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# A MULTI-COMPONENT EDUCATION, SKILL, AND RESOURCE EVIDENCE-BASED PRACTICE INTERVENTION FOR THE ALZHEIMER'S CAREGIVER

by

## CHERYL GARMON, MSN, RN

A DNP scholarly project submitted in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice School of Nursing

Colleen Marzilli, Ph.D., DNP, MBA, Committee Chair

College of Nursing and Health Sciences

The University of Texas at Tyler May 2019 The University of Texas at Tyler Tyler, Texas

This is to certify that the DNP Scholarly Project of

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# Acknowledgments

I would like to thank the faculty of The University of Texas at Tyler for their assistance, training, and insight toward the development and completion of this project. Special appreciation to the following individuals:

- Dr. Colleen Marzilli
- Dr. Sandra Petersen
- Dr. Ellen Fineout-Overholt
- Luanne Harms, LMSW
- Alzheimer's Alliance of Smith County
- Dr. Barbara Haas
- Dr. Marcie Lusk

- Dr. Kathleen Helgesen
- Dr. Beth Mastel-Smith
- Dr. Barbara McAlister
- Dr. Cheryl Parker
- Dr. Jerri Post
- Dr. Jenifer Chilton
- Dr. Danita Alfred
- Dr. Susan Yarbrough

#### Dedication

This Doctor of Nurse Practice Evidence-based Practice Implementation Project is dedicated to the one who guided me into and through this academic journey, namely, my Lord and Savior. All that I have accomplished is to His Glory!

Secondly, I extend appreciation to my husband, Bobby, my family, and friends for patience, encouragement, and loving kindness during the three-year sabbatical of academic engagement.

Thirdly, A special appreciation to my mentorship team. To Luanne Harms, LMSW for her commitment to lead others in the stressful journey of dementia care. To Dr. Colleen Marzilli for her encouragement and availability as an excellent faculty mentor.

Last, but not least, to caregivers of Alzheimer's dementia and related dementias (ADRD) individuals. The extraordinary courage to support someone with ADRD as they journey through this devastating disease is remarkable. The evidence-based practice caregiver interventions help to decrease the unavoidable burden of caregiving. As we wait for an ADRD cure, we wait in solidarity knowing that the journey is selfless, loving, and worthy to travel for the sake of our loved ones.

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#### Abstract

## A MULTI-COMPONENT EDUCATION, SKILL, AND RESOURCE EVIDENCE-BASED PRACTICE INTERVENTION FOR THE ALZHEIMER'S CAREGIVER

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DNP Scholarly Project, Faculty Member: Colleen Marzilli, Ph.D., DNP, MBA

The University of Texas at Tyler May 2019

Dementia caregiving is expensive, stressful, and consumes all facets of the caregiver's (CGs) life. The purpose of this project is to introduce the evidence-based practice (EBP) interventions most helpful in decreasing stress and burden in those who are in-home caregivers for Alzheimer's disease and related dementias (ADRD) individuals.

The three primary intervention domains of the EBP studies that results in a positive impact are; providing education about the terminal course of the disease, introducing communication and caregiving skills, and furnishing resource and social network information.

The methodology included a convenient and voluntary population of CGs who sought service at a community dementia organization. The staffing team led by social workers, implemented the multi-component program over 1 - 2 months. Intervention sessions consisted of home safety assessments, legal and medical information, social support, managing stress, understanding caregiver feelings, skillful communications, relating memory problems to behavior, and additional resources helpful to the care of the dementia individual. A Risk Assessment Measure (RAM) tool was used to measure CG stress and burden level before and after all the interventions were complete.

Analysis of the data showed that the mean Pre-RAM score was 21.7, and the mean Post-RAM score was 12.6, a reduction of 9.1 points indicating an overall decrease in stress and burden. Further analysis was performed for significance level using a two-tailed hypothesis. The data concludes that educating the caregiver using a multi-component approach can reduce the stress and perceived burden of dementia caregiving. To ensure sustainability, the clinical site's policy change is to offer the program to CGs who present with moderate to high levels of stress as measured by the RAM assessment. To monitor sustainability, an annual audit of the program will be submitted to the Board of Directors. The audit includes the number of participants and the analysis of RAM data.

Keywords: Alzheimer's, caregiver, caregiving, in-home caregiver, caregiving dynamics

#### Chapter 1:

# **Development of the Clinical Question**

#### and Problem Identification

Although famous and highly profiled individuals, Maria Shriver, Stone Phillips, and Leeza Gibbons have at least one thing in common – they are children of a parent diagnosed with Alzheimer's disease (AD). This disease is progressive, complex, and characterized by the deterioration of brain cells causing loss of memory, loss of social skills, and loss of independence (Garcia-Alberca et al., 2013). Depending on the family circumstance, the caregiver (CG) of a person with AD is typically an adult child or a dedicated spouse, and yet their unexpected burden is the same. Alzheimer's disease and related dementias (ADRD) are not discriminatory toward whom it strikes. All socioeconomic populations, cultures, ethnicities, and aging adults are subject to the ADRD diagnosis or becoming an in-home CG. For this paper, Alzheimer's disease (AD) will be referenced throughout the document. However, the burden of in-home caregiving is common for those who have Alzheimer's disease and related dementias.

#### **Background and Significance**

Alzheimer's disease is prevalent worldwide as a leading cause of death that occurs in the elderly and threatens younger populations. In 2009, it was reported that over five million people in the United States were afflicted with AD, and in 2017 the number increased to 5.5 million (Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014;

Alzheimer's Association, 2017). This population of AD persons requires a CG. Approximately 83% of elderly assistance is provided by an in-home family CG, however, elderly AD persons require additional care needs (Alzheimer's Association, 2017).

Globally, the incidence of AD among older people is expected to grow throughout the world from 35.6 million, recorded in 2011, to 115.4 million by the year 2050 as predicted by the World Health Organization and Alzheimer's Association (Cheung et al., 2015). Caregiving (CGing) for these persons requires significant time, energy, and money over an extended period, often exhausting resources for both the care recipient (CR) and CG (Lykens et al., 2014). Studies have shown that CGing responsibilities can lead to depression, stress, and an overall feeling of burden (Lykens et al., 2014). Evidence-based clinical studies reveal that interventions are successful in reducing stress, burden, and depression that is associated with CGing (Chee, Gitlin, Dennis, & Hauck, 2007; Chen, Huang, Yeh, Huang, & Chen, 2014; Garcia-Alberca et al., 2013).

The impact of AD upon individuals diagnosed with the disease is life-changing. Unlike cancer and other terminal diseases, AD attacks the brain first and progressively destroys and incapacitates the entire body (Lykens et al., 2014). In 2014, data from the Centers for Disease Control (CDC) ranked AD mortality as number 6 out of the 15 leading causes of deaths in the United States (U.S.). Nearly 80% of all the U.S. deaths in 2014 ranked in the top 15, with AD rates increasing annually at about 0.8% (Kochanek, Murphy, Xu, & Tejada-Vera, 2016). As AD becomes more prevalent in the global population, informal CGing rendered in the home setting will also increase (Beinart, Weinman, Wade, & Brady, 2012). Furthermore, in the U.S., the expense of CGing is over \$5,000 a year for about 18.1 billion hours of unpaid care (Kochanek et al., 2016).

The scope and impact of this global issue reinforce the importance of addressing the CGing dynamics experienced by caregivers (CGs).

Family members are often the first to notice changes in their family member's cognitive behavior and social skills, which is typically the first sign of AD (Lykens et al., 2014). Close family relations with a sense of responsibility, propel the CG into the role of CGing. Early on, as the AD diagnosis is confirmed, CGs may experience a sense of tragedy and loss for both, their loved one and themselves, as the normalcy of their lifestyle is now interrupted. The *Alzheimer's and Dementia Caregiver Center* (2017) reported that it is common for a CG to experience stages of grief such as denial, anger, guilt, and sadness, before accepting the diagnosis. The family member becomes tasked with the new role of a CG and is at risk for developing inadequate coping strategies because of the stressors inherent to CGing (Lykens et al., 2014). Moreover, McKee and Smyth reported that 80% of AD persons live in a home setting in which informal family CGs renders assistance (2013).

As researchers continue to search for a cause and cure for this terminal disease, the family and significant others who care for those stricken are at risk for inadequate coping strategies, and poor lifestyle behaviors (Laukkonen, 2016; Elvish, Lever, Johnstone, Cawley, & Keady, 2013). Caregivers are at risk for becoming physically and emotionally ill from the increased stress levels of CGing (Beinart et al., 2012; Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2008; Snyder et al., 2015). The impact of dementia affects the CR and the CG, who has this substantial role 24 hours a day. Caregivers have described their feelings as being "stressed, overwhelmed, and depressed, lacking emotional and social support" (Lykens et al., 2014, p. 1). In a meta-analysis

published in 2014, researchers "found that the CG has 23% higher levels of stress hormones and the level of their antibodies are 15% lower than non-caregivers", making them susceptible to disease and illness (Lykens et al., 2014, p. 2). High-stress hormone levels can also lead to an increase in heart rate, blood pressure, and can affect kidney function. Lower levels of antibodies in the body can affect the ability to fight infection and respond to injury. The CG may not eat or sleep properly because they must be alert and attentive toward the CR. These changes in the body can contribute to CG morbidity and mortality.

In families of a first-degree relative with AD, studies show family members experience anticipatory stress believing they too will develop the disease at some point in their lives (Cutler & Brăgaru, 2015). Evidence also shows that CGs may lose their employment because of their increased responsibilities with CGing and frequent absence from their jobs. The CG faces significant physical, mental, social, and emotional risk as they journey with AD in the role of CGing.

#### **Development of Clinical Question**

The first stage of developing the clinical question was merely wondering why friends and acquaintances were sharing CGing stories. It seemed that often the stories reflected upon the sadness and burden of losing a parent or two to AD. However, few people knew that help was available in the community in which they lived. Their stories were weighted with hopelessness and loneliness.

A quick search of CGing studies revealed that there are interventions specific to CGing that addresses several domains: the knowledge deficit of AD etiology and disease progression, skills to manage CR behaviors, social support issues, and strategies to

maintain the caregiver's health (Lykens et al., 2014). Two meta-analyses demonstrated that an improved "small to moderate effect" was achieved for CG knowledge, skills, burden, and overall well-being following an evidence-based intervention program (Elvish et al., 2013, p. 107). Lykens and colleagues (2014) further showed that interventions designed to decrease burden were effective in reducing CG burden and depression following the interventions (p<0.0001 for depression; p< 0.025 for CG burden).

Without adequate coping strategies, the CG can progress toward a state of anxiety, stress, and burnout. The likely consequence of this type of exhaustion is the placement of the CR into a long-term care facility. Typically, the goal is to keep the CR in the home setting; however, as the care recipient's ability to care for themselves decline, families are faced with the decision to place the CR into long-term care, mainly if they no longer have the appropriate resources to keep them in the home (Belle et al., 2006).

The education and skill building interventions include increasing knowledge of the behaviors of the CR, understanding CG feelings, and resources for the activity of daily living (Lykens et al., 2014). One evidence-based practice (EBP) education program proven to be most effective is *The Resources for Enhancing Alzheimer's Caregiver Health (REACH) II* intervention which is a community-based Alzheimer's support program (Lykens et al., 2014; Elvish et al., 2013; Hatch, DeHart, & Norton, 2014). The REACH program has been shown to reduce CG depression, stress, and burden through implementing a multi-component, multi-site intervention program (Hatch et al., 2014). Other programs such as the *Caring for Older Adults and Caregivers at Home (COACH)* program and the *Two-Component Psychosocial Intervention* programs have been known

for reducing CG burden with their CG intervention strategies (Garcia-Alberca et al., 2013). Studies such as these have contributed much to the foundation of establishing the evidence-based platform that specifies the interventions that will help to decrease CG perception of burden.

Across the studies, the evidence most prominent and consistent is the component of increasing the knowledge base of the CG through providing educational materials. Once the CG is oriented to the written material, their engagement in learning how to care for the CR is at peak interest (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Lins et al., 2014; Lykens et al., 2014; Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). In addition to education, telephonic follow up, teaching coping strategies, and face to face counseling was found to be an effective intervention across the studies (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Elvish et al., 2013; Hatch et al., 2014; Lins et al., 2014; Lykens et al., 2014; Nichols et al., 2011).

The formation of a clear question that includes population, intervention interest, comparison of interest, outcome, and time required to achieve the best clinical outcome (PICOT) drives the evidence search and subsequent steps in the evidence-based practice implementation project (EPIP). Therefore, the question arose, "In caregivers of Alzheimer's patients who access support resources, how does an organized caregiver self-care program compared to no self-care program affect caregiver knowledge and self-efficacy over a 1 - 3-month period?"

#### **Evidence-Based Practice (EBP) Model**

The framework that guided and supported the CG project is the *Academic Center* for Evidence-Based Practice (ACE) Star<sup>©</sup> model, which integrates research evidence

with clinical expertise, and patient preferences, as well as stimulating the quest for knowledge and clinical decision making (Dang et al., 2015, pp. 305-309) (see Figure 1). The use of the ACE Star model as applied to the CG project emphasizes the importance of searching for the best evidence and transforming that evidence into best practice with predictable outcomes for CGs (Dang et al., 2015, p. 306). Stevens (2015) describes knowledge as a form of sequential movement through five cycles representing the discovery of research as it links to clinical practice, evidence, guidelines, practice integration, and process outcomes with evaluation. The ACE Star model begins with a discovery stage that leads to the formation of the PICOT question and systematic search (Melnyk & Fineout-Overholt, 2015, pp. 10-11). The second point of the ACE Star model involves critically appraisal of the evidence, which in the CG EPIP yielded 14 articles. Thirdly, the EBP recommendations for CG intervention guidelines identified the multicomponent intervention program, like the REACH II multi-component CG program, as evidence with predictable outcomes to decrease CG burden, depression, and ill-coping behaviors. The fourth point of the ACE model is the ability to integrate the evidence into practice. At this point, the project implementation plan guides the project and its team from the beginning to the completion and sustainability of the project change. The method includes planning, budget development, stakeholder buy-in, team building process markers, and timelines. The fifth and last point of the ACE model is the evaluation phase of the model that includes outcome measurement of variables, data analysis, and preparation for dissemination of EBP outcomes, sustainability processing, possible social policy recommendation, and completion acknowledgment.

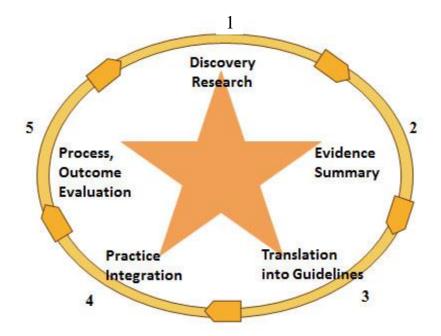


Figure 1. ACE Star Model of Knowledge Transformation<sup>©</sup>.

#### Systematic Search

Before EBP change can occur, an assessment of the internal evidence shows what is currently in place at the clinical level, the gap in best practice, and the perceived changes that may be of help to achieve best practice outcomes. The literature is systematically searched to find the best evidence by the process of reviewing research, clinical practice models, practice guidelines, and health topic summaries for best practice (Hartzell, Fineout-Overholt, Hofstetter, & Ponder, 2015).

