DECREASING DEMENTIA CAREGIVER BURDEN: A QUALITY IMPROVEMENT INTERVENTION

A Dissertation
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Science

By

Kayla Marie Weigel

In Partial Fulfillment of the Requirements
for the Degree of
DOCTOR OF NURSING PRACTICE

Major Department:
Nursing

March 2018

Fargo, North Dakota

North Dakota State University
Graduate School

Title

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

DOCTOR OF NURSING PRACTICE

SUPERVISORY COMMITTEE:

Dean Gross, Ph.D., FNP-BC, RN
Chair

Kelly Buettner-Schmidt, Ph.D., RN

Paul Rokke, Ph.D.

Sarah Matcha, FNP-BC, RN

Approved:

April 5th, 2018
Date

Carla Gross, Ph.D., RN
Department Chair

ABSTRACT

A caregiver is defined as someone who offers care to another individual who is not capable of carrying out activities essential for daily living. The role of caregivers is often overlooked, but their contributions are foundational to the nation's long-term healthcare organizations. Numerous reasons exist for the projected increase in caregiver burden, including: the nation's aging population, increased dementia prevalence, increased caregiver demand, and increased long-term care turnover rates. A current and projected shortage of caregivers will profoundly impact the long-term care workforce.

Job turnover and burden rates are often reported highest among dementia caregivers related to increased physical, mental, and emotional demands. Research emphasizes the importance of enhancing dementia caregiver education levels to decrease turnover, reduce burden, and enhance outcomes. Based on practicality, scope of practice, a detailed literature review, and a community needs assessment, a dementia caregiver training program was chosen as a priority dementia caregiver need.

The practice improvement project design focused on increasing dementia caregiver knowledge and decreasing levels of burden through implementation of a dementia caregiver training program at a local long-term care agency. Twenty-six agency dementia caregivers attended a training session followed by pre-post and two-month post-education questionnaires and scales.

During the training program, education was provided to caregivers through an interactive PowerPoint presentation. The training session included an introduction followed by participant completion of a pre-education knowledge questionnaire and a pre-education burden scale. Training content included burden, self-care tips, communication, and managing dementia associated behaviors. Evaluation included group discussion and completion of the post-education knowledge questionnaire and the post-education burden scale. Two-months following program completion, a two-month post-education knowledge questionnaire and a two-month post-education burden scale were completed by participants. Data analysis indicated implementation of the dementia caregiver training program resulted in increased knowledge, increased comfort, and decreased caregiver burden.

ACKNOWLEDGEMENTS

My success through the Doctor of Nursing Practice program would not have been possible without the support and guidance from many individuals. I would like to begin by extending sincere gratitude to my advisor and committee chair, Dr. Dean Gross. His constant encouragement, support, insight, and patience throughout the practice improvement project and doctoral program was vital to my success.

I would also like to thank my other dissertation committee members, Dr. Kelly Buettner-Schmidt, Dr. Paul Rokke, and Sarah Matcha. Their time, knowledge, and guidance are greatly appreciated and will never be forgotten. I would also like to extend immense gratitude to Sarah Matcha, FNP-BC. Her expertise, educational resources, support, and guidance, enhanced development of the dementia caregiver training program and ultimately enhanced project success.

DEDICATION

This dissertation is dedicated to my husband, Jonathan, my best friend and biggest source of support, guidance, and encouragement through the challenges of graduate school and life. I was able to successfully persevere through the challenges thanks to your constant encouragement, patience, and belief in me. No words can express how grateful I am to have you by my side to navigate through life's experiences and challenges. Also, I would like to dedicate this project to our children, Joshua and Hailey, they provided me with constant motivation to be the best I could be and to enjoy each day to the fullest no matter how busy life got.

This dissertation is also dedicated to my family and friends for their support, encouragement, and endless love. My parents, Rick and Paula, and brother, Brett, provided me with endless support. Without their continuous love and encouragement, I would not have accomplished what I have today. Furthermore, I am extremely grateful for my in-laws, Rod and Jeanne, for the constant support they provided to our family and my education.

