relatively easy to perform and complete, the sustainability of this project is high. This project can be used in the future as the clinic staff sees fit. If a provider sees this project as a positive, he/she can utilize it and further educate their patients. In the future, the nurse clinicians could do follow up calls on the caregivers to assess their burden without the need for a clinic visit. This could be a challenge, however, if the office staff are too busy to perform these follow up phone calls. However, assessing caregiver burden early could help limit future issues such as other health issues that could arise in the caregiver. It could help eliminate any issues that may come with caregiving or even identifying them early.

Efforts to Minimize the Study Limitations

Due to the limited number of participants in this study, the study was seen as not as successful as expected. For the future, this project could have worked well if follow up was maintained. Following up with patients and participants could have helped reach a higher number. Also, spending more time recruiting could have helped lead the student investigator to more participants.

The clinic where the project was performed has a nurse practitioner and a physician. The issue with this clinic is the nurse practitioner only sees a limited number of patients as the

physician sees the bulk. This then limits the number of patients the student investigator was able to use as participants.

Another limitation is the long time for return visits. The patients seen in the clinic are not seen as frequently as this study required. Most of these patients are established and are seen at 6 months or even yearly intervals. If these patients were seen more frequently, they could have aligned properly with the inquiry time frame of 4 months. In the future, this project would be successful if the time frame was extended.

Interpretation

With the world-changing to have access to more things online, this project could be more sustainable in the future with online education. Caregivers can be easily referred to educational resources online with minimal assistance. The online resources might prove to be easier to access than attending support groups where getting away from their caregiving duties might seem cumbersome. These online resources will provide educational information on the caregiver's own time.

Expected & Actual Outcomes

This study would have been successful if the correct number of participants would have been available. Due to the limited number of participants this study was unable to fully be successful. It was expected that participant participation would be low, hence why the previous sample size was decreased from 30 to 15. However, the limited number of patients seen in the clinic did not allow for this sample size.

One issue that could be a factor in decrease sample size was the type of patients seen in the clinic. The low number of patients seen was a deterrent as the majority were there for acute visits and many were younger patients who were not dealing with taking care of a loved one with

AD. While there is a diverse age group of patients seen in this clinic, the majority seen by the nurse practitioner were young patients with acute visits.

Also, patients were lacking in their follow up appointments. Many times patients were missing appointments and the no show visits were happening too frequently to capture all the patients necessary for the project. While this was not expected nor ideal, it should have been taken into account while first implementing the study. This barrier could have been eliminated had the student investigator better assessed the clinic.

Intervention Effectiveness

This study could have possibly been successful in another clinic setting. While this clinic was a family practice clinic, to reach a wider audience, a clinic in a neurology or geriatric specialty clinic would have sufficed. These clinics would have been able to reach more caregivers as AD patients are seen in these clinics typically. While the caregivers are bringing their loved one to clinic appointments, the intervention for caregiver education could still be relayed.

While this study and the current literature were closely aligned, this project could have a few factors that may contribute to a change in burden levels. Other life factors or even personal mental health issues could correlate with high burden levels in the pre and posttest assessments. It is difficult to know the prior knowledge that can affect the caregiver in such a way. Also, the interventions could be modified to help the caregiver learn in a certain way. Understanding how one learns best can also prove effective in getting appropriate information to the caregiver.

Intervention Revision

For future project successes, ensuring this project takes place in a primary care setting where geriatric patients are seen would suffice. It would also be beneficial to have a location

where a larger number of patients of diverse ages and backgrounds are seen. Implementing follow up phone calls or appointments would help conclude the assessment part of the intervention. This would allow participants to be seen after their intervention or discussions made about their burden post-intervention. Also, extending the time frame might be beneficial. With caregiving, finding time outside of caregiving might prove difficult. Therefore, extending the time frame to at least 6 months from pre-test and intervention implementation could help the participants get proper education on their caregiving roles.

Expected and Actual Impact

The main impact on the healthcare of this project is keeping patients and caregivers informed. Keeping the caregivers informed about their loved one's disease process can help them become better caregivers. This can help keep them well mentally. This can also limit the need for long term care facilities as these can be costly to the patient, family, or even the healthcare system as a whole. Limiting the need for caregiving assistance can help the patient live at home as long as humanly possible while still being with family as they age.

While caring for those with AD is costly, allowing them to age at home has cut down on those costs of long term care expenses. This study had limited funds and utilized more manpower than actual monetary needs. The study cost was estimated at \$0.51 for printing costs and that was the only expense of this project. The student investigator conducted most of the research at no cost to the clinic or even the patient. This limited use in funds helped ensure the project costs were low and sustainable in the clinic after project completion.

Conclusion

AD proves to be a disease that involves not just the patient, but also the caregiver. The stress that is associated with caring for a loved one with AD can become challenging. The

burden of caring for a patient with AD can decrease, as the lack of knowledge of the disease and its process are present. With the implementation of caregiver education, caregivers experience a decrease in burden as the progressive symptoms are unknown. This project was helpful to increase knowledge and awareness of the disease and its processes involved. For further implementation, carving out clinic time for the caregivers to encourage more support from a multidisciplinary standpoint can be increasingly effective as well. Multidisciplinary meetings with other disciplines can help the caregiver and the AD patient collectively with additional services that were unknown prior. When a provider is doing a social history on a patient, identifying those who are caregivers can help identify those who may benefit from an educational resource.

While caregivers are being seen in a primary care clinic for their health care, their needs of caregiving at home may be overshadowed unless it is identified. While this project was geared to those who are caring for loved ones with AD, this project can be modified to be helpful to those of different disease processes. There are multiple local support groups and online resources for several disease processes where a caregiver is necessary.