Based on the PICOT question, keywords and phrases were used to guide the systematic search. The keywords and phrases for the caregiver project are: *Alzheimer's family caregiver, caregiver self-care interventions, caregiver self-efficacy, and REACH II.* A systematic search strategy of databases included Cochrane Library, CINAHL, PubMed, and PsycINFO. After controlling for English language vocabulary, keywords and phrases, and peer-reviewed results, a search yield of approximately 1204 articles was

found. Inclusion criteria included studies with a sample of diagnosed AD patients with an in-home adult CG. Inclusion criteria also incorporated English language publications, peer-reviewed, and no date restrictions. Exclusion criteria included studies which used pharmaceutical agents as the primary intervention for the CR, and studies that did not include an intervention. The CINAHL systematic search (see Figure A1 in Appendix A) began with the key phrase, "Alzheimer's caregivers" and yielded 663 hits. Additional keywords and phrases were caregiver self-care intervention, caregiver self-efficacy, and REACH II. Modification of the search allowed adjustment of the Boolean operators AND OR. The Cochrane, PubMed, and PsycINFO searches were performed similarly with an overall yield of 1204 hits (see Figures A2–A4 in Appendix A). An overview of the publication titles and abstract reviews further reduced the systematic search yield to 44 articles. The excluded articles included duplications, caregiver subjects other than an in-home adult, non-dementia related caregivers, and interventions not related to an outpatient program. Of the 44 remaining articles, 30 were excluded through rapid critical appraisal. Fourteen articles were included in the final cohort of studies to address the question about Alzheimer's CG interventions (see Figure A5 in Appendix A).

### **Body of Evidence**

The external evidence that supports AD caregiver interventions to decrease stress and burden, and improve self-efficacy has both quantitative and qualitative underpinning. The first phase of appraisal is the rapid critical appraisal (RCA) in which the general appraisal overview (GAO) offers the general purpose of the study, its design, aims, population, variables, data analysis, and measurements (Stevens, 2015). Another tool used in the RCA process is the RCA checklist, which is used to establish study validity

and reliability, and usefulness to practice (Melnyk & Fineout-Overholt, 2015). The studies included in the evidence cohort were the most complete for the CG project when appraised.

#### Chapter 2:

### **Critical Appraisal and Evaluation of Evidence**

Appraisal checklists were used to critically appraise the evidence for attributes across the evidence table (see Appendix B). Fourteen articles were appraised at both the quantitative and qualitative level, building the body of evidence for CG coping strategies. Several studies determined caregiver's success in coping with the role of informal CGing before the intervention and afterward (Beinart et al., 2012; Chee et al., 2007; Chen et al., 2014; Del-Pino-Casada et al., 2011; Garcia-Alberca et al., 2013). Three studies demonstrated how the multi-component REACH II EBP program was translated to a Hong Kong setting, a Veteran CG group, and a general community (Cheung et al., 2015; Lykens et al., 2014; Nichols et al., 2011). Ten of the 14 studies were purposed to determine the effect of multi-component interventions and CG response pre- and posttreatment. Lins and colleagues (2014) aimed to assess the impact of only telephonic intervention for CG self-efficacy. The study designs ranged from level I randomized control trials (RCT) to a level VI descriptive study. Across the studies, an aggregate sample of approximately 4700 CGs participated. The articles were appraised for independent variables (IV) and dependent variables (DV). The IV included a variation of education sessions, face-to-face interventions, telephonic communications, and caring skills. Dependent variables measured CG psychosocial response to CGing, knowledge gain, coping strategies, and general wellbeing. The evidence supports the most common

intervention timeframe as 6 to 24 months resulting in effective intervention outcomes (Beinart et al., 2012; Belle et al., 2006; Cheung et al., 2015; Fortinsky et al., 2008; Hatch et al., 2014). Studies also reported time in the context of session attendance instead of weeks and months (Chee et al., 2007; Chen et al., 2014). One three-month intervention study reported evidence that CG burden was decreased (p<0.017) (Chen et al., 2014). A level V systematic review of evidence acknowledged intervention plans from two hours to two years (Del-Pino-Casado et al., 2011; Elvish et al., 2013).

Across the evidence (11 of 14 studies), the most frequently used measurement tools were the REACH II RAM, Zarit burden instrument (ZBI), Caregiver Burden Inventory (CBI), and Centers for Epidemiology Depression Scale (CES-D). Data analysis of the evidence was performed using Pearson r, p-value, correlation, mean scoring, confidence interval (CI), bivariate analysis, and standard deviation. Data analysis from 8 of the 14 studies were statistically significant with a 95% CI and measured a reduction in CG burden p < 0.0083, 0.001, 0.025 and a decrease in CG depression p<0.007, 0.001, 0.009 (Beinart et al., 2012; Belle et al., 2006; Cheung et al., 2015; Del-Pino-Casada et al., 2011; Garcia-Alberca et al., 2013; Hatch et al., 2014; Lykens et al., 2014; Nichols et al., 2011). The appraisal process also helped to identify the value of patient preferences in the studies, and how the evidence is used for individual and practical ways for the CG. Study limitations were assessed, including any gaps in the research. The final cohort studies were chosen for the similarity in the measurement tools and instruments, data analysis, and conclusions that supported CG interventions as an EBP clinical recommendation.

Before considering the cohort group of articles to keep as best evidence, the studies were assessed for ethical integrity. Several studies included a brief discussion about consent and the institutional review board (IRB) process. However, some studies acknowledged that their sample of participants was CGs who were registered with an Alzheimer's organization with little or no formal IRB committee approval requirement.

#### Synthesis of Evidence

As an overview of the body of evidence, six synthesis tables were constructed that included CG population description, study design and hierarchy level of evidence, CG perception of being at risk for adverse personal outcomes, interventions used in the studies, instruments used to measure variables, and reported findings (see Tables C1–C6 in Appendix C). Many CGs are not aware of the challenges they may encounter in the CG role as based on their limited knowledge of CGing (McKee & Smyth, 2013). Acquiring, synthesizing, and using best practice evidence to plan for improvements in CGing is necessary for implementing changes that will yield beneficial outcomes for the CG.

The description of study participants is essential to the body of evidence because it helps to understand who the CG is to a population of individuals who are forced to cope with CGing (see Table C1 in Appendix C). Across the studies, the evidence indicates the average age of the family CG is approximately 64 years old, and these studies identified participants as typically of Caucasian race (Chee et al., 2007; Chen et al., 2014; Cheung et al., 2015; Fortinsky et al., 2008; Hatch et al., 2014; Lykens et al., 2014; McKee & Smyth, 2013; Nichols et al., 2011). The evidence also indicates the relationship of the CG to the CR may be a spouse or an adult child of the CR.

Three out of 14 studies used in the evidence cohort were level I, and 6 out of 14 were level II. The remaining level of hierarchy for the evidence was one level III, three-level V, and one level VI (see Table C2 in Appendix C). The mixed levels of studies are valuable to building the best evidence for the CG, not only for the strength of the RCT research but also for the value of descriptive lived experiences of CGing (Stevens, 2015).

The CG perception of the risk that is most threatening to their wellbeing is foundational to the CG project. Understanding the CG perspective is important as it identifies the areas of high need and where the project and planning need to focus (see Table C3 in Appendix C). In comparing the evidence for CG risk, 10 out of 14 studies reported CG burden as a significant risk (Beinart et al., 2012; Belle et al., 2006; Chen et al., 2014; Cheung et al., 2015; Del-Pino-Casada et al., 2011; Elvish et al., 2013; Garcia-Alberca et al., 2013; Hatch et al., 2014; Lins et al., 2014; Lykens et al., 2014). Nine out of 14 studies included CG depression as the second most reported risk measure and threat to the CG health and psychosocial status (Beinart et al., 2012; Chee et al., 2007; Chen et al., 2014; Del-Pino-Casada et al., 2011; Garcia-Alberca et al., 2013). Across the evidence table, 7 of the 14 studies reported CG stress, psychological distress, disinterest in self-care, and inadequate skills to care for the CR as a risk.

The level I RCT studies compared a control group of minimal intervention to a multi-component intervention group, to measure the effect of post-intervention stress, burden, and overall wellbeing (Beinart et al., 2012; Elvish et al., 2013). Six of the level II RCT studies support the evidence of multi-component CG intervention as evident by their use of components of the REACH II EBP program (Belle et al., 2006; Chee et al., 2007; Chen et al., 2014; Fortinsky et al., 2008; Hatch et al., 2014; Lykens et al., 2014).

Lins and colleagues (2014), although tested only one intervention, implemented frequent telephone calls to educate the CG on several topics of CGing. Ten of the 14 studies identified electronic or telephone communications as an additional component that helps to establish the body of evidence contributing to the success of CG interventions. Therefore, the evidence supports that a multi-component CG intervention program may also include multiple scheduled communications and sessions. In the absence of a face to face session, the use of telephonic communication is useful in educating the CG (Lins et al., 2014).

Across the studies, the most prevailing evidence for CG intervention is the component of written education for the CG (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Chen et al., 2014; Cheung et al., 2015; Elvish et al., 2013; Fortinsky et al., 2008; Hatch et al., 2014; Lins et al., 2014; Lykens et al., 2014; Nichols et al., 2011). Eleven out of 14 studies that were successful in decreasing depression and burden through CG intervention consistently used educational sessions (see Table C4 in Appendix C). The handbook titled; A Caregiver's Notebook published by Scott & White healthcare (2006) is a resource supported by the evidence found in studies that reference the REACH II program. The education component carried out through a structured format included face to face sessions, telephone sessions, and some group sessions (Nichols et al., 2011). The content of the education intervention included developing an individual family profile, assessing home safety, learning about social support, and managing stress (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Cheung et al., 2015; Hatch et al., 2014; Lykens et al., 2014; Nichols et al., 2011). Additional content included recognizing pleasant things for the CG, engagement in healthy living,

understanding CG feelings, skillful communications, and relating memory problems to the CR (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Cheung et al., 2015; Hatch et al., 2014; Lykens et al., 2014; Nichols et al., 2011). The final two areas of educational content inform the CG about legal and medical resource options (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Cheung et al., 2015; Hatch et al., 2014; Lykens et al., 2014; Nichols et al., 2011).

Evidence supported by the REACH II program also identifies education to increase coping strategies and general counseling as an additional component of effective CG intervention. Thirteen out of 14 studies support the coping strategy education and counseling component. McKee and Smyth (2013) level V study measured CG quality of care (QOC) of the CR, using a self-assessment mail-out, which lacks scientific research strength, yet is valuable in understanding the CG perspective.

Instruments and scales used to measure the variables were reduced to eight for the evidence synthesis because they represent the instruments more often used in the studies (see Table C5 in Appendix C). The Risk Assessment Measure (RAM) instrument includes attributes of the CES-D scale, CBI, Self-Care scale, Social Support scale, Revised Memory and Behavior Problem Checklist (RMBPC) scale, Katz Activity of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Positive Aspects of Caring, and Quality of Life scale (Czaja et al., 2009). When all the attributing instruments are combined with the RAM, 13 out of 14 studies included the RAM pre- and post-intervention measurement tool as the instrument most often used. Reference to the RAM as the REACH II measurement tool was explicitly noted in 9 of the 14 studies (Beinart et al., 2012; Belle et al., 2006; Chee et al., 2007; Chen et al., 2014; Cheung et al.,

2015; Hatch et al., 2014; Lins et al., 2014; Lykens et al., 2014; Nichols et al., 2011). The Zarit CG burden tool was also utilized in 9 of the 14 studies.

The studies reported outcomes after the CG interventions and data analysis (see Table C6 in Appendix C). Ten out of the 14 studies reported a decrease in CG burden after CG intervention. Secondly, depression and feeling positive when the burden is decreased was reflected in 6 of the cohort of 14 studies (Belle et al., 2006; Chen et al., 2014; Cheung et al., 2015; Elvish et al., 2013; Fortinsky et al., 2008; Hatch et al., 2014; Lins et al., 2014; Nichols et al., 2011).

#### Recommendation

The synthesis and analysis of the body of evidence support the recommendation that CGs who seek a structured intervention program to improve their knowledge and CGing skill can benefit as shown in the increased satisfaction in the quality of their life (Beinart et al., 2012; Belle et al., 2006; Elvish et al., 2013; Fortinsky et al., 2008). Providing education is the most prominent and effective intervention revealed across the evidence and is supported by the EBP REACH II program. The evidence also supports the use of telephonic communications as a means of providing for the education and counseling sessions when a face-to-face encounter is not possible (see Appendix D). Based on the sound evidence, all CGs who seek the educational component of support service from an Alzheimer's resource organization for CGng education and skills may find the experience beneficial.

### **EBP** Operationalized Model

Through the EBP ACE Star model, the following cycles were demonstrated:

- The PICOT was established: "In caregivers of Alzheimer's patients who access support resources, how do an organized caregiver self-efficacy program compared to no self-care program, affect caregiver knowledge and self-efficacy over a 1-3month time period?" The systematic search was performed using the databases of CINAHL, Cochrane, PsycINFO, and PubMed.
- 2. The critical appraisal of evidence, evaluation of evidence hierarchy, and synthesis of evidence yielded 14 articles.
- 3. The EBP recommendation for CG intervention to increase self-efficacy is the multi-component program like the REACH II CG program with the underpinning of CGing theoretical framework, *Advancing Research and Clinical Practice Through Close Collaboration* (ARCC) change model, and the ACE Star EBP model.
- 4. The EPIP project implementation plan guided the project team from beginning to completion and sustainability. The plan included planning, budget development, stakeholder buy-in, team building process markers, and timelines.
- 5. The evaluation phase of the model included outcome measurement of variables, data analysis, and dissemination of EBP outcomes, sustainability process plans, social policy recommendation, and completion celebration.

## **Change Model**

Dang and colleagues (2015) illustrates several evidence-based practice (EBP) models in the text, *Evidence-Based Practice in Nursing & Healthcare* by Melnyk and Fineout-Overholt. The ARCC model is one model, that is suitable for implementing change requiring education, skill building, and behavior changes (Dang et al., 2015, pp. 289-294) (See Figure 2). The ARCC model was ideal for a project involving CG burden and stress. The ARCC model addresses the educational deficit, skill needs, and emotional support of the Alzheimer's CG in sequential steps. The model also incorporates the actions of assessing the organization and its readiness for a change.

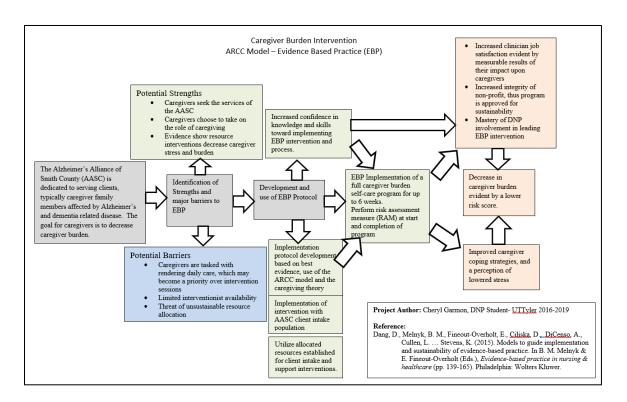


Figure 2. ARCC model of EBP change.

In the area of strengths and barriers, the established Alzheimer's Alliance of Smith County (AASC) organization has a presence within the community of being the "go-to" place for dementia-related support. A potential barrier was the uncertainty of whether the CGs who accessed the organization would be willing to engage a program over a period of 1 - 2 months. However, by using the EBP protocol, the doctor of nurse practice (DNP) prepared for both strengths and barriers through instruction and guidance.

Lastly, the pre- and post-RAM scores provided the primary data that was to be analyzed to determine outcome significance.

Overall, the components of the model are clear and potential strengths and barriers were identified before implementation. As with any project, flexibility was necessary as the team worked through the elements of implementation toward sustainable and improved CG education change. The DNP as the EPIP lead accepted the responsibility of organization and guidance for the project team members in learning the importance of trusting the EBP concepts and models to influence positive outcomes for the CG and CR.