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CHAPTER ONE. INTRODUCTION

Allowing another individual to care for a family member is a tough decision, but it is often a necessary choice to ensure the family member receives the care required to meet needs and enhance outcomes. A caregiver is defined as someone who offers care to another individual who is not capable to carry out activities essential for daily living (National Center on Caregiving [NCC], 2016). Caregivers can be grouped into informal or formal caregivers (Adelman, Timanova, Delgado, Dion, & Lachs, 2014; Ducharme et al., 2011). Formal caregiving includes those who are usually professionally trained and paid for their care such as nurses (Alzheimer's Association, 2017; Ducharme et al., 2011). The most common forms of informal caregivers are the spouse and children. However, an informal caregiver can be any person caring for the individual (NCC, 2016). An informal caregiver is unpaid and is usually untrained to provide non-professional care (Alzheimer's Association, 2017).

Every day, millions of Americans provide help to adult individuals who can no longer care for themselves independently (Adelman et al., 2014). Furthermore, the role of caregivers is often overlooked, but, their contributions are foundational to the nation's long-term healthcare organizations (AARP, 2015). There is a current and projected shortage of formal and informal caregivers that will profoundly impact the long-term care workforce and outcomes for long-term care residents (U.S. Department of Health & Human Services [HHS], 2016). Furthermore, job turnover and overall burden rates are often reported highest among dementia caregivers related to increased physical, mental, and emotional demands associated with caring for individuals with dementia (Adelman et al., 2014; Alzheimer's Association and National Alliance for Caregiving [AANAC], 2014; Ducharme et al., 2011). Support provided to dementia caregivers is essential to decrease burden and enhance outcomes.

Background

High turnover rates and burden have direct negative effects on providers, consumers, and workers. The cost of replacing workers is high. Formal caregivers in understaffed environments may suffer higher rates of injury and chronic diseases further perpetuating turnover and burden. Understaffed environments are associated with a decrease in the quality of care provided which leads to negative patient outcomes (Cheng, 2017; Fearon & Nicol, 2011; HHS, 2016). Providing support to caregivers is essential to decrease burden, decrease turnover rates, and enhance outcomes (Adelman et al., 2014; Bastawrous, 2013; Chiu, Wesson, & Sadavoy, 2013; Sprangers, Dijkstra, & Romijn-Luijten, 2015).

Research suggests various ways to support formal and informal caregivers. However, many studies indicate the highest need for both formal and informal caregivers is increased training and education to best reduce burden (Adelman et al., 2014; Chiu et al., 2013; HHS, 2016). Other top dementia caregiver needs include increased wages, increased benefits, and decreased resident-staff ratios (HHS, 2016). Wage, benefit, and staffing ratios require change on a much larger organizational scale and were not within target range for the intervention project. However, primary care providers and other healthcare personnel can focus on decreasing caregiver burden by providing dementia caregivers with additional training (Aldelman et al., 2014; Chiu et al., 2013; HHS, 2016).

Significance of Proposed Project

The topic of dementia caregiver burden was identified from a previous literature review which was conducted in preparation for completion of a needs assessment project. Numerous research articles and studies emphasize the importance of enhancing dementia caregiver education to increase utilization of dementia caregivers, decrease turnover, and enhance caregiver outcomes (Broughton et al., 2011; Chien et al., 2011; Chiu et al., 2013; Cook et al., 2012; Ducharme et al., 2011; Fearon & Nicol, 2011; Forbes, Blake, Thiessen, Peacock, & Hawranik, 2014; HHS, 2016). Providing education to dementia caregivers has been identified as a top need to address burden and turnover. The primary reasons the concept of dementia caregiver burden has steadily grown is due primarily to the steadily increasing demand for caregivers and increasing prevalence of dementia (Alzheimer's Association, 2017). Currently, one in every five households utilize either an informal or formal caregiver to help assist with care for another individual (AANAC, 2014). Since dementia caregivers are such a prominent part of our society, it is vital to provide support to best decrease turnover, decrease caregiver burden, and enhance care provided to recipients.

Project Purpose

The nation's aging population, shortage of long-term care facilities, and increasing prevalence of chronic diseases (especially dementia) are the primary reasons noted for the exponential increase in caregiver burden (Adelman et al., 2014). Motivation and need for the proposed dementia caregiver training program was identified based on the results of the needs assessment and literature review discussed below. To target formal caregiver burden in the local area, a dementia caregiver training program was developed and implemented at a local long-term care agency. The purpose of the project was to increase dementia caregiver knowledge, decrease caregiver burden, and identify program effectiveness for future development and implementation.