The plans for dissemination of this project were presented at the Advanced Practice of the Ozark in Branson, Missouri in November 2019. This project poster was presented and discussed with other advanced practice nurses attending the conference. This project poster was intended to be presented at the University of Missouri-Kansas City poster sharing days but was unable to due to a conflict. Additionally, this project's manuscript will be submitted to The Gerontologist journal for possible publication.

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Appendix A

First author, Year, Title, Journal	Purpose	Research Design ¹ , Evidence Level ² & Variables	Sample & Sampling, Setting	Measures & Reliability (if reported)	Results & Analysis Used	Limitations & Usefulness
Education (lack of and education to the caregiver)						
<p>Du, L., & Hu, J. (2016). The effects of health education on knowledge about Alzheimer's disease and health-promoting behaviors of older Chinese adults in a nursing home: A pilot study. <i>International journal of nursing practice</i>, 22(1), 31-42.</p>	<p>The effectiveness of health education.</p>	<p>Quasi-experimental, one-group study, convenience sampling, Level IV</p>	<p>35 older adults who were not diagnosed with known AD or dementia</p>	<p>Pre-test, post-test, 1 month follow up of intervention on knowledge of AD and a health-promoting lifestyle. Used the ADKS</p>	<p>The study found that health education was effective in increasing knowledge of AD and improving lifestyle.</p>	<p>Pilot study with a small convenience sample and no comparison group. The reliability and validity of the ADKS have not been tested. Study was done in China-culture in China is different than in the US with caregiving, could be difficult to correlate with caregiving in the US.</p>
<p>Jackson, D., Roberts, G., Wu, M. L., Ford, R., & Doyle, C. (2016). A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's,</p>	<p>A review of the effects of telephone, internet, or combined support for caregivers of those living</p>	<p>RCTs, non RCTs, quasiexperimental, Level 1</p>	<p>22 studies from literature review addressing the effects of telephone, internet, or combined support for caregivers.</p>	<p>In this review the successful outcomes from the combined telephone and internet delivery exceeded that of telephone alone and internet alone. Very few studies addressed programs for specific types of dementia.</p>	<p>Combined telephone and internet delivery of multicomponent interventions demonstrated relatively more positive outcomes in reducing depression, burden, and increasing self-efficacy than telephone alone or</p>	<p>This study's findings were limited by potential sources of bias and methodological limitations.</p>

<p>vascular or mixed dementia in the community. <i>Archives of gerontology and geriatrics</i>, 66, 218-236.</p>	<p>with patients with AD.</p>		<p>13 telephone only studies. 5 internet only studies 4 combined studies</p>		<p>internet alone. Further research is needed to determine which is most effective.</p>	<p>More research is needed.</p>
<p>Bartfay, E., & Bartfay, W. J. (2013). Quality-of-life outcomes among Alzheimer’s disease family caregivers following community-based intervention. <i>Western journal of nursing research</i>, 35(1), 98-116.</p>	<p>To examine the impact of two specific community-based interventions on the QOL of primary caregivers</p>	<p>experimental, specifically cross-sectional. Level IV.</p>	<p>Participants for the pilot study were recruited from six caregiver support groups and five adult day programs employing a nonprobability convenience sampling technique because of associated savings in both time and costs. 62 caregivers involved</p>	<p>Use of the QOL-Alzheimer’s Disease Scale Reliability Cronbach’s alpha 0.83-0.90</p>	<p>Two adult day program groups showed findings suggest that caregiver’s QOL ratings were comparable regardless of the disease status of the family member they cared for. Pilot study suggests that community-based interventions such as caregiver support groups and adult day programs have positive and desirable benefits, including social and emotional support for the primary caregivers.</p>	<p>small sample size</p>
<p>Smyth, W., Fielding, E., Beattie, E., Gardner, A., Moyle, W., Franklin, S., ... & MacAndrew, M. (2013). A survey-based study of knowledge of Alzheimer’s disease among health care staff. <i>BMC geriatrics</i>, 13(1), 2.</p>	<p>Knowledge levels were investigated via the validated 30-item Alzheimer’s Disease Knowledge Scale (ADKS).</p>	<p>cross sectional survey level IV, quantitative</p>	<p>360 people interviewed who are currently working in a health care setting</p>	<p>Knowledge levels were investigated via the validated 30-item Alzheimer’s Disease Knowledge Scale (ADKS).</p>	<p>moderate level (average of 79% correct) of dementia knowledge the current study confirmed positive correlations between self-assessed knowledge of dementia and having attended a dementia-specific educational session with ADKS score observed in the original study Dementia education has been identified as a means of improving</p>	<p>None identified. It needs to be noted that knowledge alone does not necessarily translate into change in care</p>

					dementia knowledge especially for health professionals.	
Caregiver Burden						
Abdollahpour, I., Nedjat, S., & Salimi, Y. (2018). Positive aspects of caregiving and caregiver burden: a study of caregivers of patients with dementia. <i>Journal of geriatric psychiatry and neurology</i> , 31(1), 34-38.	The positive side of caregiving	Cross-sectional, Level II	132 caregivers	Linear regression model with positive aspect of caregiving	Caregiver burden was negatively associated with positive aspects of caregiving. Adjusted for caregivers age and marital status. Reinforces a need for interventional and/or educational programs aiming at decreasing the overall imposed burden.	There is a need for interventional and/or educational programs aiming at decreasing the overall imposed burden.
Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., ... & Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. <i>Journal of clinical nursing</i> , 26(9-10), 1291-1300.	Caregiver burden and factors influencing that burden in caregivers of AD patients.	Quantitative, cross-sectional design, Level VI	309 caregivers and their patients and looking at patient's cognitive, psychological and functional status and the caregiver's burden, sleep, and mental state.	Information collected via questionnaire. Also used the 30-point Chinese version of the MMSE, and the ZBI	Caregiver burden is influenced by the caregiver's physical condition and mental status and the patient's disease progression.	Study takes place in China, may not be relevant due to cultural changes. Smaller sample size
Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: a systematic review. <i>International nursing review</i> , 62(3), 340-350.	Caregiver burden on informal caregivers of those with dementia.	Systematic Review of 21 articles, Level I	21 articles from four databases: PubMed, PsycINFO, CINAHL, and Cochrane Library	Caregiver burden information within the systematic review	Caregiver burden was not clearly defined, broadly defined	Caregiver burden was clearly defined and therefore can help healthcare professionals assist caregivers and relieve their burden.