#### **Operationalized Logic Model**

The implementation of the project is also depicted by using a logic plan. Project inputs consisted of assumptions, constraints, resources, and activities (see Figure 3). The assumptions set the foundation by which the plan progressed. It was essential to have stakeholder and industry mentor buy-in and support. The constraints were linked to time, resources, and budget. The resources included physical space for intervention, materials, and scheduling of CG education sessions. The final input was to determine who, when, and how the education components would be planned and executed, unique to the individual CG.

Projected outputs comprised of staff training and competency as interventionists, adherence to the EPIP plan, and stakeholder continued support. The impact of the outputs was classified as short term, intermediate, and long term. The short-term plan was to offer the intervention to as many CGs as possible and assure them that their feelings of stress and burden would be decreased. The intermediate plan was to maintain

the interest of the CG until all educational components and sessions of the plan was executed. Nine of the 11 CGs finished 100% of the education sessions. The long-term plan is for the continuation of the multi-component program as a viable option for CGs in the community. By incorporating the ideas of the organization's staff and using hours of operations to implement, the chance for sustainability increases as the team observe the CG benefit of reduced stress and use their CG stories to motivate others in seeking help.

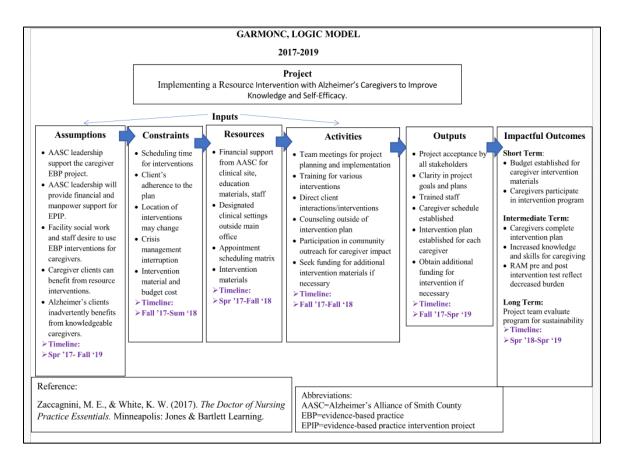


Figure 3. Logic model.

#### Chapter 3:

#### **Project Design and Methodology**

Evidence-based practice project design and methodology set the stage and guide implementation (Gallagher-Ford, 2017). The Alzheimer's clinical site is a 501(c)3 notfor-profit organization located in East Texas. The city is the county seat of Smith County, Texas, that has a population of approximately 250,000 people. The AASC gave full support to serve as the clinical site for the CG EPIP (see Figures E1–E4 in Appendix E). Alzheimer's Alliance of Smith County is governed by an executive board and board of directors. This board includes community interest leaders, physicians, and philanthropists. The service site is staffed by an executive director, office manager, client service director, development and community relations director, program director, program assistant/community health worker, and volunteers (see Figure 4). The primary goal of the organization is to meet the social needs of the clients who seek services for ADRD by walking alongside of them through the journey. The clinical site approval was given by the executive board and board of directors during a regular board session held in the fall of 2016. The executive director embraced the opportunity to assist in a project that advances the well-being of dementia caregivers with EBP focus. Along with the board of directors, the key stakeholders were identified as the executive director, client service director, industry mentor who is a Licensed Master's Social Worker (LMSW), all staff of the AASC, CGs, and the patients/care recipients.

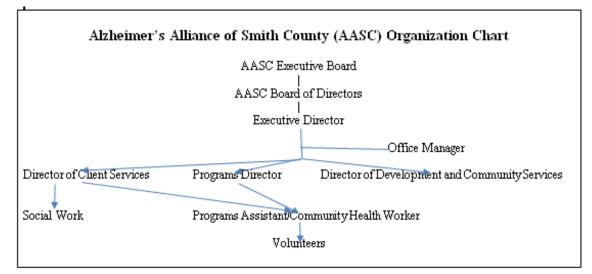


Figure 4. Clinical site organization chart.

Caregiver clients who seek services at the AASC are demographically and socioeconomically diverse; however, they share common challenges in CGing. Studies show CGs perceive they are at risk for stress, burden, and even grief as they render care to someone diagnosed with AD (Beinart et al., 2012; Del-Pino-Casada et al., 2011; Elvish et al., 2013; Hatch et al., 2014; McKee & Smyth, 2013). Studies also show interventions such as education, skill building, and coping strategies, are significant in reducing overall stress of CGing (Beinart et al., 2012; Del-Pino-Casado et al., 2011; Garcia-Alberca et al., 2013; Hatch et al., 2014; McKee & Smyth, 2013). Based on the synthesis of evidence, there is reliability, validity, and clarity for which EBP is foundational and underpins the EPIP.

#### **Project Design and Methodology**

Foundational to the EPIP's success is the EBP implementation model, theoretical model, and logic model. The five subsequent cycles or steps in the ACE Star model was used to provide structure to the implementation (Stevens, 2015). In the first cycle of

discovery, the inquiry was developed out of the awareness that many people were being diagnosed with AD and that unprepared family members caring for them were growing exponentially in numbers bringing awareness that a community need existed (Alzheimer's Alliance of Smith County, 2013). The second step in the ACE Star model is the evidence summary. The body of evidence was developed by a systematic search of the literature for sound and reliable research studies and used to formulate a plan (Stevens, 2015). Critical appraisal of the studies helped to generate a yield of 14 articles that represented a strong and coherent body of evidence. From the body of evidence, the third step of the model is the translation of the evidence into guidelines. A thorough synthesis of the evidence produced six tables of comparative studies: CG population description, level of design and methodology hierarchy, CG risk measures, interventions, measurement scales, and outcomes (see Tables C1–C6 in Appendix C). At this cycle, a well-designed plan for change is created to guide the implementation of the EBP change.

The fourth point of the ACE Star model is the ability to integrate the evidence into practice. This critical step launched the project into action. The project team became familiar with all aspects of the project with the goal being to sustain the change after the outcomes were examined. The plan included budget development with an emphasis on the return on investment, stakeholder identification, roles, and relationships, team building process markers, and timelines (see Appendix F). The fifth and last point of the ACE Star model is the evaluation phase that included outcome measurement of variables, data analysis, and preparation for dissemination of the EBP project outcome. Additional evaluative steps included; sustainability processing, social policy recommendations, and project completion acknowledgment.

### **Theoretical Framework**

The theoretical model for the CG EPIP was the Loretta Williams' *Caregiving Dynamics* (CD) model in which the needs of the CG follow the trajectory of the CR disease process (see Appendix G). Unique to this model is that the past, present, and future journey of the CR directly affects the CGs' ability to cope with caring dynamics through the disease process (Williams, 2007). The model describes the pre-AD period where CGing is not needed, and the following stage where the role of the CG becomes apparent. After the CR diagnosis stage, the CG becomes acutely aware of stressors and challenges. It is at this point that CG intervention is critical in providing the knowledge, care skills, and coping strategies necessary to render adequate and manageable care. The concept of "resource" in the model includes three attributes; empirical need, the source of supply, and perception of benefit. These attributes displayed in the present and future phase of the model may cycle back and forth as CG needs are demonstrated (Smith & Liehr, 2008).

The CD model was modified for the CG intervention project, namely the *Alzheimer's Enhanced Caregiving Related to Resource Access Model (CRRA)* which includes the concept of CGing and the concept of resource, integrated into the original CD model. The guidance of the CRRA model was to visually identify the phases of CG relationships, and identifiable needs along the trajectory of the illness. The dynamics in all three phases (past, present, future) can be categorized and measured using instruments and tools in determining individualized dynamics such as burden and depression, with implications of resource appropriateness (Smith & Liehr, 2008).

Finally, the circles in the model depict the relationship of the CG and CR past, present, and future, along with the path of the illness (Smith & Liehr, 2008). The CRRA model follows this same course in educating the CG about the disease process and anticipated CR needs. Overall, the linear trajectory unique to the model's framework defined the relationship of disease progression in comparison with CGing reliance. The model also supports the possibility that CGs may require repeated interventions as the care recipient's clinical status deteriorate.

#### **Logic Model and Implementation Guidance Tools**

The logic model guides the project in all facets of implementation, including assumptions, stakeholder buy-in, inputs, outputs, resources, and outcomes (see Figure 3). A logically thought out process keeps the team focused on the detail of implementation, measurable goals, and sustainability. The project assumptions were that the implementation team would agree that the intervention brings value and worth to the CG population and that the outcome would be favorable. As with all projects, constraints are possible, but when anticipated, can be managed without complete disruption of the project. One limitation was the unavailability of CG notebooks. The team developed a very similar notebook that included all information for all sessions. The CG project inputs included the resource of engaging the clinical site to allow the project implementation with minimum cost and maximum accommodation in scheduling clients for intervention sessions. This was achieved within the regular hours of operation for the agency.

For the short term and intermediate term, the agency did not expend any additional cost for materials or staffing, and 11 caregivers accepted enrollment into the

program. The pre- and post- RAM scores demonstrated a reduction in the stress and burden perceived by the CG which sets the stage for sustainability. Overall, the timeline was useful in projecting the start and finish of the project.

### **Additional Tools for EPIP**

There are several tools used to logically help with the project's goal attainment. A detailed implementation calendar helped identify who, what, where, how, and when the project events were to take place and the specific outcomes expected (see Appendix F). The calendar included the process markers that identified the milestones of the project, as well as alerts of delays or failures. The calendar tool was formatted to provide; date of specific activity, persons to carry out the intervention, where it is planned to take place, the manner of the communication, and immediate evaluation of the session by reviewing the anticipated outcome for the intervention.

Additional tools used was the data table and Gantt chart that helped to visually review and follow timelines, process markers and any delays that proposed a threat (see Appendix H & I). The CG Gantt chart was set to follow the EBP Star ACE model in five phases. Twenty tasks were identified as tasks for completion, and an added attribute of "end date" helped to stay on course for project completion.

# **Internal Evidence: Clinical Site**

With the intent to launch the EPIP, a clinical site was selected based on the availability of a large CG population. The AASC mission to serve clients diagnosed with AD and their CG is well known throughout East Texas. In addition to supporting the

journey for the CR, they recognize the CG who is typically a family member and is also at risk and in need of support (Alzheimer's Alliance of Smith County, 2013).

The clinical site has several stakeholders. The organization governance board and executive director can both approve and disapprove programs and projects and were very important in the planning phase for the projects' success. Additional stakeholders included the clinical site staff and client service leadership. Stakeholders also included CG clients and their CR, who contributed by sharing their story and wishes with the team. Client preference is integral to the success of the EPIP and must be considered in the planning, implementation, and completion phase of the project.

#### **Data Collection and Analysis Plan**

Baseline CG data was gathered as the CGs accepted and enrolled in the CG program. Completion data was defined as the assessment following the last scheduled education component and session. The measurement tool used in this project was the 16item RAM assessment tool (see Figure J1–J2 in Appendix J). Nine out of the 14 EBP cohort studies acknowledged the RAM in assessing CG risk of ill-coping behaviors (see Table C5 in Appendix C). This instrument includes attributes of the CES-D scale, CBI, Self-Care scale, Social Support scale, RMBPC, Katz ADL, IADL, Positive Aspects of Caring, Quality of Life (Czaja et al., 2009). The RAM instrument measures six domains related to CG risk and can predict their individualized responses to interventions and are applicable for use in evidence-based clinical projects as well as research studies. The following are attributes of the RAM instrument:

• In general, the RAM measures CG needs in the target areas of support, which is perceived to be of benefit to the CG (Michigan Dementia Coalition (MDC),

2009).

- The Zarit Burden Interview (ZBI) is a 5-point scale of self-assessment to measure personal burden from distress, social, financial, and relationship challenges associated with CGing (MDC, 2009). The ZBI will not be administered to specifically measure burden because it is a component in the RAM instrument.
- The ZBI measures the CG self-efficacy, commitment, and coping behaviors before resource interventions and afterward to determine the effectiveness of resource intervention (MDC, 2009). The ZBI will not be administered to specifically measure self-efficacy because it is a component in the RAM instrument.

The pre-intervention risk score and post-intervention risk score is analyzed to determine CG risk improvement at the completion of the intervention program (Beinart et al., 2012; Chee et al., 2007; Chen et al., 2014; Cheung et al., 2015; Hatch et al., 2014; Lykens et al., 2014). The risk scoring of low, moderate, and high can determine the CG's baseline risk of coping difficulties, and later determine the significance of the intervention by re-assessment using the same RAM instrument (see Figure J3 in Appendix J). Studies indicate there will be an improvement in the caregiver's self-rating of depression, stress, and burden. The CGs' attendance for scheduled sessions was also monitored as a variable to be measured in the outcome analysis of the data (see Table J4 in Appendix J). Correlation analysis helped determine the effect if any, that inconsistent attendance would have a negative impact.

### Synthesis of Evidence Referenced to Intervention Protocol and Guidelines

The evidence that supports the CG EPIP is crucial to the project's validity, strength, and integrity, which justifies the proposed change. Level I evidence is the most reliable evidence used in making clinical decisions, although lower levels of evidence are acceptable. This project is supported by the studies which have been published and appraised as being the best evidence for the specific interventions tested to help reduce CG stress and burden (see Appendix B). Twelve to 14 synthesized studies indicate education, supportive communication, and skill building support the CG project intervention plan representing the best evidence for predictable outcomes to decrease CG burden and depression (see Appendix D).

The protocol for the program is also strongly linked to the EBP interventions (see Appendix K). The individualized sessions had the option to be conducted at the caregiver's home or an approved alternate location such as a day club or the clinical site. The interventionists were given the opportunity to assess and select the order in which the information would be covered and the number of components per session. In addition to face to face appointments, telephonic communications were also accepted.

### **Resources Necessary to Implement a Project**

As with any project, resources are required to guarantee success in implementation. The resources were identified in four categories:

1] Capital

• Financial support is necessary for start-up expenses, marketing, training, equipment and supplies, and educational material.

- 2] Labor
  - People are required to execute the roles of the EBP team.
  - The positions for the project are the project leader, the industry leader, interventionists, and administrative support. Salaries for hours these individuals render interventions are considered a resource expense.
  - The AASC have offered the current employee's regular work shift within the hours of operation, as participants of the project team.
- 3] Facilities
  - The clinical site for the project is the AASC office building and annex buildings.
  - The clinical site is open for business between the hours of 8:30 am to 4:30 pm, Monday through Friday. Special meetings and outreach events are by appointment only and held elsewhere.
- 4] Commitment
  - A committed team shares a vision that the project is valuable and worthy to be implemented.
  - Stakeholders are identified and embrace the idea to succeed as they support the intervention plan from the beginning to completion.
  - Stakeholders are also valuable in helping the project by contributing to the financial, labor, and operational requirements for the project.

### **Project Implementation Cost and Budget**

The purpose of the projects' budget was to demonstrate the anticipated cost of the CG intervention program. With the support of the AASC, some costs were inherently absorbed by the organization's operations as its primary mission is in line with the best

interest of CGs. The cost of launching a new program independent of the AASC, but with some community support was estimated at approximately \$41,000 (see Table 1 and Figure 5).