CHAPTER TWO. LITERATURE REVIEW

A search was conducted utilizing the Cochrane Database of Systematic Reviews, Medline, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The North Dakota State University (NDSU) online ejournal database was utilized to complete a general search utilizing the limitations and the keywords explained below. Multiple variations of keywords and phrases were used to generate the most pertinent search results for the intended topic of dementia caregiver burden and training program. Truncation was utilized to ensure all variations of caregiver, burden, training, and program were included in the search results. Furthermore, "and" and "or" were utilized between various combinations and phrases of the keywords within the search. First, both phrases connected the keywords with "and." However, the search only yielded three articles. By substituting an "or" instead of "and," around 30 articles populated. The search was limited to research articles published in peer-reviewed English journals and published within the last ten years. The final Cochrane Database search included the following keywords: dementia, caregiv*, behavi* management, nursing home staff, and burden.

A critical appraisal of each identified pertinent study was performed to determine reliability, validity, and usability in practice (Melnyk & Fineout-Overholt, 2015). The areas evaluated for each study during the critical appraisal process were: study results, date of publication, population (dementia caregivers), how pertinent the study was to the topic of interest, and validity. Even though no identified studies were noted for the focused population of dementia caregivers in Fargo, ND, numerous studies were identified which focused on the aging population, dementia, and caregiver burden on a national level.

After completing the rapid critical appraisal, six individual studies and two systematic reviews were considered pertinent. To enhance understanding and organization of the eight research studies chosen for further analysis, a data synthesis table was constructed. The synthesis table helped to organize each study in the following categories: citation, conceptual framework, design, setting, variables, measurement, data analysis, study findings, and strength of evidence (Appendix A.). Current studies were utilized to ensure current guidelines and evidence-based practice were identified.

Seven out of the eight research articles developed and trialed a caregiver training program focused on enhancing caregiving abilities and decreasing caregiver burden. All training programs were developed with minimal-risk reported to the population of interest. After evaluation was performed for each developed program, positive results were identified including decreasing caregiver burden and increasing dementia caregivers' confidence with providing care (Broughton et al., 2011; Chien et al., 2011; Chiu et al., 2013; Cook et al., 2012; Ducharme et al., 2011; Forbes et al., 2014; Hermans, Htay, & Cooley, 2009; Samia, Aboueissa, Halloran, & Hepburn, 2014).

Of the evidence identified, various programs and interventions were utilized to enhance dementia caregiver abilities and decrease caregiver burden. Some identified interventions included: support groups, light therapy, DVD based training program, music therapy, therapeutic touch, occupational therapy, physical therapy, and dementia caregiver training programs (Broughton et al., 2011; Chien et al., 2011; Chiu et al., 2013; Cook et al., 2012; Ducharme et al., 2011; Forbes et al., 2014; Hermans et al., 2009; Samia et al., 2014). Conducting dementia caregiver training programs targeted at increasing the caregiver knowledge, support, and confidence were identified as a successful approach to decrease caregiver burden and enhance outcomes (Chiu et al., 2013; Ducharme et al., 2011; Forbes et al., 2014; Samia et al., 2014).

Identified Literature Review Themes

Completion of a detailed literature review highlighted numerous reasons for the exponential increase in caregiver demand and burden. Some of the many reasons will be discussed next including: the nation's aging population, increased dementia prevalence, increased caregiver demand, and increased long-term care turnover rates (Adelman et al., 2014).

Aging Population

Nationally, by 2050, the number of Americans aged 65 or older is estimated to reach nearly 90 million, which is over double the number of older adults living in the United States during 2010 (Centers for Disease Control and Prevention [CDC], 2016). The number of adults aged 65 and older in ND is projected to increase by 50% from approximately 100,000 in 2011 to 150,000 in 2025 (ND Department of Health Division of Vital Records [ND Vital Records], 2014). In 2011, ND held the second highest proportion of residents 85 years and older when compared to the rest of the nation (ND Vital Records, 2014). The high proportion of older adults in ND and nationwide, emphasizes the importance of focusing on the needs of older adults. As a result of the aging population and longer life spans, chronic diseases have replaced infectious diseases as the leading cause of death (NCC, 2016). In fact, the leading risk factor for dementia is aging (Adelman et al., 2014).