<p>Sallim, A. B., Sayampanathan, A. A., Cuttilan, A., & Ho, R. C. M. (2015). Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. <i>Journal of the American Medical Directors Association, 16</i>(12), 1034-1041.</p>	<p>To determine mental health disorders in caregivers caring for patients with AD.</p>	<p>Systematic review and meta-analysis, Level I</p>	<p>17 studies for a systematic review</p>	<p>Random effect model.</p>	<p>The odds of having depression was 1.53 times higher in female caregivers, 1.86 times higher in caregivers to male care-recipients, and 2.51 times higher in spousal caregivers.</p>	<p>More research needs to be done on the prevalence of anxiety.</p>
<p>Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: health of caregivers of Alzheimer's and other dementia patients. <i>Current psychiatry reports, 15</i>(7), 367.</p>	<p>AD and dementia caregiver health and psychosocial interventions</p>	<p>Cross-sectional, non-experimental, Level IV</p>	<p>A look at all AD caregivers as whole</p>	<p>Zarit Burden Interview, Montgomery Borgatta Burden Measure, and Caregiver Well-Being Scale</p>	<p>Caregivers are generally family members and there needs to be help to caregivers to decrease anxiety and depression.</p>	<p>Informational, not necessarily an article with much data.</p>
<p>Bialon, L. N., & Coke, S. (2012). A study on caregiver burden: stressors, challenges, and possible solutions. <i>American Journal of Hospice and Palliative Medicine, 29</i>(3), 210-218.</p>	<p>Factors impacting caregiver burden and solutions for family caregivers of those terminally ill.</p>	<p>Qualitative study, Level VI</p>	<p>Unknown</p>	<p>None reported.</p>	<p>Early identification, intervention, education and coordination of services may help alleviate caregiver burden. Caregivers who work outside the home, care for two parents, little assistance, and who were caring for longer time experienced the most burden. They reported a need for more caregiver training and education. Faith played a positive</p>	<p>For terminally ill patients.</p>