# Table 1

Item	Description	Quantit	Cost per	Total
		у	each	
Education Manuals	REACH II	120	\$20.00	\$2,400.00
Marketing Brochure	Color tri-fold	1200	\$1.00	\$1,200.00
Postage-donated by AASC	Bulk rate	0	\$0.00	\$0.00
Manpower Hours per Month (4	Process Mail-	48	\$20.00	\$960.00
hrs.)	outs			
Annual Salary for Part-time Interventionists #1	\$1000 per month	1	\$12,000.00	\$12,000.0 0
Annual Salary for Part-time Interventionists #2	\$1000 per month	1	\$12,000.00	\$12,000.0 0
Annual Salary for Part-time Interventionists #3	\$1000 per month	1	\$12,000.00	\$12,000.0 0
Budget Total				\$40,560.0 0

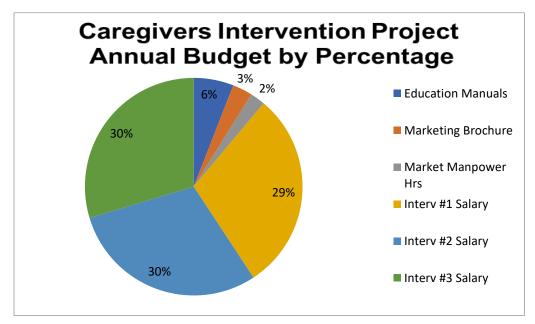
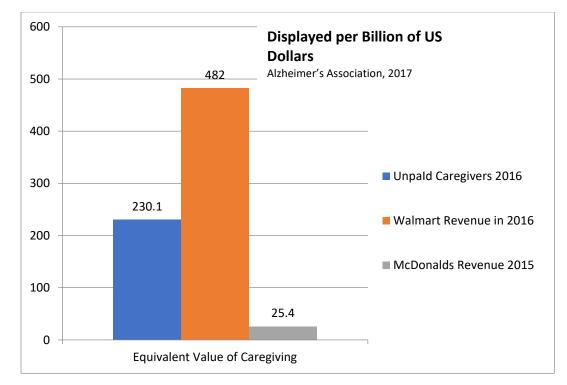


Figure 5. Caregiver intervention project annual budget.

Because the AASC is a non-revenue generating organization and operates as a not-for-profit business, most monies are generated from private donations and grants. The \$41,000 budget was set to cover the cost of materials, marketing, and labor associated with the direct expense of the CG project. The CG notebook is valued at \$20 per client, and only one notebook was needed per CG. Marketing expenses include a trifold brochure and the manpower to batch and distribute the items for mailing, delivery to primary care offices, and dementia educational events. Approximately 90% of the proposed budget expense was for the provision of three current staff members of the AASC to work as interventionists beyond their regularly scheduled work hours.

The return on investment (ROI) for this project is not depicted by an income to offset the budgeted expenses or to be considered as a revenue-generating venture. The status of non-profit community service organizations is mission-driven. The AASC mission is to walk beside those "on their journeys with Alzheimer's disease and dementia-related illnesses" (Alzheimer's Alliance of Smith County, 2017). However, data indicates that approximately \$230 billion worth of unpaid in-home care is rendered by CGs (see Figure 6). If not for CGing in the home setting, those dollars would become an expense of insurance providers and the federal healthcare system through home care services, frequent inpatient hospitalizations, and early admission to long term care facilities (Fortinsky et al., 2008). Training and equipping CGs to continue the role of CGing in the home saves the government, community, and individuals money. According to the *Genworth 2017 Cost of Care Survey* (2017), the monthly cost of individual long-

term care in a nursing home is approximately \$6,000. Over the course of a year,



insurance or government tax funds, or private payers will pay \$72,000 for one person.

Figure 6. Reported value of unpaid caregiving.

If funding is needed for sustainability, the monthly expense of a program can be pro-rated amongst several CGs, and the savings would offset an operational budget. The overall benefit of the Alzheimer's CG project is to help develop a healthier community, especially for those families who are engaged in caregiving full time. Of the CGs who care for a dementia person, 35% report that their health has declined due to the burden of caregiving versus 19% of caregivers of non-dementia persons (Alzheimer's Association, 2017). A decline in a caregiver's health leads to even more money spent to maintain the health of the family. If not for the generosity of the AASC organization, the cost to launch the CG project would have been significantly more than the proposed budget. The expense related to the clinical site's overhead (utilities, rent, and general business operations) was absorbed by the AASC's operational budget. The in-kind value of the operational cost of the CG program as a "stand-alone" service would have cost more than of \$100,000 annually.

#### **Stakeholder Identification and Market Focus**

The AASC served as the clinical site for the EPIP. The primary stakeholders included the AASC executive board and board of directors who are actively engaged in the operations of the organization. The executive director and LMSW (industry mentor), along with employees of the AASC, worked closely to implement the EPIP. The informal stakeholders include several community leaders who are members of the board of directors and several special interest individuals who represented families who have had the experience of living with someone with AD and continue to serve to ease the burden of CGs by supporting the non-profit organization. All stakeholders unanimously support the activities that directly impact the burden of CGing. Other stakeholders include the CG, the CR, and the DNP project leader (see Appendix L).

The market population for the project is primarily for those who are CGs for a dementia-related family member living in the home setting. These CGS are most likely found accessing the AASC, healthcare systems such as hospitals, home health, long-term care, and physician offices. One of the benefits of this project is that it is of no charge to the caregiver. That alone helps to lift the burden of CGing.

### **Chapter 4:**

#### Results

The next logical step following the execution of an EPIP is to evaluate the outcomes of the implementation process and determine if there is benefit from the change (Melnyk, 2016a). This chapter aims to review the completion of the intervention and appropriate analysis of the data.

### **Process and Completion**

Based on the synthesis of research evidence, the successful process steps for the Alzheimer's CG project included comprehensive education about the disease prognosis and progression, care recipient behaviors, caregiving skill building, and identification of resources that are helpful for the chronically ill elderly adult with AD and ADRD (Beinart et al., 2012; Belle et al., 2006; Chen et al., 2014; Elvish et al., 2013; Hatch et al., 2014; Lykens et al., 2014; Nichols et al., 2011). The *Caregiver's Notebook* developed by the REACH research study was used specifically for the needs of the AD caregiver and was used as a guide for all instructive categories within the EPIP program (Cheung et al., 2015; Lykens et al., 2014; SAMHSA, 2007). A comprehensive list of the project actions and expected outcomes were evident by the synthesized evidence that defined the EPIP (see Appendix D for more information on the synthesized evidence).

The project steps included offering the CG the multi-component education program and the performance of a pre- and post-intervention test. The RAM tool tested the degree of burden and stress of the CG before the intervention. The same RAM tool upon completion of all components of the program assessed the post-intervention level of burden and stress for comparative data analysis.

The industry mentor's credentials as an LMSW with extensive training in dementia care including the *REACH* program also had over five years of experience with the ADRD and CG population. The role of the industry mentor as a stakeholder was vital in driving the project toward short-term, intermediate-term, and long-term sustainable goals. Worth mentioning was the industry mentor's guidance in determining when to adjust the plan based upon the AD person and their caregiver's personal and unique dynamics. An example was the need for flexibility in the order that the CG education sessions were to occur. Instead of following the CG notebook's table of content order, the individualized implementation plan was adjusted to fit the order of the caregiver's greatest and most significant need. A change in the process such as this was more logical for the CG client and the experienced interventionist. As a part of the EPIP plan, the DNP leader prepared adequately for adjustments by carefully identifying assumptions, constraints, inputs, and outputs that imposed a potential risk to the implementation (see Figure 3 for the components of the logic model). It is also noted that the risk of allowing the interventionists the freedom to carry out the educational sessions in the order in which they determined best, became a priority for the team and was viewed as an acceptable action in order to meet the individualized needs of the CG (Chee et al., 2007). An added benefit is that the flexibility in the order of the education sessions encouraged the clinical site staff to use professional judgment as they interacted with the CGs. The autonomy of

using professional judgment helped the EPIP team as they accepted the changes in their processes and prepared them for the sustainability of the change.

#### **Data Analysis Results**

Data collected by the industry mentor (lead data collector) commenced at the time the CG agreed to enroll in the multi-component education, skill, and resource program. The data collection for the EPIP included demographic information, RAM assessment tool, and an attendance roster. The data collection process began once the CG sought assistance from the AASC and agreed to be evaluated and tested. Demographic information was recorded describing the CR and the CG.

The analysis plan included data from the pre- and post-comparison of a single CG who participated in the multi-component intervention. The parametric statistical test was appropriate for testing the difference between the same variable at two points (Sylvia & Terhaar, 2014; Dallal, 2005; Social Science Statistics, 2018). The risk scoring of low, moderate, and high determined the caregiver's baseline risk of coping difficulties, and later, after the intervention assessed the significance of the intervention (see Figure J3 in Appendix J) for the numeric scoring points in the categories of the tool). The paired *t*-test and *p*-value calculation identified the statistical significance.

The principal data collector (industry mentor) recorded the data using the attendance tool, RAM assessment tool and recorded demographics of the CG. The data demonstrated uniformity and consistency. The presentation of the data set was logical, understandable, and captured the primary results of the EBP change.

For the pre- and post-intervention measurement, the body of evidence, supported the power data analysis as a level of significance or alpha. In this analysis, the data tested

was in support that the null hypothesis (no significant change) is rejected (Sylvia & Terhaar, 2014). The common *p*-value is <0.05 which calculated that there is less than a 5% chance that the outcomes data is in error (Sylvia & Terhaar, 2014).

The number of participants in the intervention program was 11 and data was collected in uniformity (see Table 2). There were 73% of females and 27% males. The average age of the caregiver was 61 years old, and the average completion of all educational sessions were 7.6 out of 8. Three caregivers only attended 6 to 7 sessions, as their CR was admitted to a dementia community before they completed the sessions.

Participants	Identifier	A.c.o	Gender	Pre RAM	Post RAM	Difference	Sessions Attended	Care Recipient Placed?
		Age						
1	J49	69	F	23	18	5	8	N
2	S53	65	F	31	12	19	6	Y
3	D42	76	М	21	13	8	8	Ν
4	M59	59	М	12	10	2	8	Ν
5	C57	61	F	19	12	7	7	Υ
6	H65	53	F	19	13	6	8	Ν
7	T59	59	F	14	12	2	8	Ν
8	A76	42	F	31	8	23	7	γ
9	B50	68	F	20	11	9	8	Ν
10	K64	54	F	22	18	4	8	Ν
11	L50	68	М	27	12	15	8	Υ
TALLY		61.272	3M/8F	21.727	12.636	9.090	7.636	7N/4Y
		avg					avg SESSIONS	
		AGE	M=27%				KEPT	N=64%
			F=73%					Y=36%

Table 2 *Participant Data* 

The mean Pre-RAM score was 21.7, and the mean Post-RAM score was 12.6, a reduction of 9.1 points in the RAM assessment. A range of 12 to 27 is a moderate risk for ill coping patterns, with a high range of 28-40 for CGs who present in a crisis. The post-intervention showed a mean reduction in the moderate risk category at the lowest score in the range. A *t*-test calculator for two dependent variable means was useful in calculating the *t* and *p* values. At the significance level (p = .05) and a two-tailed

hypothesis, the data was subjected to statistical testing (see Appendix M). The purpose of the data analysis was not to mimic research but to substantiate that the recommended EBP to decrease CG burden is sustainable, and that significance is obtained (t = -4.3298546; p=.00149) indicating that this may be appropriate to implement in other settings (Social Science Statistics, 2018) (see Appendix M).

The review of the data also included anecdotal comments from CGs and interventionists. The mitigating factor that threatened the data validity was the high chance of the participant's bias in responding to the questions. The interventionist commented that some of the participants presented with a more obvious display of stress than what they self-recorded themselves as being. Response bias is the belief that individuals often respond to subjective questions in a way they anticipate they should, rather than an accurate reflection.

### **Implications and Impact**

The implication for the EPIP is that healthcare professionals become aware of a population at risk for situations of chronic stress and the problems related to their health from the effects of continuous stressors such as in CGing. Primary care providers can then plan for successful in-home CGing that would include a referral to an Alzheimer's or dementia organization for EBP multi-component education intervention. Health care policy is potentially impacted through the realization that caregivers are a population at risk and provisions should be made possible to assist with both the patient affected by AD and for their CGs. Such resources will not only save federal dollars by avoiding early institutionalization of persons with AD, but it may help in the care coordination of the in-home CGing relationship and the caregiver's needs (Cherry, Connolly, & Scott, 2018).

### **Chapter 5:**

## Discussion

#### **Discussion of Results and Impact**

The evidence shows that CGs, in general, perceive the risk which most affects them, as the state of not knowing how the AD will affect their family member who has been diagnosed (Chen et al., 2014). For the CG, the unfamiliar role of CGing is manifested as feeling burden and stress, along with developing trial and error ways of coping. This EPIP provided the interventions that are proven to significantly reduce the feeling of stress and burden and increase the positive coping behaviors required to deliver care to the CR effectively. The evidence is consistent across the studies in showing that there is a reduction in stress when the CG is educated, skilled, and socially supported as they live through the CGing journey. The significance of lower levels of stress and burden has a positive impact on the caregiver's health and wellbeing, in addition to the CR successfully remaining in the home setting for a more extended period (Belle et al., 2006; Cheung et al., 2015; Elvish et al., 2013).

#### **Discussion of Sustainability Plans and Implementation**

The plan for sustainability was to show the benefit of a multi-component education program for CGs in reducing their stress and burden, thus improving their knowledge about ADRD and improving their self-efficacy. Caregivers seek help when they need it. Some seek help upon learning of the care recipient's diagnosis, and some seek help almost too late. Regardless of when they seek help, they are in a place of stress and feeling overwhelmed. Over time, they become at risk for physical, mental, and emotional sickness. This can be harmful to themselves as well as the CR.

The clinical site already has in place some of the components of education, skill building, and resource counseling. The clinical site policy change is to offer and provide a purposefully coordinated program for CGs who test *moderately high - high* in the RAM scoring. An annual report consisting of total participants and RAM score analysis will be reported to the Board of Directors. Evidence-based practice will strengthen the organization's presence in the community, including a catalyst for nonprofit support.

#### **Implications of EPIP Results**

**Community and organization.** Currently, the AASC has three trained interventionists who can assist in the caregiver's multi-component education program. No additional monies were spent for the pilot project, although it is predicted that CGing for ADRD persons will steadily increase over the next few years, tripling in the United States by the year 2050 (Alzheimer's and Dementia Caregiver Center, 2017; Lykens et al., 2014). An anticipated increase in referrals will increase the demand for more staff or creative ways of providing EBP CG support in the future. The challenge for small not-for-profit organizations is to re-assess their infrastructure and needs to meet the growing demand for CG referrals. Providing a self-care program can also equip and empower CGs in becoming better able to handle behaviors and make appropriate CGing decisions without relying on the AASC for crisis help. The EBP multi-component education program will free up more time for new referrals to be processed. Another sustainability

option is to offer a one-hour CG multi-component education session twice a month. The schedule would include volunteers such as CGs who can share their experiences and help to instruct others. These meetings would not be support groups, but formal educational intervention sessions with time allowed for open discussion.

**Patient and healthcare**. Evidence-based practice CG intervention once implemented, equips the CG with the knowledge to coordinate the care of the CR. The coordination of care for the elderly and those chronically or terminally ill such as with AD, continue to challenge the health care system. Symptoms of AD are subtle for a few years until there is a change in mannerisms and memory. Known as a disease of the elderly, primary care providers can help with early screening for this disease, and when appropriate an early referral to organizations such as the AASC. Currently, care coordination services are coded using the G0505 code for billing dementia assessments (Alzheimer's Association, 2017). The aging population is entitled to a dementia assessment that is much needed and can be billed for reimbursement annually.

Care recipients and CGs, both benefit directly from care coordination. However, implementation and benefits are not clearly defined. The description and detail of care coordination, who coordinates the care, and who pays for it, continue to be crafted (Schwartz, 2016). As mentioned earlier, economically, the equivalent cost of unpaid caregiving is annually over \$230 billion in the U. S. (Alzheimer's Association, 2017). The cost of care for dementia patients is about three times more than a non-dementia aging adult and is related to frequent hospital admissions (Cherry et al., 2018). Medicaid dollars are twenty-three times higher when a dementia person is admitted to a long-term care facility (Cherry et al., 2018). Therefore, there is an excellent benefit financially, for

insurers in keeping cost contained by coordination and maintaining the AD person in the home setting with a CG.