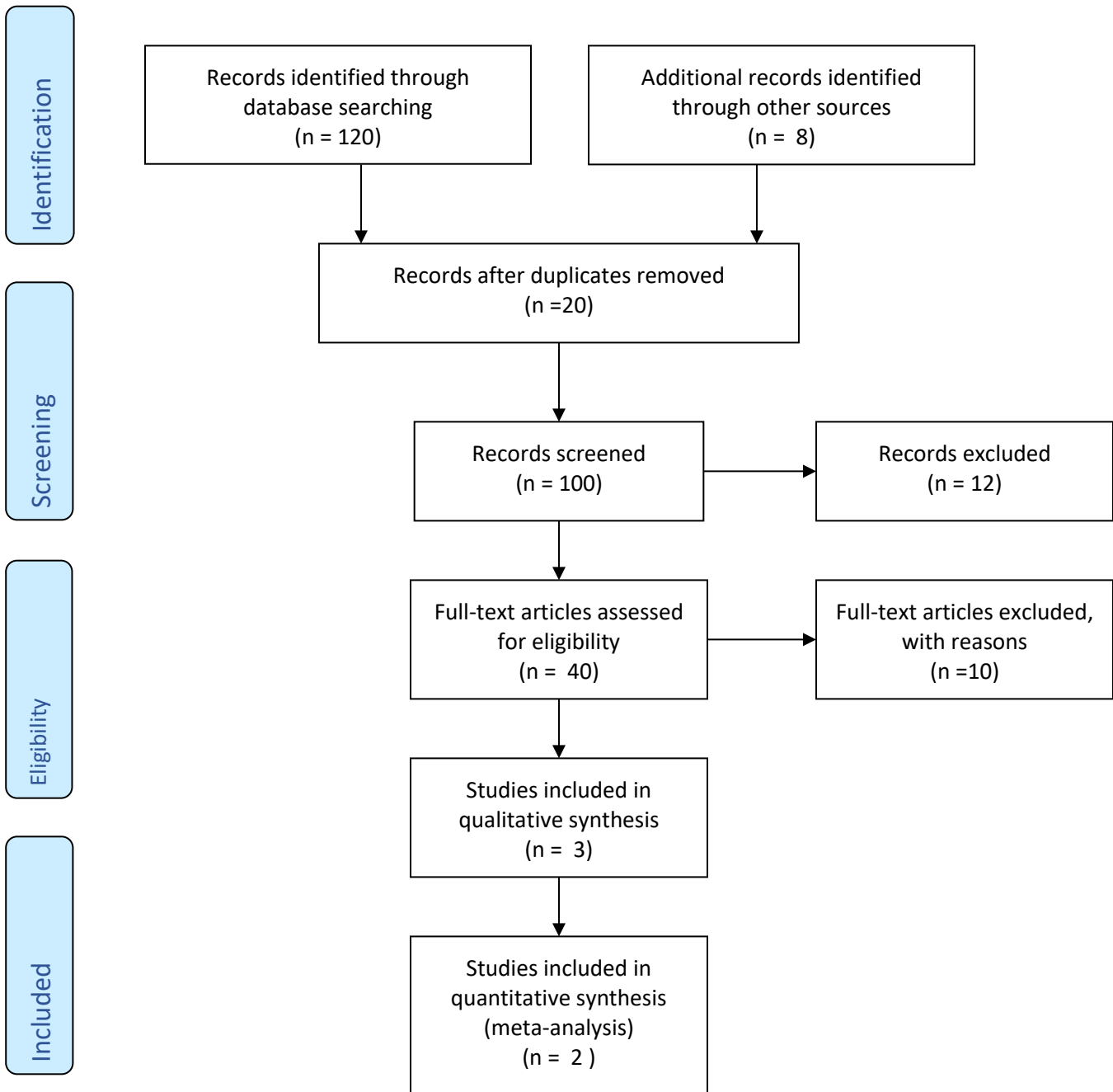
						role to decreasing caregiver burden.
Caregiver Types						
Myhre, J., Bjørnstad Tonga, J., Ulstein, I. D., Høye, S., & Kvaal, K. (2018). The coping experiences of spouses of persons with dementia. <i>Journal of clinical nursing</i> , 27(3-4), e495-e502.	Everyday life of spouses caring for those with dementia.	Qualitative, semi structures in-depth interviews, Level VI	Semi-structures in-depth interviews with six spouses of those with dementia	Uses the Norwegian CORDIAL study (cognitive rehabilitation and cognitive behavioral treatment for early dementia in Alzheimer’s disease)	The caregivers had increased awareness of possible coping strategies 6-12 months after intervention.	Small sample study. Research done in Norway yet still may prove helpful.
Caceres, B. A., Frank, M. O., Jun, J., Martelly, M. T., Sadarangani, T., & De Sales, P. C. (2016). Family caregivers of patients with frontotemporal dementia: an integrative review. <i>International Journal of Nursing Studies</i> , 55, 71-84.	To identify the characteristic s of family caregivers of patients with dementia, explore the impact of providing care on family caregivers health and wellbeing, and identify coping strategies used by family caregivers.	Integrative review, Level I	Whittemore and Knafl methodology for conducting an integrative review. 11 articles reviewed.	Crowe Critical Appraisal tool	Family caregivers noted behavioral disturbances as most troubling. Spouse and female caregivers’ experiences greater caregiver burden, depression, sleep disturbances. Female caregivers will exhibit coping strategies.	Effective interventions to reduce family caregiver burden are poorly understood but family caregivers suggest education and internet-based support groups are most helpful.
Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A., & Rongve, A. (2016). Caregiver burden in family carers of people	To differentiate caregiver distress in those who care for patients with	Cross-sectional, Level II	100 patients with AD and 86 patients with DLB	Relative Stress Scale from the Norwegian Dementia Register	Moderate to high caregiver burden in caring for patient with AD and DLB	Norwegian study-may need to find something from the US instead.

with dementia with Lewy bodies and Alzheimer's disease. <i>International journal of geriatric psychiatry</i> , 31(9), 1075-1083.	Lewy body dementia and AD.					
Boltz, M., Chippendale, T., Resnick, B., & Galvin, J. E. (2015). Anxiety in family caregivers of hospitalized persons with dementia: contributing factors and responses. <i>Alzheimer disease and associated disorders</i> , 29(3), 236.	How anxiety is measured in caregivers.	Descriptive secondary analysis using a combined quantitative and qualitative approach. Mixed methods. Cross sectional level IV with qualitative level VI	50 patients and family members from 3 hospitals in Northeast US.	Quality of relationship-Mutuality Scale Strain-Modified Caregiver Strain Index Depression/Anxiety-Hospital Anxiety and Depression Scale	Lower patient physical functions and higher caregiver strain were associated with higher family caregiver anxiety.	Smaller sample size.
Geiger, J. R., Wilks, S. E., Lovelace, L. L., Chen, Z., & Spivey, C. A. (2015). Burden among male Alzheimer's caregivers: Effects of distinct coping strategies. <i>American Journal of Alzheimer's Disease & Other Dementias</i> ®, 30(3), 238-246.	To identify Male caregivers of AD patients utilizing 3 coping strategies (task focused, emotion focused, and avoidance focused) and how each affects the caregiving burden.	Secondary data from previous cross-sectional analysis, Level II	138 male AD caregivers in southern US, including African Americans in the sample, survey, 2 phase data collection	Study included demographic information, caregiver coping strategy, and caregiving burden. Standardized measures used the coping inventory for task stressors and the Zarit Burden Interview with the Revised Memory and Behavior Problems Checklist to measure caregiver burden.	Male AD caregivers benefit more from task-focused coping.	The study was unable to determine the coping strategies of male AD caregivers over time. Smaller sample size Should do a randomized sampling next time.
Park, M., Sung, M., Kim, S. K., Kim, S., & Lee, D. Y. (2015). Multidimensional	Family caregivers burden factors	Systemic Review, Level I	1133 primary caregivers in South Korea in a	Retrospective secondary data analysis	25.6% of caregiver burden was associated with caregiving-related factors. Variables	Could be helpful but taking place in South Korea