A more organized system leads us into considering the stakeholders who help to implement care coordination. In-home CGs, ADRD persons, primary care providers, care coordinators, and assistive services are the primary providers and users of care coordination. Once the primary provider makes the assessment, a plan of care is developed encompassing the EBP multi-component education, skill building, and resource allocation program with a network of coordinated efforts (Lemieux-Charles et al., 2002).

Nursing and advanced practice nursing. The implications of the EPIP results toward nursing and advanced practice nursing, is to be acutely aware of the dynamics of CGing and to include in the plan of care for AD persons, information that helps patients thrive in a home CGing setting. It is prudent to assist the AD person and their CG with resources for care coordination to include a dementia support organization. Moreover, the DNP expert is equipped to teach nursing and health care systems how EBP change can provide sustainable outcomes for any population of people including the ADRD persons and their families.

## **Key Lessons Learned**

The key lessons learned from the EPIP are three-fold. First, when appraising the evidence, anecdotal thoughts that help to frame the tone of the study could be included. Such will help to determine if the study exhibits a tone of innovation, technicality, traditional logic, or science. Later, during the design phase of the EPIP, there was a need for evidence that supported attributes of a multi-generational team

impacting an economically diverse population of CGs. As I scanned the evidence table, it would have been helpful to examine anecdotal notes along with the appraisal components.

Secondly, when working with populations of people, it is helpful to find what motivates them to change or accept change. Although the design, methodology, theoretical component, and models were selected, the actual project team were selfmotivated by reasons other than what was expected and planned. Their ideas were much better and broader in scope. The caregivers' motivation to improve their self-efficacy was sometimes complicated by co-dependence, guilt, and fear of obligation. For future projects, introducing the concept of *motivation* would be beneficial.

Thirdly, including the project team in each step of the EPIP model is vital. The primary interventionist (who was most experienced in dementia care), embraced the plan and yet did not hesitate to adjust the sequence of educational sessions and the method of providing the education, such as on-site sessions and telephone follow-up. Remembering the logic model's assumptions and constraints, the DNP leader would be better prepared to adjust the plan to fit the clinical site's culture.

### Conclusions

One caregiver's testimony is that he wished the program had been offered earlier in the CGing journey. Comments such as his were very common, although, the CG often experiences a period of denial in which they deny the need for help. So, there must be another component of the CG self-efficacy question.

The evidence supports the multi-component intervention for CGs to improve their perception of stress and burden. The intervention was significant

amongst the CGs of the AASC. The next challenge for this population is early screening and early referral. As primary care physicians and nurse practitioners perform annual assessments, it is beneficial to incorporate a dementia screening which is billable under the Medicare insurance. If dementia is a suspect, further testing should be offered. In such, the CGing relationship might begin earlier than desired, but AD research and treatment is progressively better, and the CG can prepare with the CR, how the journey will affect them both.

By empowering CGs in their self-care, ADRD persons will benefit from the competence and love of those closest to them. The journey will continue, and the care recipient's health will decline, but the voice of the CG will speak loudly as to how the multi-component education, skill, and resource program made a difference in their family lives and sustained them in the AD journey.

#### **Recommendations for Dissemination**

Dissemination of EBP change is essential to creating an environment of improved healthcare quality as research becomes a practice with the predictability of success (Melnyk, 2016b). Advanced practice nurses are equipped to advance the practice of nursing through EBP knowledge and EPIP leadership. As planned, a final presentation will be conducted for the appropriate DNP faculty at the University of Texas at Tyler, followed by a formal presentation to the Board of Directors for the AASC (major stakeholder). Also, a power point presentation will be presented at a monthly staff meeting for the clinical project team.

Dissemination will also occur on a scholarly level. A manuscript for publication is prepared for submission. A poster abstract has been submitted for the 2019 Texas

DNP Inaugural Conference in Austin, TX. Presenting a poster to a target audience is an outstanding way of increasing the knowledge base of EBP improvements and sharing how the burden of CGing can be decreased (Melnyk, 2016b).

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Appendix A:

Literature Search

Logo - Link to Search	Searching: CINAHL Complete   Choose Databases		
	"Alzheimer's caregiver"	Select a Field (option	Search Clear ?
	AND - caregiver self care interventions	Select a Field (option	
	AND - caregiver self efficacy	Select a Field (option •	
	OR - "REACH II"	Select a Field (option	+ -
	Basic Search Advanced Search Search History	•	

#### Search History/Alerts

S S	Select / deselect all Search with AND Search with OR Delete Searches						
	Search ID#	Search Terms	Search Options	Actions			
	S4	"Alzheimer's caregiver" AND caregiver self care interventions AND caregiver self efficacy OR "REACH II"	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (21)	🗹 Edit		
	S3	"Alzheimer's caregiver" AND caregiver self care interventions AND caregiver self efficacy OR REACH II	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (663) 🕧 View Details	Edit		
	\$2	"Alzheimer's caregiver" AND caregiver self care interventions AND caregiver self efficacy AND REACH II	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (0) 👔 View Details	🗹 Edit		
	S1	"Alzheimer's caregiver" AND caregiver self care interventions AND caregiver self efficacy	Limiters - Peer Reviewed	Q View Results (2) 🚺 View Details	🧭 Edit		

Robert R. Muntz Library

Figure A1. CINAHL search history.

wiley Online Library				
Cochrane Library	Trusted evidence. Informed decisions. Better health.		1	Log in / Register 💿
Search	Search Manager	Medical Terms (MeSH)	Br	owse
To search an exact word(s) use quotation marks, e.	g. "hospital" finds hospital; hospital (no quotation marks) f	finds hospital and hospitals; pay finds paid, pays, paying,	, payed)	
Add to top				•
😑 Edit 🕂 #1 "Alzh	eimer's caregiver"		1+1	1
- Edit + #2 careg	iver self care interventions		THE	<u>501</u>
🕞 Edit 🕂 #3 careg	iver self efficacy		TH	408
	d #2 and #3		TH	1
🕞 Edit 🕂 #5 "REA	CH II"		111	<u>0</u>
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Save strategy				
Strategy Name	Save Strateg	y		
Comments				

Figure A2. Cochrane search history.

S NCBI Re	isources 🕑 How To 🕑	<u>cgarmon3</u>	My NCBI	<u>Sign</u>
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MeSH Adva	nced Search Builder			
	Use the builder below to create your search			
	Edit		<u>Clear</u>	

Builder	
All Fields	Show index list
AND  All Fields	Show index list
Search or Add to history	

History Download history Clear history Add to ltems Search Query Time builder found Search ((("Alzheimer's caregiver") AND caregiver self care interventions) AND caregiver self efficacy) OR "REACH II" <u>2</u> 11:43:39 <u>#3</u> Add 0 11:42:38 <u>#2</u> <u>Add</u> Search Alzheimer's caregiver 0 11:42:26 <u>#1</u> Search "Alzheimer's caregiver" Add

# *Figure A3.* PubMed search history.

	arch History/Alerts I Search History   Retrieve Searches   Retrieve Alerts   Save Searches / Alerts										
S	elect / dese	lect all Search with AND Search with OR Delete Search	es		<b>Refresh Search Results</b>						
	Search ID#	Search Terms	Search Options	Actions							
	S11	AVD Self-efficacy AND Adult caregiver of adult OR "REACH II"	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (25) 👔 View Details	🗹 Edit						
	S10	"Alzhemer's caegiver" AND ( interventions or strategies or best practices ) AND Self-efficacy AND Adult caregiver of adult OR "REACH II"	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (25)	🗹 Edit						
	S9	AD "Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND Burden OR "REACH II"	Limiters - Peer Reviewed Search modes - Find all my search terms	Q View Results (25)	🗹 Edit						
	S8	"Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND Burden OR "REACH II"	Search modes - Find all my search terms	Q View Results (35) 👔 View Details	🗹 Edit						
	S7	AD "Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND Burden OR "REACH II"	Limiters - Linked Full Text Search modes - Find all my search terms	Q View Results (2) 👔 View Details	🧭 Edit						
	S6	"Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND Burden OR "REACH II"	Search modes - Find all my search terms	Q View Results (35) 👔 View Details	🗹 Edit						
	S5	"Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND Burden OR REACH II	Search modes - Find all my search terms	Q View Results (1,044) View Deta	ils 📝 Edit						
	S4	Alzhemer's caegiver" AND Intervention strategies AND Self-efficacy AND	Limiters - Linked Full Text; Publication Type: Peer	Q View Results (8,654) 🚺 View Deta	ils 📝 Edit						

Figure A4. PsycINFO search history.

P= Alzheimer's CG who access support services I= Organized CG self-care program C= No self-care program O= Affect CG knowledge and self-efficacy T= Over 1-2 months or greater

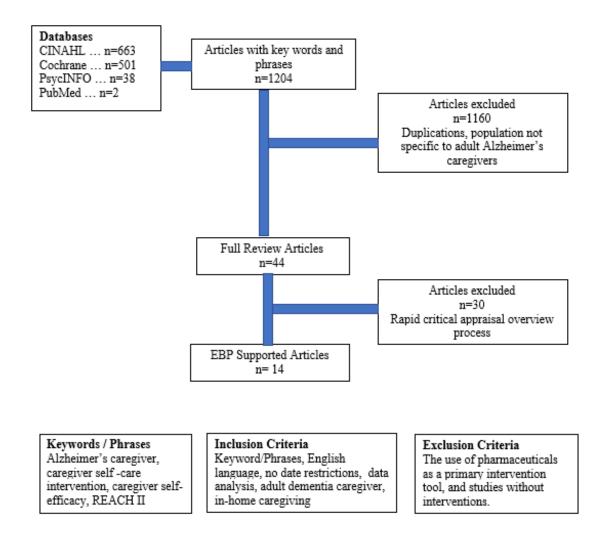


Figure A5. Flow diagram of systematic search and study selection process.

Appendix B:

**Evidence/Evaluation Table** 

Evidence / Evaluation Tables – Caregiver Burden, Interventions, Self-efficacy	
Used with permission, © 2007 Fineout-Overholt	

Citation: author(s), date & title Beinart et al., 2012 CG burden & psycho ed interv in AD	Purpose of study Examine +/- aspects of CGng from CG and CR	Conceptual framework Not listed	Design/ method RCT SR Method LOE I Synth of evid RCT	Sample /Setting N=8 studies 1376 subj 6 to 24 months.	Major variables studied and their definitions IV 1: Face Interv IV 2: Phone Interv DV: Measurement of CG response • effects CGng • in social • psych • financial • physical challenge	Measurement of major variables Study synthesis MMSE, PIP, SET tools	Data analysis • Pearson r	Study findings IV: DV r= ↓depress=p- 0.007 ↓bother =p- 0.04 ↓ anxiety =p- 0.01 ↓ burden =p- 0.0083 Narrative format • - effects • in social • psych • financial • physical challenge	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) <u>RECOMMENDATIONS</u> LOE 1 Strengths: 55 references listed to support study; Interventions recognized in other studies Weaknesses: Study findings in narrative format Conclusion: Some lack of standard study design Recommendation/ Implication Pract. Tailor interv to subj Consider drug therapy as adjunct CG edu, Healthcare Worker support Pt interaction, medication use
Belle et al. 2006 Enhancing qual of life of dementia CG from ethnic grp	Determine diff in CG support by multicomp interv w phone +, vs ed material and 2 calls only meas by depress rate and CR institution admit.	Unknown	RCT Lev II	N=642 Rand to interv and min interv Using REACH II model Interv home, phone 6 months	<ul> <li>IV: Interv</li> <li>depression interv</li> <li>burden interv</li> <li>self-care interv</li> <li>social support interv</li> <li>prob behave interv</li> <li>IV 2: Control</li> <li>Ed material</li> <li>2 phone calls</li> <li>DV: CG response to interv</li> </ul>	<ul> <li>Depression=CES-D</li> <li>CG burden=Zarit</li> <li>Self-care=0-1 scale</li> <li>Social Supp=4 pt scale of 10 items in 3 domains</li> <li>Prob Behav=RMBPC</li> </ul>	Depress= I-12.6% C-22.7% P=0.001 Institu adm. I-4.3% C-7.2% P=0.118	Mult component interv for CG increase quality of life.	LOE II Strengths: 33 references listed to support study Interventions Weaknesses: Refer to web version PubMed Central for supplementary material Conclusion: Multi-comp interv including phone is significant in decreasing depression. Recommendation/ Implication Pract.: Individualize interv to subj Phone intervention valuable Materials to ed CG, along with several scheduled follow-ups may decrease CG depression.

dementia caregivers	Purpose of study Examine CG socio-demo & psycho charc, patient illness severity, & treatment implement as predictors of CG adherence to a skills training interv to help families manage dementia care problems at home.	Conceptual framework Lichstein treatment implementation framework Health Belief Model Social Co genitive Theory Trans theoretical Model of Change.	Design/ method RCT Lev II Identify predictors of CG ad- herence as it relates to skill building skill interv.	Sample /Setting N=105 CG ran- domized to HESBP using the REACH data sample Requir attend at least 4 of 6 interv	Major variables studied and their definitions IV: Predictor: • CG socio demo • CG psych • Pt illness severity • Treat delivery • Receipt DV: • Adherence • Treat implem char	Measurement of major variables Predictor: Avg of 27 strategies (median of 76%) of 18 most used. Predictor: • CG charac: age, gender, race, CG relationship, • CG psych: CES-D, CAFU, ADL • Illness sever: MMSE, RMPBC • Tx Deliv: TEI • Tx Receip: # of contacts • Adherence: attend of 7 to 9 skill building interv. • Treatment implement - avg time therapeutic techniques used	Data analysis • Univariate stats • CG health: B=1.70, p=.000 • CG psych: B=5.04, p= .068 • Tx deliv: B=6.16, p=.004 • Tx receip: B=7.5, p=.000 • Depress: M=13.5±11.9 • CR demo: MMSE &RMBPC 11.8±7.2 and 9.4±3.8 • CG pos engage w tx: ESP (M=41.6±5.0)	Study findings If interv is delivered & recvd as intended tx adherene is enhanced. CG with better health used more tx strategies. CG with poor health may benefit from learning strategies to care for self Strategies of role play, tx dosage, # prob areas = sig predictors of adherence. Factors without predic were CR cognitive status, prob behaviors.	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS LOE II Strengths: References used 26 Identify factors of predictors of adherence In studying dementia CG interv to better cope with CG stress, this study supports identification of the predictors of adhering to skill-building interv of the role they are in as CG of a family member. Weaknesses: interventionists provided data w poss bias (added variance component to regress analy) Conclusion: Data suggest interv should attend to CG health, use instruct techniques and allow enough support to address problem areas. Recommendation/ Implication Pract.: The benefits of "predictor identification" is to help the CG engagement in various stages of CGng and for clinicians to support the CG in those stages. Like Kuebler-Ross stages of stress may be helpful for CG wellbeing.
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Citation: author(s), date & title	Purpose of study	Conceptual framework	Design/ method	Sample /Setting	Major variables studied and their definitions	Measurement of major variables	Data analysis	Study findings	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS
Chen et al. 2014 Effect of coping interv on CG of dementia.	Eval effect of coping strategy intervention for dementia CG		RCT Lev II	N=46 Interv grp Control grp w no interv 3 months	IV Interv: CG Interventions Bi wkly visit 6 sessions 1-know of dementia 2-support serv 3/4-care skills 5-CG self-care skills 6-CG support syst. IV: Control: "usual" treatment of CG DV: CG knowledge and coping strategies	<ul> <li>RMBPC&gt;24 item CG assess of the severity of the CR dementia</li> <li>WCCL-R&gt;42 item CG assess of +/- stress in CGng</li> <li>CBI&gt;burden</li> </ul>	<ul> <li>CBI=p0.017</li> <li>WCCL-R</li> <li>Prob solv=p</li> <li>0.007</li> <li>Seek Social=p</li> <li>0.04</li> <li>Blame Self=p</li> <li>0.989</li> <li>Wishful=p</li> <li>0.096</li> <li>Avoid=p 0.543</li> <li>Diff</li> <li>p=0.007(prob focus)</li> <li>p=0.04 (social support)</li> </ul>	CBI=p0.017 WCCL-R Prob solv=p 0.007 Seek Social=p 0.04 Blame Self=p 0.989 Wishful=p 0.096 Avoid=p 0.543 CG w interventions reported decreased burden. Individual psychosocial and education intervention can help CG to adopt more problem- focused and social support coping strategies to reduce CG burden.	LOE II Strengths: 23 references cited. Abstract clearly describe study. Keywords: caregiver burden, coping strategies, dementia, problem-focused cooping, social support Weaknesses: Small study size Conclusion: CG w intervention reported \burden as a result of \coping strategies Recommendation/ Implication Pract.: Interventions help CG adopt prob-focused & social support strategies. Does not help to reduce negative coping strategies.
Cheung et al. 2015 Multcomp interv enhance dementia CG well-being & reduc behave prob HK	Examin effect of translated vers of REACH II in HK serv deliv context	Translational	Lev III quasi-exp w no random Pre/post interv no control grp	N= 201 CG using REACH data sample 6-month interv	<ul> <li>IV: REACH II translational interv prog</li> <li>DV: Pre- &amp; Post- test of domains of CG burden Disease ed CG health</li> </ul>	Depress scale Zarit burden int PAC Rev mem/behavior prob chk list	SPSS Depress, burden, PAC Ps<0.001 ↓depress to behave Z=-3.30 P=0.001 CG bother: Memory	Only 17.3% discon rate Mean demo: female 35-89 yrs, spouse, 5+ yrs of CGng Stat imprv (ps<0.001) in depression, subj burden, PAC	LOE III Strengths: 37 references listed to support study Weaknesses: There was not a control group CG low education limited understanding of written materials