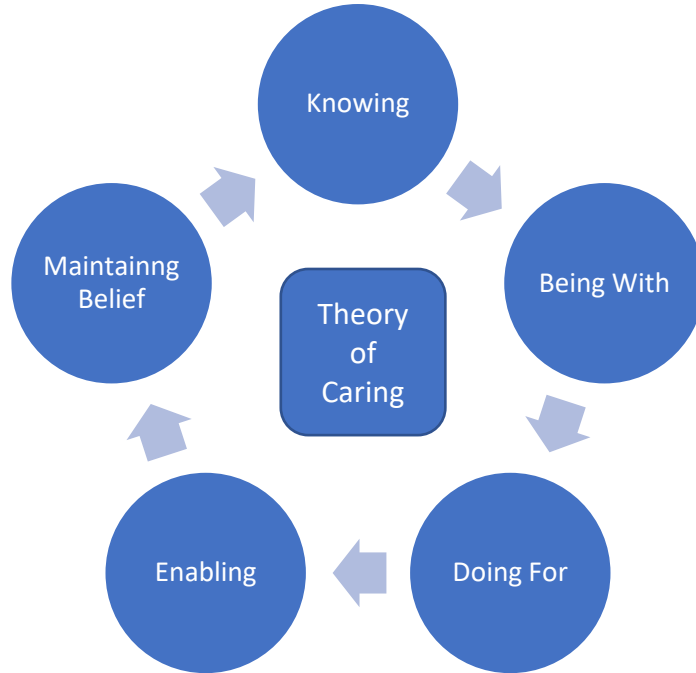
determinants of family caregiver burden in Alzheimer's disease. <i>International Psychogeriatrics</i> , 27(8), 1355-1364.	associated with caregiver burden in AD patients.		metropolitan city dementia center		included behavioral problems, ADLs, spousal relationship, hours of caregiving, and the number of diseases associated with the caregiver	where the Asian culture is different than that of the United States.
Day, J. R., Anderson, R. A., & Davis, L. L. (2014). Compassion fatigue in adult daughter caregivers of a parent with dementia. <i>Issues in mental health nursing</i> , 35(10), 796-804.	How caring for a parent with dementia impacts the adult daughter carer.	Qualitative, semi structures in-depth interviews, Level VI	Interviews with 12 adult daughter caregivers	Utilized the Project ASSIST and semi-structures interviews	Four themes were found being: uncertainty, doubt, attachment, and strain in relation to caregiving.	Small sample study of only 12 adult daughter caregivers. Yet outlines a specific type of caregiver.
Choi, J., Tate, J. A., Hoffman, L. A., Schulz, R., Ren, D., Donahoe, M. P., ... & Sherwood, P. R. (2014). Fatigue in family caregivers of adult intensive care unit survivors. <i>Journal of pain and symptom management</i> , 48(3), 353-363.	Self-reported fatigue in caregivers of ICU survivors	Cross-sectional, Level II	47 patient-caregiver pairs	Short-Form 34 Health Survey Vitality subscale. Shows how caregiver fatigue is measured.	43-53% of caregivers reported worse scores in depressive symptoms, health risk behaviors and sleep quality, and patients' symptom burden.	Small sample size with 45 patient-caregiver pairs. Focused more on ICU patients, however, can prove beneficial as it still discusses caregiver fatigue.
Milbury, K., Badr, H., Fossella, F., Pisters, K. M., & Carmack, C. L. (2013). Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung	Spousal caregiver's caregiving burden effects	Cross-sectional, Level II	158 couples with baseline reports of caregiving-related health problems, assessed at 3 and 6 months follow ups.	Brief Symptom Inventory to measure distress	Reports of distress, schedule disruptions, and financial strain, lack of support that increased at 3 months to 6-month time frame.	Limited to those who were caring for a spouse with lung cancer. Still could provide sufficient information

<p>cancer. <i>Supportive Care in Cancer</i>, 21(9), 2371-2379.</p>						<p>for caregiving strains on a spouse in general.</p>
<p>Lynch, S. H., & Lobo, M. L. (2012). Compassion fatigue in family caregivers: a Wilsonian concept analysis. <i>Journal of Advanced Nursing</i>, 68(9), 2125-2134.</p>	<p>Analyzing the concept of compassion fatigue in family caregivers</p>	<p>Concept analysis with systemic review, Level I</p>	<p>Concept analysis using model, contrary, related, and borderline cases.</p>	<p>Wilson’s concept analysis of caregiver compassion fatigue</p>	<p>The concept of compassion fatigue has potential use with family caregivers.</p>	<p>Compassion fatigue can relate to nurses, doctors, and social workers. This can be used with caregivers but is used in the professional field.</p>
<p>Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2011). Family stigma and caregiver burden in Alzheimer’s disease. <i>The Gerontologist</i>, 52(1), 89-97.</p>	<p>Use of the Zarit Burden Scale to assess caregiver burden.</p>	<p>Cross-sectional, non-experimental and level IV. Convenience</p>	<p>185 adult children who were primary caregivers of an elderly parent with possible AD 75% female Convenience sampling. Mean age: 53</p>	<p>Caregiver burden assessment-Zarit Burden Interview Short</p>	<p>Caregiver stigma variables improved the prediction of caregiver burden by adding an additional 18% to the explained variance over and above the other covariates. The 2 caregiver stigma variables of shame and decreased involvement with caregiving were found to be the major contributing factors.</p>	<p>Convenience sampling limits and may not be representative of all adult child caregivers. Focused in Israel-may not be used due to not being done in the US and cultures are different.</p>

Appendix B



Appendix C



Appendix D



Institutional Review Board
University of Missouri-Kansas City

5319 Rockhill Road
Kansas City, MO 64110
816-235-5927
umkcirb@umkc.edu

July 26, 2019

Principal Investigator: Lyla Jo Lindholm
Department: Nursing - General

Your IRB Application to project entitled "Caregiver Education on the Patient with Alzheimer's Disease to Decrease Caregiver Burden" was reviewed and determined to qualify for IRB exemption according to the terms and conditions described below:

IRB Project Number	2016134
IRB Review Number	250896
Initial Application Approval Date	July 26, 2019
IRB Expiration Date	
Level of Review	Exempt
Exempt Categories	45 CFR 46.101b(3)
Risk Level	Minimal Risk

The principal investigator (PI) is responsible for all aspects and conduct of this study. The PI must comply with the following conditions of the determination:

1. No subjects may be involved in any study procedure prior to the determination date.
2. Changes that may affect the exempt determination must be submitted for confirmation prior to implementation utilizing the Exempt Amendment Form.
3. The Annual Exempt Form must be submitted 30 days prior to the determination anniversary date to keep the study active or to close it.
4. Maintain all research records for a period of seven years from the project completion date.

If you are offering subject payments and would like more information about research participant payments, please click here to view the UM system Policy on Research Subject Payments:
https://www.umsystem.edu/oei/sharedservices/apss/nonpo_vouchers/research_subject_payments

If you have any questions, please contact the IRB at 816-235-5927 or umkcirb@umkc.edu.

Thank you,
UMKC Institutional Review Board

Appendix E



July 17, 2019

DNP Project Proposal Approval
UMKC DNP Student

This letter serves to provide documentation regarding Brienne Ketterlin's Doctor of Nursing Practice (DNP) project proposal. Ms. Ketterlin obtained approval for her proposal, *Caregiver Education to Decrease Caregiver Burden of the Alzheimer's Disease Patient*, from the School of Nursing and Health Studies DNP faculty on July 17, 2019.

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

Sincerely,

A handwritten signature in black ink that reads "Cheri Barber".

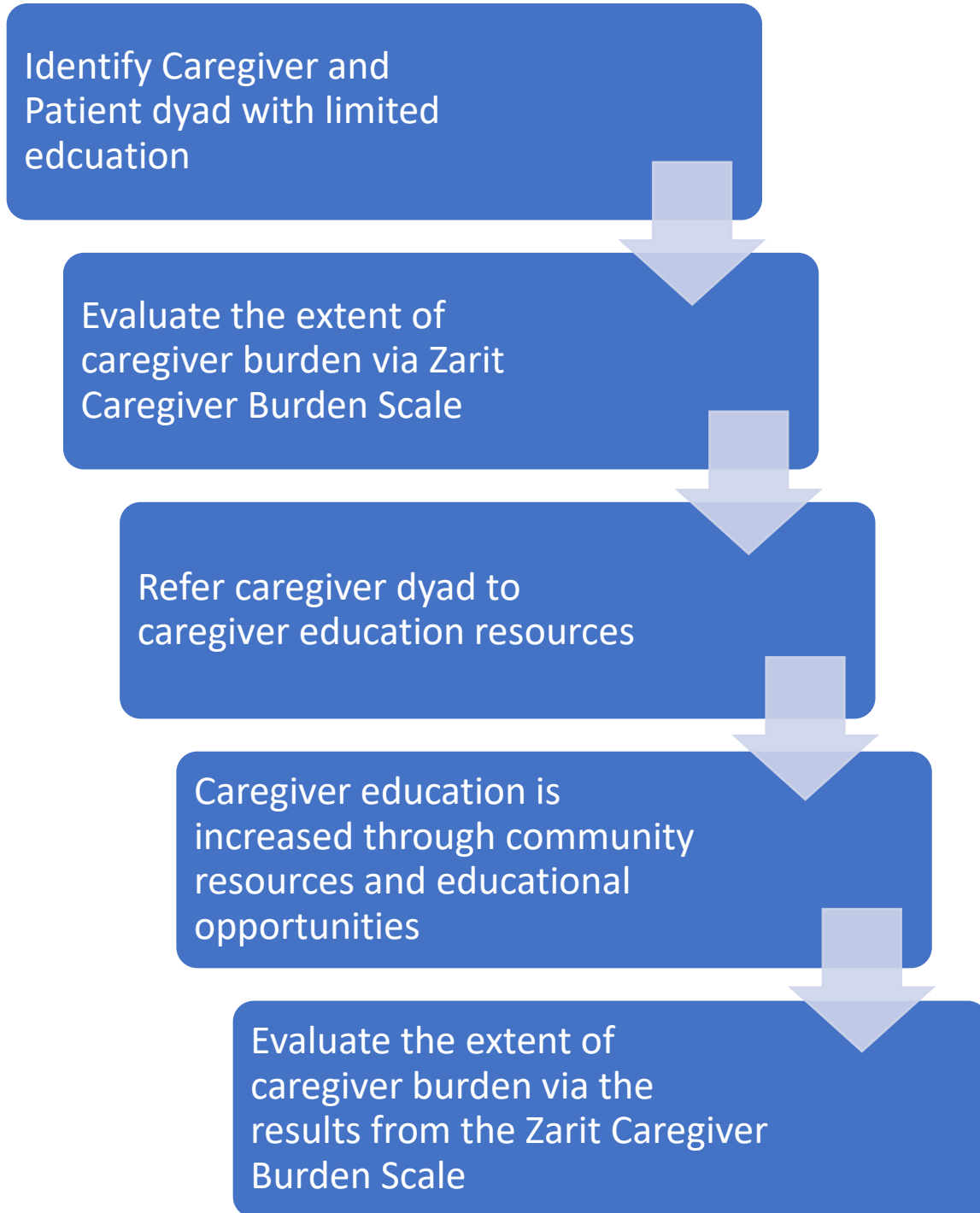
Cheri Barber, DNP, RN, PPCNP-BC, FAANP
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Clinical Assistant Professor
DNP Faculty