Citation: author(s), date & title	Purpose of study	Conceptual framework	Design/ method	Sample /Setting	Major variables studied and their definitions	Measurement of major variables	Data analysis	Study findings	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS
translat REACH II					CG well-being Behav prob		Z=-2.93 P=0.003 Depress Z=-4.64 P=<0.001 RAM: CG risk P<0.005 RAM: Self-care P=0.054	Reduc in depress related behave prob (Z=-3.30, p=0.001) Sig improve: Educ, safety, CGng, Social sup, emotional well-being, health (p<0.005, except self-care (p=0.054)	Conclusion: Statistically sig improve w depress, burden, PAC Recommendation/ Implication Pract.: One of first cross cultural translational REACH II based CG interv Benefit of this article was to eliminate Western cultural bias. The researches did a great job in developing the translational framework which included some modifications inherent to the Chinese culture and norms. The basic concept of interventions over a period was maintained and the data analysis supported the positive outcomes such as in the United States study.
Del-Pino- Casado et al. 2011 Coping and subjective burden in CG of older relatives: a quantita systematic review.	Determine SB coping strategies from CGng.	Caregiver burden w Lazarus & Folkman and Transactional Stress Theory	SR Method: Cross sect Level 5 SR of quality studies	N=10 studies 1116 subj	IV Coping strategy effect DV subj burden	Subj buden •Zarit •COPE •CBI •Screen for CG burden Coping Folkman & Lazarus, Health & Daily Living •Self-control sched •Revised ways of coping *CRI	Avoid: Pearson r 0.98; 0.43; 0.34 p=0.0009 p=<0.001 p=0.001 p=<0.05 Emotion focused: P<0.05 P=0.001 Problem focused: P=<0.05 Approach: P<0.05 P<0.001	+ Assoc avoid/coping and SB CG benefit from nurse interv to help promote quality of life for home CG.	LOE V Strengths: 77 References; Similar analysis instruments; Similar measurement scales/tools. This study referenced Melnyk & Fineout-Overholt (2005) hierarchy of evidence. Weaknesses: Not all inclusive of other coping strat Title confusion: quantitative SR of qualitative sudies Conclusion: + association between avoidance coping and subj burden (SB)

Citation: author(s), date & title	Purpose of study	Conceptual framework	Design/ method	Sample /Setting	Major variables studied and their definitions	Measurement of major variables	Data analysis P<0.0001	Study findings	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS Recommendation/
									Implication Pract.: Nursing to approach SB with an approach to coping skill set

Citation: author(s), date & title Elvish et al. 2013 Psych interv	Purpose of study Psych interv for CG of people with	Conceptual framework Stress mediation framework	Design/ method SR Method:	Sample /Setting N= 16 studies	Major variables studied and their definitions IV: CG EBI • Psychoed	Measurement of major variables Psychoed skill bldg ● ↓distress ● ↑depression mgmt.	Data analysis Synth Quality scoring not clearly	Study findings • Psycho skill + 66% • Psych ther	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS LOE I Strengths: 39 References. Detail in synthesis table
for carers of people w dementia: systematic review of quanti and qualita evidence	dementia	Theoretical ideas of stigma, culture esp.	Level I Synthes- quanti (RCT) & qualita [used quanti data]	RCT	<ul> <li>b) and b) and</li></ul>	<ul> <li>↑self-efficacy</li> <li>Stable self-efficacy over 24-month period</li> <li>↑self-efficacy, communication, preparedness as CG</li> <li>↑interv = to ↑use of skills designed to dev coping</li> <li>Insig outcome for one 3hr ed prog and 6 2hr grp sessions w ad hoc counseling</li> <li>Multicomp care interv</li> <li>↓ burden</li> <li>↑levels of satisfaction w social support</li> <li>↑obj and subj view of social support</li> <li>↑reduction in depression</li> <li>↓ admissions to LTC</li> <li>Tech based interv</li> <li>↓ depression in religious coping</li> </ul>	defined	<ul> <li>Nulticomp Interv 65%</li> </ul>	Correlated two strong researches in the review. Weaknesses: Analysis of data not addressed scientifically Conclusion: +assoc of cognitive and behavioral interventions. Recommendation/ Implication Pract.: Use of multi component and tech- based interventions most effective.
						<ul> <li>↑quality of life</li> <li>↓burden</li> </ul>			

Citation: author(s), date & title Fortinsky et al. (2008) Dementia care consult >family CG: collaborative model link Alzh w PCP	Purpose of study Report efficacy of individ care consult interv for CG	Conceptual framework Not listed	Design/ method LOE II RCT	Sample /Setting 84 RCT to interv and control 12 months	Major variables studied and their definitions IV: CG counseling interv DV: CG depress scoring CG phy health CG burden CR adm to LTC	Measurement of major variables LTC: admissions rate CG Burden: Zarit Depress: CESDI CG phy health: Hopkins Symptons Checklist Interv process: Likert scale & Med Rec review LTC admit Interv:16% Cont: 33%	Data analysis Logistic regression to test efficacy of interv. Other vari=SAS mix frm base-12 m • Self eff p-0.89 • Support: • p-0.80 • CES Depr: • 0.41 • Zarit Bur: p=0.73 • Hop sym: p- 0.87	Study findings Evidence suggests CG interv of counselng in addition to written plans and community resources support that CR remain at home longer.	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) <u>RECOMMENDATIONS</u> LOE II Strengths: 37 References 3 tables display charc of CG, LTC adm by logistic regression and mixed model regression. Weaknesses: None noted Conclusion: Consult interv show favorable results for LTC admits, although a gap is identified between PCP and Alzh org Recommendation/ Implication Pract.: Study supports the need for PCP collaboration to refer CG/CR to an org which can help reduce burden.
Garcia- Alberca et al 2013 Exp of CG: influ of coping strat on behave & psych symp in pts w AD	CG coping strategies independ assoc w behavioral & psycho symp (BPS)	Cross-sectional data analysis	Lev V Qualitat Cross Section	N=80 Non-Rand	IV: CG (NPI) measure DV: Coping strategies (engage vs disengage)	Instruments: • CBI: a=0.92 • BDI: a=0.90 • STAI: a=0.93 • CSI: a=0.63-0.89	<ul> <li>Descrip Statistics</li> <li>Mean age 77</li> <li>Mean BPS: 5.4±1.87</li> <li>Engage cope: R=0.59</li> <li>P&lt;0.0001</li> <li>CSI diseng cope: R=0.58</li> <li>P&lt;0.0001</li> <li>Burden: r=0.41, p&lt;0.001</li> <li>Depress: R=0.36</li> <li>P=&lt;0.001</li> </ul>	Most report associate with BPS and disengage coping strategies Recc further studies to test interventions for adequate coping strategies	LOE V Strengths: 45 References Detail socio-demographics 4 Tables attributes of study Weaknesses: Not significant Conclusion: + association with ↑AD severity and disengaged behavior by CG. Recommendation/ Implication Pract.: Nursing assess of BPS, create coping strategies. Further studies to explore a "pkg" approach to help with BPS Notes: The author takes credit as the first to inves- tigate the relationship be- tween BPS and engagement and disengagement coping strategies

Citation: author(s), date & title Hatch et al. 2014 Subj stress mod effect multi-comp & site interv on CG depress/ burden	Purpose of study Assess CG factors mod outcomes of a CG interv	Conceptual framework Stress process model	Design/ method RCT Lev II	Sample /Setting N=498 Rand assign to interv and control groups 6 months	Major variables studied and their definitions IV: Intervention Grp CG Interventions from REACH II IV: Control Grp Pkt of materials and 2 call checks in 6 months. DV: CG knowledge and coping strategies • Manage source of stress • Perception of source of stress • Stress symptoms	Measurement of major variables CG context @ baseline for CR: a=0.86, ADL a=0.81 RMBPC=a=0.84, 0.60 CES-D = low reliability a=0.59 ZBI= r=0.92 to 0.97	Data analysisBivariate analysisControl: CES-D $B=-0.19$ $P=0.009$ Interv: CES-D $B=-0.13$ $P=0.05$ RMBPC Interv: $B=-0.16$ $P=0.03$	Study findings Both groups similar in demographics • CG low in religious>hi in baseline depression: r=-0.29, p<0.001 • Burden: r=- 0.22, p<0.001 • Young CG burden R=-0.21, p<0.001 • Non-spouse CG T=2.73, p=0.007	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) <u>RECOMMENDATIONS</u> LOE II Strengths: 31 References Comparison data displayed in tables Weaknesses: none noted Conclusion: ↑interv contributed to ↑ efficacy among CG exp subj stress. CG depression and burden interv outcomes moderated by the CGng context, including depression, CG stress, and cognitive funct of CR. Recommendation/ Implication Pract.: Reference REACH II for data extant Recommend more interventions for those experiencing more stress, burden, and depression
Lins et al. 2014 Efficacy and exper of phone counsel for CG of dementia	Quanti review of efficacy of phone counsel for CG with a small quality review	Not listed	Lev I RCT 9 studies Qual=2 studies	9 quant studies 2 qual studies Retriev from scholar databases	IV: CG phone inter DV: CG depress response rating	Overall, data extraction and syntheses of the data w RCA. Studies used depress Scales (CES-D, CDS, Zarit, and RMBPC).	Depress 0.32 SD lower (0.63, 0.01) Burden 0.45 SD lower (0.90 low to 0.01 hi) Support 0.25 SD hi (0.24 low to 0.73 hi)	Depress 95% CI 0.01, 0.63 Burden 95% CI -0.24, 0.90 Phone counsel can ↓ depress.	LOE I Strengths: 11 References for syntheses 40 Additional references overall (51) Figures and tables succinct Weaknesses: Excessive citations Conclusion: Analysis show phone intervention can decrease depression in CG. Recommendation/ Implication Pract.: Extensive evaluation of studies for efficacy.

Citation: author(s), date & title Lykens et al. 2014 Impact of comm based implement of REACH II prog for CG of Alz pts.	Purpose of study Implem REACH II interven into community setting	Conceptual framework Not listed	Design/ method RCT Method Level II Multi ethnic	Sample /Setting N=177	Major variables studied and their definitions IV: CG > REACH II interv prog DV: CG score of Pre- & Post- testing of CG burden	Measurement of major variables DV: Definition: CG score of Pre- & Post- testing of CG burden Instr Descrp: Pre-/Post- 4 domain scales Depression CG burden, Self-care, social support REACHII, completion of interv prog	Data analysis Confid interval Mean, SD	Study findings • Sig for ↓Depression (<0.0001) • CG burden (0.025). Not Sig: • P-value for Self- care (0.108) • Social support (0.495) not stat sig	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) <u>RECOMMENDATIONS</u> LOE II Strengths: 19 References Abstract well written 3 Tables and 3 Figures Familiar measurement scales/tools Weaknesses: 19 References Relatively small study Conclusion: ↑ improvement in depression, CG burden Requires funding in community type program Recommendation/ Implication Pract.: Supports the ability to implement in community settings.
McKee et al. 2013 Quality of in formal care for persons w dementia: Dimension & correlates	Expand limited knowledge of styles of hi quality vs poor quality care w CG personality	Developed Extended stress process model for QOC of person w dementia	Qualit Method: Lev V	N= 148 Self id Conv sample	IV: Definition: CG Self assessed QOC DV: Definition: Hi QOC Poor QOC	Instr / Scales AD8 44 items Big 5 Pruchno/Resch Multi dimen Fun Depression Neuropsych	SEM Sr2	<ul> <li>Coeff ↑ QOC .075</li> <li>Coeff ↓QOC .086</li> <li>6 QOC sclaes .082</li> </ul>	LOE V Strengths: • 43 References • Quality of Care Appendix • 5 Synthesis tables • + scales display / comparison. Weaknesses: Not significant Conclusion: Predictor of ↑QOC > respect care Predictor of ↓QOC> disresp care Recommendation/ Implication Pract.: Nursing offer support to CR for at risk CR due to QOC

Citation: author(s), date & title	Purpose of study	Conceptual framework	Design/ method	Sample /Setting	Major variables studied and their definitions	Measurement of major variables	Data analysis	Study findings	Appraisal of worth to practice Strength of the evidence (i.e., level of evidence + quality [study strengths and weaknesses]) RECOMMENDATIONS
Nichols et al. 2011 Translation of	Describe pop and outcomes of REACH II	Not listed	Lev VI Translat study (Descrip)	127 repre 24 VA sites	IV CG REACH participants DV CG burden,	Mixed-effects models w unstructured correlaton to compare baseline	Burden p=0.0001 Depress p=0.0009	Gen Benefit Knowledg 97.8% Impr skills	LOE VI Strength: • 29 References • Used EBP research
CG support program REACH VA	prog translated to a VA site.				depression, general health, social support, bother w behave, CG	and 6 mon FU. 95% CI <i>P</i> values less than or	CG frustr p=0.003	96.6% CG confid 93.3%	Weakness: Small study Conclusion: Depress & frustration decreased Skills & Confidence increased
					difficulties	equal to 0.05 consid. Stat sig.			Recommendation/ Implication Pract.: This study supports translating EBP research into practice.