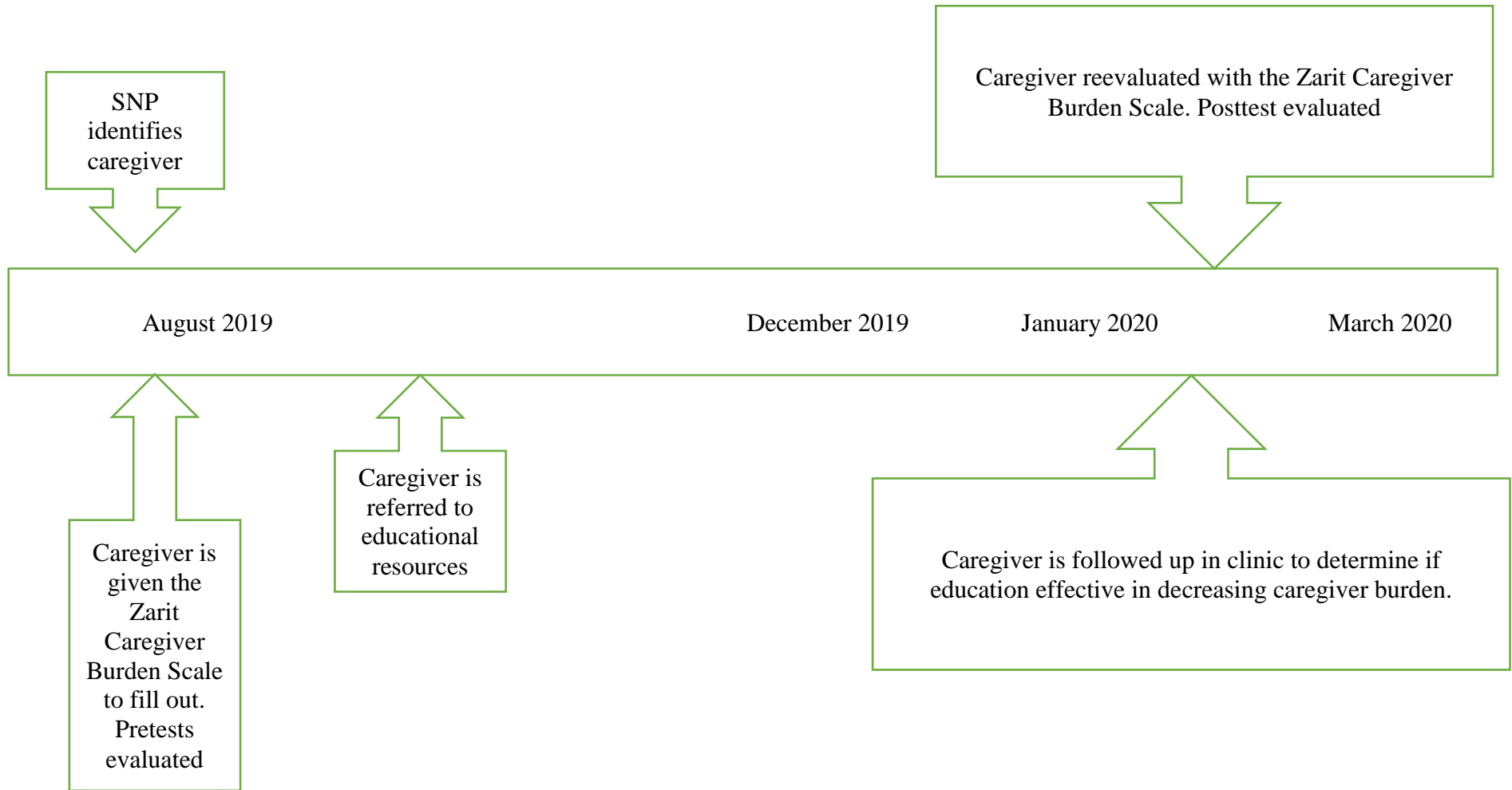
Appendix F

Item	Item Description	Quantity	Unit Cost	Anticipated Cost
Print materials	Printed material with information regarding where to access information and support groups	30	Copies \$0.017/page	Copies \$0.51
Equipment	None needed		\$0	\$0
Miscellaneous			\$0	\$0
Student Time	82.5 clinical hours to support this project as unpaid hours.		\$0	\$0
Total				\$0.51

Appendix G



Appendix H



Appendix I

Logic Model for DNP Project					
Student: Brianne M. Ketterlin					
Inquiry, PICOTS: In caregivers of Alzheimer’s Disease patients, does increased educational versus non educational referral by the student Nurse Practitioner near time of diagnosis, decrease caregiver burden as measured by the Zarit Caregiver Burden scale, pre and post-test intervention, within four months at Capital Region Medical Center primary care clinics?					
Inputs	Intervention(s) Outputs		Outcomes -- Impact		
	Activities	Participation	Short	Medium	Long
Evidence, sub-topics 1. Caregiver education of the AD patient 2. Caregiver burden 3. Caregiver types Major Facilitators or Contributors 1. Low cost 2. Sustainable 3. Easily teachable Major Barriers or Challenges 1. Time constraints 2. 15 Willing participants 3. Length of project time (~4 months)	EBP intervention which is supported by the evidence in the Input column (brief phrase) Caregiver’s of the AD patient will be given education or directed to educational support to help decrease caregiver burden. With increased education or access to support groups, caregiver burden can be potentially be decreased. Major steps of the intervention (brief phrases) 1. Pre-Evaluation 2. Education 3. Intervention 4. Post Eval 5. Implementation 6. Follow up	The participants (subjects) Caregivers of AD patients (15 Dyads) Site CRMC primary care Time Frame 4 months Consent or assent Needed Yes, prior to pre-eval questioning Other person(s) collecting data (yes,no) No Others directly involved in consent or data collection (yes/no) No	(Completed during DNP Project) Outcome(s) to be measured Primary: Caregiver Burden Measurement tool(s) 1. Zarit Caregiver Burden Scale Statistical analysis to be used 1. t-tests scores from the pre-eval and post eval	(after student DNP) Outcomes to be measured Caregiver Burden	(after student DNP) Outcomes that are potentials <ul style="list-style-type: none"> • Increased caregiver education • Increased awareness • Decreased caregiver burden • Decreased stress, anxiety, and fear with diagnosis

Appendix J

Caregiver burden: happens when a caregiver has been physically, emotionally, or mentally depleted from caring for another person (Lilly, Robinson, Holtzman, & Bottorff, 2012). This depletion causes stress and fatigue in the caregiver. Caregiver burden can also be defined when the caregiver fails to recognize their own health concerns (Johnson, 2014).

Alzheimer's disease: characterized by increased cognitive impairments, decrease in activities of daily living, and behavioral and emotional problems that affects patient's quality of life in a number of ways (Alzheimer's Association, 2019).

Caregiver: The caregiver can be a family member, spouse, friend or neighbor. All of whom have increased risk for caregiver fatigue when caring for a loved one (Day, Anderson, & Davis, 2014).

Education: knowledge of the disease process of Alzheimer's disease to understand the course and nature of the disease (Bialon, & Coke, 2012).

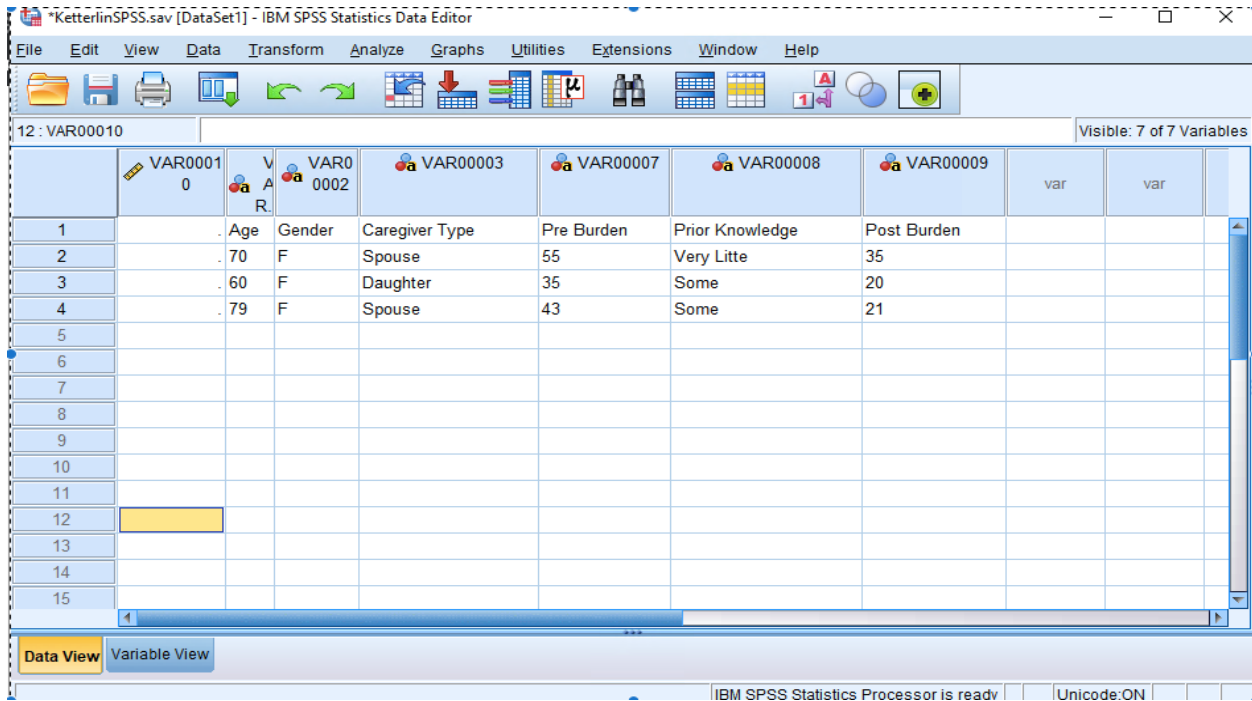
Appendix K

Zarit Caregiver Burden Interview-Permission for Tool

Permission from tool was obtained from eProvide through the website:

<https://eprovide.mapi-trust.org>. This tool was downloaded via this site after permission was obtained. While this tool is readily available through the internet, proper consent for use was obtained.

Appendix L



Data Collection Template

Table 1: Demographics

Age (N=3)	Number (%)
20-29=0	0%
30-39=0	0%
40-49=0	0%
50-59=0	0%
60-69=1	33.3%
70-79=2	66.6%
80+=0	0%

Gender (N=3)	Number (%)
Male=0	0%
Female=3	100%

Caregiver Type (N=3)	Number (%)
Spouse=2	66.6%
Friend=0	0%
Child-Male=0	0%
Child-Female=1	33.3%
Partner/Significant Other=0	0%
Other Relative=0	0%

Appendix M

Statistical Analysis Table

Table 2: Group Statistics

	Mean	N	Std. Deviation	Std. Error Mean
Pre Burden	44.333	3	10.06645	5.81187
Post Burden	25.333	3	8.38650	4.84195

Paired Samples Correlations

	N	Correlation	Sig.
Pre Burden & Post Burden	3	.940	.222

Paired Sample Test

	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		T	df	Sig. (2-tailed)
				Lower	Upper			
Pre Burden & Post Burden	19.00000	3.60555	2.08167	10.04331	27.95669	9.127	2	.012