Appendix C:

Synthesis Tables for the Body of Evidence

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
N=	8	642	105	46	201	10 of 1116	20 of 146	84	80	498	395	177	148	127
Gender Female / Male			F	F	F		F	F	F	F		F	F	F
Race Black/White/Othe r		B>211 O=212 W=21 9	B/ W					W		B/W		W	W	W
Age			61	67	64.5		67	65	62	61		62	69	71
Relationship Spouse/Adult Child			S/C	С	S/C		S	S	С	S				S
Level of Education in yrs.			12+	12+	9+								15.7	

Table C1 Synthesis Table of Mean Caregiver Population Descriptive

Abbreviations: CCS = case-controlled study; Descrip = descriptive; NRCT = non-randomized control trials; RCT = randomized controlled trials; Syst Rev = systematic reviews; Qualita = qualitative

#### Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

#### Table C2

Synthesis Table of Study Design – Hierarchy of Evidence

Level	1	2	3	4	5	6	7	8	9	10	11	12	13	14	N=
I: Syst Rev or meta-analysis of RCTs	Х						Х				Х				3
II: Well-design RCTs		Х	Х	Х				Х		Х		Х			6
III: Well-design, NRCTs					Х										1
IV: Well-design cohort/CCS															
V: Syst Rev of Descrip & Qualita						Х			Х				Х		3
studies															
VI: Descrip & Qualita studies														Х	1
VII: Expert Consensus Reports															

Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

# Table C3 Synthesis Table of Caregiver Attributes / Risk Measures

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	N=
Positivity															1
Adherence to Skill															1
Stress															7
Depression					$\checkmark$	$\checkmark$				$\checkmark$		$\checkmark$			9
Psychological Distress/Self Care	$\checkmark$														7
Physical Distress	$\checkmark$														5
Anxiety															4
Inadequacy in Providing Care / Skills	$\checkmark$														7
Financial Challenge															2
Burden															10
Social Isolation															4
Morbidity / Chronic Illness															3
Mortality															1

#### Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

#### Table C4

Synthesis Table of Interventions

1	2	3	4	5	6	7	8	9	10	11	12	13	14	N=
														7
								$\checkmark$						9
				$\checkmark$						$\checkmark$	$\checkmark$		$\checkmark$	11
													$\checkmark$	6
											$\checkmark$		$\checkmark$	5
											$\checkmark$		$\checkmark$	8
									$\checkmark$					6
				$\checkmark$						$\checkmark$	$\checkmark$		$\checkmark$	10
				$\checkmark$									$\checkmark$	6
				$\checkmark$							$\checkmark$		$\checkmark$	10
									$\checkmark$					7
														1
											$\checkmark$			9
														7
			$\begin{array}{c ccccccccccccccccccccccccccccccccccc$											

Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	N=
REACH scale	$\checkmark$											$\checkmark$		$\checkmark$	6
REACH-RMBPC (Roth, 2003)											$\checkmark$			$\checkmark$	5
Zarit	$\checkmark$							$\checkmark$			$\checkmark$			$\checkmark$	8
RAM															2
ZCGB							$\checkmark$								2
CESD (Radloff, 1977)											$\checkmark$		$\checkmark$		6
NPI (Cummings, 1994)															2
CBI															3

Table C5 Synthesis Table of Stress, Coping Instruments and Scales Used by Title (excluded "n=1" instrument)

Symbols: + = positive; = negative;  $\uparrow$  = elevated or increased;  $\downarrow$  = decreased or lowered;  $\checkmark$  = present

Abbreviations: ADL=Activity of daily living; CBI = Caregiver burden inventory; CES-D = Center for Epidemiologic Studies Depression scale; CG=caregiver; CGng=caregiving; IADL=Lawton and Brody Functional Impairment; NPI = Neuropsych Inventor; RAM = risk appraisal measure; REACH = Resources for Enhancing Caregiver Health; RMBPC = Revised memory & behavioral problem checklist; ZCGB = Zarit CG Burden Scale

Note: RAM include attributes of the instruments: CES-D scale, CBI, Self-Care scale, Social Support scale, RMBPC, Katz ADL, IADL, Positive Aspects of Caring, Quality of Life (Czaja et al., 2009).

Fineout-Overholt via AJN Series, used with permission

#### Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	N=
Stress	$\downarrow$				$\rightarrow$		↓					→			4
Depression		↓					↓	↓		→	↓			$\rightarrow$	6
Burden	$\downarrow$	↓		$\rightarrow$		$\rightarrow$	↓	↓		→	↓	→		$\rightarrow$	10
Adherence			↑												1
Finance Stability															
Coping Strategies				↑		↑	<b>↑</b>					↑			4
+ Associations = ↓ CG burden	↑	↑			↑		←		→						6
Decision Making	↑			↑			←								3
Anxiety	$\downarrow$										$\rightarrow$			↓	3
Quality of Life	↑	↑					↑↓	↑		↓					5
Positive Aspect of CGng		↑			↑		<b>↑</b>								3
LTC Placement		-						↑							2

Table C6Synthesis Table of Reported Outcomes after Interventions

Abbreviations: CG = caregiver; CGng = caregiving; LTC = long term care

Symbols: + = positive; = negative;  $\uparrow$  = elevated or increased;  $\downarrow$  = decreased or lowered;  $\checkmark$  = present

#### Reference List:

(1) Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

Appendix D:

Synthesis of Evidence for the Most Effective Interventions

Evidence	Evidence Reference Cite	CG Project Intervention	Outcome	Analysis Tool	Time
11 out of 14 studies support written educational material as beneficial to CGing.	1, 2, 3, 4, 5, 7, 8, 10, 11, 12, 14	Provide A Caregiver's Notebook (educational material) and plan follow up sessions Location: AASC office or home visit	CG oriented to notebook, and develop individual intervention session appointments <b>Measure:</b> Check sheet that CG received notebook and schedule developed for sessions.	RAM pre/post intervention scoring	Weekly sessions to complete the 8 sessions
10 out of 14 studies support telephonic follow up	1, 2, 3, 5, 7, 8, 10, 11, 12, 14	Weekly educational sessions via face to face or telephonic Location: AASC office or telephonic or home visit	CG will stay connected in attending sessions and referring to handbook as needed <b>Measure:</b> Check Sheet to record CG attendance for each session	Descriptive anecdotal notes	Weekly to complete the 8 sessions
10 out of 14 studies support teaching coping strategies	1, 2, 3, 4, 5, 6, 7, 10, 12, 14	Education plan include topic of coping strategies Location: AASC office or telephonic or home visit	CG will experience exposure to coping strategies <b>Measure:</b> Post intervention RAM assessment scoring	RAM pre/post intervention scoring	Within the 8-week sessions
9 out of 14 studies support face to face interview and counseling for CG	1, 2, 3, 7, 8, 9, 10, 12, 14	CG will access the clinical site for consult and possible support related to CGing role. Location: AASC office	CG will decide how much to engage in clinical site resources. Measure: Session attendance	<b>Percentage</b> of CG who completed partial or complete sessions (Appendix E)	Initial visit to the clinical site
9 out of 14 studies support a pre and post intervention measurement of CG stress	1, 2, 3, 5, 7, 8, 10, 12, 14	Pre and Post Assessment using REACH II RAM scoring tool. Location: AASC office	Assess CG Burden, Depression, Quality of life pre/post intervention <b>Measure:</b> Risk Assessment Measure (RAM Scale) 16 item assessment	Before intervention, record baseline data for each CG After intervention, record completion data for each CG	Initial or 2 <sup>nd</sup> session <b>AND</b> Last session
14 out of 14 studies support a decrease in burden and/or depression and/or increase quality of life	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14	Post EPIP Data Analysis	<b>Measure:</b> Baseline and Completion Data analyzed to show that multi-component CG intervention is beneficial to CG.	Percentage of attendance of individual sessions Correlation of baseline to completion analysis for RAM score risk categories Aggregate data analysis for all CG participants ( <i>P</i> value, confidence interval) Anecdotal descriptive notes	

Appendix E:

Approvals

#### **Organization Approval**

November 16, 2017





Dear Cheryl Garmon,

903-539-8557

Thank you, Cheryl, for seeking us out to conduct your Doctor of Nurse Practice (DNP) Scholarly Project (EPIP) entitled, Alzheimer's Caregiver Intervention to Improve Self-Efficacy, in our organization. We have reviewed your project proposal and are happy to partner with you as you implement your evidence-based change project. We realize that this project is part of your studies at the University of Texas at Tyler DNP Program. We also realize that the timeframe for the projects is launching approximately the week of January 15, 2018 and concluding the week of April 29, 2019.

We believe that this is a valuable endeavor and support your project. We are looking forward to working with you.

Sincerely,

Stephanie Taylor

Executive Director Alzheimer's Alliance of Smith County Stephanie@alzalliance.org 903/509/8323

> 211 Winchester • Tyler, Texas 75701 903-509-8323 • Fax: 903-509-8373 • www.alzalliance.org

#### **EPIP** Approval

NURS 5202 Capstone II Organizational Approval Form for Onsite Project

Student Name: Cheryl Garmon Project Name: Alzheimer's Caregiver Intervention to Improve Self-Efficacy Project Purpose: To implement EBP interventions proven to increase knowledge, skills, and caregiver self care. Agency Name: Alzheimer's Alliance of Smith County Please initial the following statements to provide student approval of conducting and evidence-based change project in your organization. Our agency has a clinical facility agreement with UT Tyler. I recognize that an agreement must be in place before students can implement projects at our agency. \_X\_I approve of the above student's implementation of an evidence-based change project in our agency. Ulunne & Carmos MSK Agency Representative Signature (must have authority to sign for agency) INITIALS Luanne Harms Stephanie Taylor 11.16.2017 Agency Representative PRINTED NAME DATE arinon Cheryl Garmon Student Signature Student PRINTED NAME

#### **Industry Mentor Agreement**

UTTYLER DNP INDUSTRY MENTOR MEMORANDUM OF UNDERSTANDING

THE UNIVERSITY OF TEXAS AT TYLER

#### COLLEGE OF NURSING AND HEALTH SCIENCES

## SCHOOL OF NURSING - DOCTOR OF NURSING PRACTICE PROGRAM.

#### DNP INDUSTRY MENTOR AGREEMENT

I have reviewed the industry mentor guidelines. I can provide the student with advanced experiences that meet the DNP Scholarly Project (EPIP) goals as agreed upon by the student, the faculty mentor, and me. I understand that there will be no remuneration for this service. I will facilitate and review the student's learning activities and will submit the required evaluations to the DNP Program.

Juanne Harms, agree to serve as an Industry mentor for the DNP student, Chury 1, 1 Yarmori (name of industry mentor) (name of student)

from  $\frac{Fall}{(\text{beginning date of mentorship})}$  to  $\frac{princl}{(\text{anticipated end of mentorship})} \ge 019$ 

OR

□ For ALL Semesters

OR

For specifically indicated semesters: \_\_\_\_Fall \_\_\_\_\_Spring \_\_\_\_\_Summer

Please indicate if UTTYLER may disclose your contact information for future students seeking mentors? □ yes

Ino

Juanne Carmes Date 11/21/17 Industry Mentor Signature

For office use only:

Reviewed by \_\_\_\_\_Date \_\_\_\_

Approved as a DNP Industry mentor \_\_\_\_\_ yes \_\_\_\_\_ no

#### **Industry Mentor Biographical Data**

UTTYLER DNP INDUSTRY MENTOR MEMORANDUM OF UNDERSTANDING

## COLLEGE OF NURSING AND HEALTH SCIENCES

## SCHOOL OF NURSING - DOCTOR OF NURSING PRACTICE PROGRAM

### Industry Mentor Biographical Data

The UTTYLER School of Nursing complies with all federal and state laws related to the confidentiality of patient medical information including the Privacy Regulations issued pursuant to the Health Insurance Portability and Accountability Act of 1996. Students are required to comply with such laws and the medical record confidentiality policies and procedures of any health care facility where they are engaged in DNP Scholarly hour attainment. All DNP student mentors are tracked in a database for the purpose of ensuring and validating qualifications

\*This document is designed to be used in conjunction with the UTTYLER Student Handbook.

Appendix F:

**Caregiver Implementation Calendar with Process Markers** 

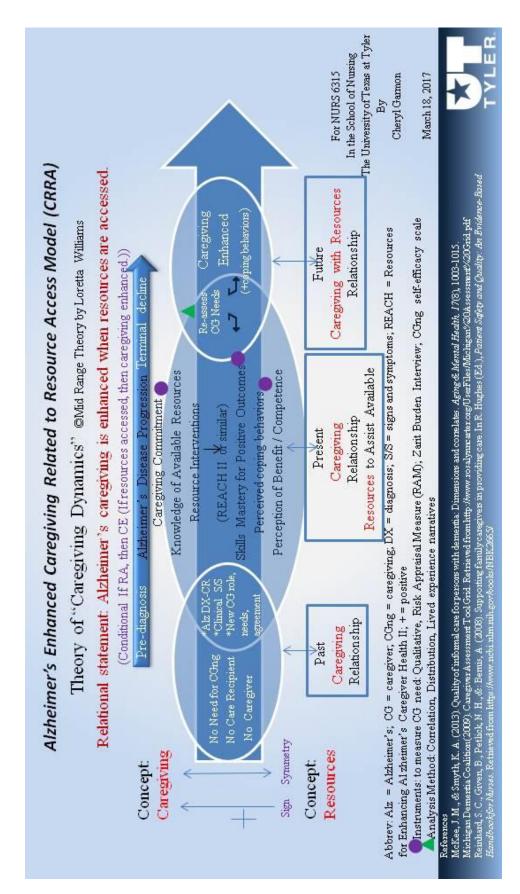
Process Markers	Date / When	Who	What	Where	How	Outcome
Chk Point 5: Prelim- inary Plan Approval	November 27, 2017	Project Leader (PL), Exe Director (ED), LMSW-Industry Leader (IL) Caregivers (CGs)	Meet to review implementation plan, clinical site baseline status(data), budget, resources, and obtain signed mentorship papers	AASC office	Face to Face mtg PL to bring written plan/calendar	Mentorship established
Chk Point 6: Plan Approval	Spring 2018	UTTyler Faculty	Components in place to launch Official permission to launch		Communicatio n	Faculty Approval March 2018 Begin to implement
	Spring 2018	PL, IL	Discuss intervention program plans, materials, components of intervention Set calendar for January	AASC office	Face to Face, EBP synthesis	Calendar reviewed and accepted
Chk Point 7: Project Team Meeting	April 2018	PL, IL, AASC Project Team (PT)	Review implementation plan, training, discussion of interventions and roles, Q&A	AASC office	Face to Face	Team roles, learning needs identified, questions answered
Implem CG Interv Plan	May 2018 Month start	IL, PT	Coordination of Program Activity [Oversee of sessions by AASC staff, data gathering, direct participant with CGs]	AASC office or CG home	Face to Face or telephonic	Began sessions
	May 2018 Month end	IL, PT PL avail to BOD	Oversee of sessions by AASC staff, data gathering, direct participant with CGs Update BOD if necessary	AASC office or CG home Board Room	Face to Face or telephonic	New/Establis hed sessions
	June 2018 Month start	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	New/Establis hed sessions Provided notebooks
Chk Point 8: Plan Check	June 2018 Month end	IL, PT PL avail to BOD or PT meeting	Oversee of sessions by AASC staff, data gathering, direct participant with CGs Update BOD if necessary or meet w PT for progress, Q&A	AASC office or CG home Board Room	Face to Face or telephonic	New/Establis hed session complete Met w Ind Mentor
	July 2018 Month start	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	New/Establis hed sessions
	July 2018	IL, PT PL avail to BOD	Oversee of sessions by AASC staff, data gathering, direct participant with CGs Update BOD if necessary	AASC office or CG home Board Room	Face to Face or telephonic	New/Establis hed sessions Project Check w IM CGs dinner
Plan Check	July 2018 Month end	IL, PT PL avail to BOD or PT meeting	Oversee of sessions by AASC staff, data gathering, direct participant with CGs Update BOD if necessary or meet w PT for progress, Q&A	AASC office or CG home Board Room	Face to Face or telephonic Lunch and Learn	Check In w Ind Mentor Engagement with CGs at lunch
	August 2018 Month start	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	New/Establis hed sessions

Process Markers	Date / When	Who	What	Where	How	Outcome
	August 2018 Month end	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	New/Establis hed sessions
	Septem- ber 2018	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	Established sessions
Plan Check	October 2018 Month start	IL, PT PL avail to BOD or PT meeting	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home Board Room	Face to Face or telephonic	Established sessions wrap ups
Plan Check	October 2018 Month end	IL, PT	Oversee of sessions by AASC staff, data gathering, direct participant with CGs	AASC office or CG home	Face to Face or telephonic	Completed all sessions Met w Ind Mentor
Begin Data Analysis	November 2018 Month start	IL, PL	Intervention Data Outcomes Clinical site completion data	AASC office	Face to Face and telephonic	PL analyze data
Begin Sustain. Plan	November 2018	IL, PL	Sustainability Plan	AASC office	Face to Face	Work session to review data
	December 2018 Month start	PL, IL	Review of project outcomes	AASC office	Face to Face	Outcome data reviewed
Chk Point 9: Proj Eval	December 2018	PL, IL, ED, PT	Evaluation of Project Update Team Celebratory Breakfast	AASC office	Face to Face	Team's Staff Meeting Written Summary
Chk Point 10	January 2019	PL, IL	Discuss project outcomes	AASC office	Face to Face	Outcomes positive, discussed sustainability
Chk Point 11: Project Team Present	April 2019	PL, IL, ED, PT	PPT Presentation of project with emphasis on sustainability	AASC office	Face to Face	Project Team Presentation and Sustainability Discussion
Chk Point 12: Stake- holder Present	April 18, 2019	PL, IL, BOD, ED	Request for Sustainability, Extend Appreciation	BTH Bank	Face to Face or telephonic	Final Presentation to BOD, Stakeholders

Legend: AASC = Alzheimer's Alliance of Smith County; BOD = board of directors; CG = caregivers; Chk = check; ED = executive director; IL = industry leader; PL = DNP project leader; PT = project team.

Appendix G:

**Caregiving Dynamics Theoretical Framework** 



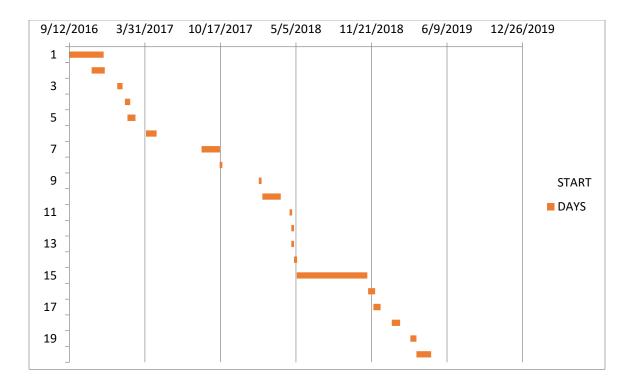
Appendix H:

**Caregiver EPIP Project Timeline** 

Alzheimer's Caregiver	EPIP			
ACE Star Model	TASK	START	APPROX	END
Timeline			DAYS	
Phase 1 PICOT	Task 1: Mature topic of interest	9/12/2016	91	12/11/2016
Development	Task 2: Create PICOT in correct	11/10/2016	35	12/11/2016
	format			
Phase 2 Evidence	Task 3: Database Search	1/17/2017	14	1/26/2017
Search and Summary	Task 4: Critical Analysis of Evidence	2/6/2017	14	2/18/2017
	Task 5: Evaluation Table and	2/13/2017	21	3/5/2018
	Synthesis of Evidence			
Phase 3: Project Plan	Task 6: Develop Implementation Plan	4/3/2017	28	4/23/2017
Guidelines	Task 7: Translate Evidence to EPIP	8/28/2017	49	10/12/2017
	Task 8: Develop Timeline and Markers	10/15/2017	7	10/21/2017
	Task 9: Obtain Industry and Faculty	1/27/2018	7	1/31/2018
	Approvals			
	Task 10: Develop Budget, ROI,	2/5/2018	49	3/26/2018
	Stakeholder Roles			
Phase 4:	Task 11: Clinical Site Team	4/18/2018	7	4/21/2018
Implementation of	Preparation			
Project	Task 12: Secure all data forms	4/23/2018	7	4/27/2018
	Task 13: Secure all education	4/23/2018	7	4/30/2018
	materials			- /= /0.0 / 0.
	Task 14: Secure scheduling matrix	4/30/2018	8	5/7/2018
	Task 15: Monitor interventions, data	5/7/2018	187	11/9/2018
<b>.</b>	collection, data storage		10	
Phase 5: Process	Task 16: Data Collection Secured	11/12/2018	19	11/30/2018
Data and Outcome	Task 17: Systematic Analysis of Data	11/26/2018	19	12/14/2018
Evaluation	Task 18: Report outcomes	1/14/2019	22	3/3/2019
	Task 19: Overall project analysis	3/4/2019	16	3/20/2019
	Task 20: Dissemination of Project	3/20/2019	39	4/26/2019
	Conclusions			

Appendix I:

**Caregiver EPIP Timeline Gantt Chart** 



Appendix J:

Instruments

(	1			C			
			REACH II R	isk Appraisal I	Measure (RAN	1)	
Do you	have written info	rmation about m	emory loss Alzh	eimer's Disease	or dementia?		
, co jour	No	Yes	Unknown	Refused			
. Can (CR)	) get to dangerou	s objects (e.g., loa	aded or unlocked	l gun, or sharp o	bjects that are u	sed as weapons)?	
	No	Yes	Unknown	Refused			
. Do vou	ever leave (CR) al	one or unsupervi	sed in the home	,			
,	Never	Sometimes	Often	Unknown	Refused		
. Does (Cl	R) try to leave the	home and wand	er outside?				
	Never	Sometimes	Often	Unknown	Refused		
. Does (CF	R) drive?						
	Never	Sometimes	Often	Unknown	Refused		
Overall	how satisfied has	ve you been in th	e past month wit	the help you h	ave received fro	om family members, friends, o	r neighbors?
. overall,	Not at all	A little	Moderately	Very	Unknown	Refused	Helbingers .
. In the pa	ast month, how s	atisfied have you	been with the su	pport, comfort,	interest and con	cern you have received from o	others?
	Not at all	A little	Moderately	Very	Unknown	Refused	
	ast month, have y	ou had trouble fa		ying asleep, or w Unknown	aking up too ear Refused	ly in the morning?	
In the pa	Never		Often				

RAM

Figure J1. 16-Item RAM Measure Instrument – Questions 1-8.

			h - lah ta						
9.	In general,	would you say y Excellent	Very good	Good	Fair	Poor	Unknown	Refused	
10	. In the pas	t month, have ye	ou felt depressed		spells or felt lik	e you often need	ded to cry?		
		Never	Sometimes	Often*	Unknown	Refused			
11	How ofter	in the past six i	months, have vo	u felt like scream	ing or yelling at	(CR) because of	the way he/she b	behaved?	
	. now once	Never	Sometimes	Often	Unknown	Refused			
12	Here often	in the past six i	months have you	u had to keep vo	urself from hitti	ng or slapping (C	R) because of the	e way he/she be	haved?
12	. How offer	Never	Sometimes	Often	Unknown	Refused	,	, , ,	
12	Is it hard (	or stressful for w	ou to take care o	f basic househol	d chores. like cle	eaning, yard wor	k, or home repair	s?	
15	. 13 11 11 11 11 11 1	Never	Sometimes	Often	Unknown	Refused			
14	Do you fe	el strained (e.g.,	stressed, tense,	or anxious) whe	n you are aroun	d (CR)?			
14		Never	Rarely	Sometimes	Quite Often	Frequently	Nearly Always	Unknown	Refused
			the half (CD) is	- hasis dailu activ	itios liko bathir	a changing clot	hes, brushing tee	th. or shaving?	
15	. Is it hard o	Never	Sometimes	Often	Unknown	Refused	nes, brushing tee	in, or sharing.	
16	Providing	help to (CR) has	made me feel ge	ood about mysel	f.				
10	Troviumg	Disagree	Disagree	Neither agree	Agree	Agree	Unknown	Refused	
		a lot	a little	nor disagree	a little	a lot			

RAM

Figure J2. 16-Item RAM Measure Instrument – Questions 9 - 16.

* Mental Health referral				
CR=Care recipient				
Responses in <b>Bold</b> indicate High Risk				
Responses in Italics indicate Moderate Risk	:			
TOTAL SCORE: Sum all answer choices and classify	y risk level bas	ed on numbers b	elow.	
<b>Risk Scale:</b> High risk: Summed all high risk answers for the up <b>Moderate risk:</b> ½ moderate answers and ½ high-ri Low risk: Upper limit of 11 is sum of all moderate	isk answers.	-40. 27 is sum of	½ high risk and	½ medium risk answer
1	RAM	Score Risk Cate	aorios	1
l	Low	Moderate	High	J
	0-11	12-27	28-40	
The scoring is compared with the CG's b post intervention scoring.	paseline sco	oring and afte	r completio	n, the CG's

Figure J3. RAM Score Risk Category [Measure] <sup>1, 2,3,4,5,10,12,14.</sup>

Reference List:

(1) Beinart et al. 2012; (2) Belle et al. 2006; (3)Chee et al. 2007; (4) Chen et al. 2015; (5) Cheung et al. 2015; (6) Del-Pino-Casado et al. 2011; (7) Elvish et al. 2013; (8) Fortinsky et al. 2008; (9) Garcia-Alberca et al. 2013; (10) Hatch et al. 2014; (11) Lins et al. 2014; (12) Lykens et al. 2014; (13) McKee et al. 2013; (14) Nichols et al. 2011

Additional Reference: Scott & White. (2006). A caregiver's notebook.

Client Initial & Consult Date	Follow up Date	RAM Assess Date	RAM Score - Result Comm. Establish Plan	Session 1 Family Profile Home Safety Visit	Session 2 Legal Info Medical Info	Session 3 Social Support	Session 4 Managing Stress	Session 5 Pleasant Things for CG Understand Feelings	Session 6 Skillful Comm.	Session 7 Memory Prob to Behavior	Session 8 Additional Resources Post Interv RAM Assess/ Result	Atten Tally

Figure J4. Caregiver Session Attendance Check Sheet Tool.

Appendix K:

**Caregiver Intervention Protocol as Referenced to the Evidence** 

Intervention	Actions	Expected Outcomes	Evidence Reference
CG consult	AASC receive call	CG appointment scheduled	
CG Interview	Initial CG interview	PT determine the CG need(s)	1,3,7,8,9,10,12
CG Follow up	PT to follow up w CG by telephone to determine any additional appts or needs.	CG support by AASC delayed or accepted.	1,3,5,7,8,10,12
CG Appt	Risk Assessment Measure (RAM)- pre-intervention Component of REACH as a baseline and will be re-assessed at the completion of the intervention program.	PT discuss results of RAM	1,3,4,5,6,7,10,12
CG Offered Program	Based on baseline RAM score, CG individualized plan created		
Schedule of Sessions	PT to schedule sessions Prefer Tue or Thur or Flexible if pre- planned	All sessions will be attended	1,3,7,10
Session 1	Education material and home safety Review, telephone follow up	CG assess their home for care recipient (CR) safety, begin to use education material to increase knowledge	1,3,4,5,7,8,10,12
Session 2	Legal and Medical Information	CG given advice and resources for power of attorney and advanced directives	1,3,4,5,7,8,10,12
Session 3	Social Support	CG aware of support events such as "Day Club" as respite outing.	1,3,4,5,7,8,10,12
Session 4	Managing Stress	CG begin aware of stressors and alternative activity to decrease stress	1,3,4,5,7,8,10,12
Session 5	Pleasant Things for CG, Understanding Feelings	CG receive information to help with self-care	1,3,4,5,7,8,10,12
Session 6	Skillful Communications	CG aware of communication skills to use	1,3,4,5,7,8,10,12
Session 7	Relating Memory Problems to Behavior	CG aware of causative factors for CR behaviors	1,3,4,5,7,8,10,12
Session 8	Additional Resources Post Intervention RAM test	CG possess folder with information which can be helpful now and in the future.	1,3,4,5,7,8,10,12
	Actual Outcomes and data collection at conclusion of project		

Reference List:

<sup>(1)</sup> Beinart et al., 2012; (2) Belle et al., 2006; (3) Chee et al., 2007; (4) Chen et al., 2014; (5) Cheung et al., 2015; (6) Del-Pino-Casado et al., 2011; (7) Elvish et al., 2013; (8) Fortinsky et al., 2008; (9) Garcia-Alberca et al., 2013; (10) Hatch et al., 2014; (11) Lins et al., 2014; (12) Lykens et al., 2014; (13) McKee et al., 2013; (14) Nichols et al., 2011

Appendix L:

**Caregiver Project Stakeholder Grid** 

Name	Role	Contact details	Internal/External	Expectations	Influence
Luanne Harms, LMSW	Industry Mentor	903-509-8323 lharms@aaasc.com	Internal	Primary resource for intervention plan	Influencer
Stephanie Taylor, Executive Director	ED of AASC	903-509-8323 staylor@aaasc.com	Internal	Oversee all operations of AASC, expect effectiveness of EBPIP	Influencer
Allison Hennigan, M.D Neurology	Physician Mentor	903-535-6092	External	Physician consulting, available as resource for unique client/caregiver situations	Neutral
AASC Board of Directors w non-clinical background	Approve allocated resources		Internal/External	Enhanced integrity of caregiver intervention program w affordable resources	Influencer (neg/pos)
AASC Board of Directors w clinical background	Approve allocated resources		Internal/External	Enhanced integrity of caregiver intervention program w improved CG outcomes	Influencer
AASC Office Staff	Support plan, assist in interventions	903-509-8323	Internal	Enhanced integrity of caregiver intervention program/offering.	Influencer
Caregivers	Participation in project		Internal/External	EBP Interventions beneficial to their individual circumstance.	Perception of benefit

Abbreviations: AASC = Alzheimer's Alliance of Smith County; LMSW = Licensed Master Social Work.

Appendix M:

**EPIP - Caregiver Data Analysis** 

#### T-Test Calculator for 2 Dependent Means

The value of *t* is -4.329856.

#### Explanation of results

The output of this calculator is pretty straightforward. The values of t and p appear at the bottom of the page. If the text is blue, your result is significant; if it's red, it's not. The only thing that might catch you out is the way that we've rounded the data. The data you see in front of you, apart from the t and p values, has been rounded to 2 significant figures. However, we did not round when actually calculating the values of t and p. This means that if you try to calculate these values on the basis of the summary data provided here, you're likely going to end up with a slightly different - and less accurate - result.

Treatment 1	Treatment 2	Diff(T2 - T1)	Dev (Diff - M)	Sq. Dev	
23,	18,	- 5	4.09	16.74	
31,	12,	-19	-9.91	98.19	
21,	13,	-8	1.09	1.19	
12,	10,	-2		50.28	
19,	12,	-7		4.37	
19,	13,	-6		9.55	
14,	12,	-2		50.28	
31,	8,	-23		193.46	
20,	11,	-9		0.01	
22,	18,	- 4		25.92	
27	12	-15	-5.91	34.92	
		M: -9.09		S: 484.91	
		é			
ignificance Level:		Differe	Difference Scores Calculations		
0.01		Mean:	-9.09		

<ul><li>○ 0.01</li><li>● 0.05</li><li>○ 0.10</li></ul>	Mean: -9.09 $\mu = 0$ $S^2 = SS'df = 484.91/(11-1) = 48.49$ $S^2_M = S^2/N = 48.49/11 = 4.41$	
One-tailed or two-tailed hypothesis?:	$S_M = \sqrt{S^2}_M = \sqrt{4.41} = 2.1$	
One-tailed	T-value Calculation	
● Two-tailed	$t = (M - \mu)/S_M = (-9.09 - 0)/2.1 = -4.33$	

The value of t is -4.329856. The value of p is .00149. The result is significant at p < .05.