Increased Dementia Prevalence

Due to the rapidly aging nation, unprecedented increases in dementia will be seen over the years to come. As of 2016, there were five million older adults with Alzheimer's disease, the most common cause of dementia (AANAC, 2014). However, without the discovery of successful therapeutic modalities to treat or prevent Alzheimer's disease, the number of American's with Alzheimer's disease is projected to triple by 2050, to approximately 15 million (Alzheimer's

Association, 2017). Nationwide, Alzheimer’s disease is ranked as the fifth leading cause of death among adults aged 65 and older (AANAC, 2014; AARP, 2015). In North Dakota, Alzheimer’s disease is ranked as the third leading cause of death, behind cancers and diseases of the heart (North Dakota Department of Health [ND Health], 2016). Additionally, as of 2016, ND has experienced an 80% increase in Alzheimer’s deaths since 2000 (Alzheimer’s Association and Centers for Disease Control and Prevention [AACDC], 2017; ND Health, 2016). In 2016, North Dakota reported the highest Alzheimer’s death rate in America (ND Health, 2016). The steadily increasing prevalence of dementia nationwide, and especially in ND, reinforces the necessity to address all facets influenced by Alzheimer’s disease at a public, private, individual, and community level.

Increased Caregiver Demand

As the lifespan lengthens and the population ages, a parallel increase is estimated to occur related to caregiver demand (Adelman et al., 2014; AACDC, 2017). A caregiver can be an individual providing support alone or arranging the work of others who give direct care (AANAC, 2014; AARP, 2015; Ducharme et al., 2011). In 2014, there were approximately 45 million caregivers in the United States (AANAC, 2014). It is estimated the number of dementia caregivers needed will increase by 85% from 2000 to 2050 (CDC, 2016). However, the number of caregivers in general is expected to only increase by 25% (CDC, 2016). Since the demand will greatly exceed the supply of caregivers, efforts to reduce dementia caregiver turnover and burden are essential.

On a more local level, in 2016, ND utilized nearly 36,000 informal caregivers who provided 35 million hours of unpaid dementia care, which can be valued at around 425 million dollars (ND Health, 2016). The number of adults aged 65 and older is expected to increase by

101% between 2000 and 2050, which is equivalent to a yearly rate of 2.3% (Adelman et al., 2014). However, over the same 30-year span, the number of caregivers projected to care for adults aged 65 and older is expected to increase by 25%, which is equivalent to a yearly rate of 0.8% (Adelman et al., 2014). Support to dementia caregivers will be crucial to help meet increasing caregiver demands.

Public Health Issue and Turnover

Authors of numerous studies have reported that without dementia caregivers, the current level of long-term healthcare could not be sustained throughout the nation (Alzheimer's Association, 2017; AANAC, 2014; AARP, 2015). Therefore, the project addresses a major public health issue and emphasizes the importance of supporting caregivers to maintain the long-term healthcare system. In 2014, informal caregivers nationwide provided an estimated 18 billion hours of unpaid care to those with dementia, which can be calculated to an estimated 220-billion-dollar contribution to society (Alzheimer's Association, 2017). Likewise, due to the aging population and increasing prevalence of dementia, especially Alzheimer's, there will be substantial increases in healthcare costs for the public, increased demands for healthcare workers, and increased needs for long-term healthcare facilities (Alzheimer's Association, 2017). In ND, the total cost in 2016 for Alzheimer's disease and other dementias including healthcare costs, long-term care, and hospice, was an estimated 236 billion dollars, and is predicted to increase to 1.1 trillion dollars by 2050 (ND Health, 2016).

Current and projected shortages of caregivers raise concern about the long-term care workforce. In 2012, the estimated average turnover rate for all long-term care staff was 43.9% (American Health Care Association [AHCA], 2014). The highest turnover rate for long-term staff was noted for dementia caregivers, at 51.5% (AHCA, 2014). Caregiving, especially a dementia caregiver, is associated with a higher than normal turnover rate secondary to the increased physical and mental demands of caregiving leading to increased burden and turnover (AACDC, 2017; Adelman et al., 2014). Organizational costs associated with turnover are significant, suggesting a further need to focus on decreasing caregiver burden to enhance retention (AACDC, 2017; Adelman et al., 2014; HHS, 2016). As the shortage worsens, staffing ratios increase, perpetuating caregiver burden and turnover (AHCA, 2014; HHS, 2016). The prohibitive costs associated with dementia greatly influence numerous facets of society especially public health, healthcare facilities, and the financial burden to families affected by dementia (HHS, 2016).

Caregiver Needs and Burden

Numerous research studies, indicate caregiver tasks can cause burden, but with proper interventions and resources, burden can be limited (AANAC, 2014; Adelman et al., 2014; Alzheimer’s Association, 2017; Ducharme et al., 2011). However, these same research studies reflect limited research-based information regarding the specific needs of dementia caregivers and what services and interventions would best decrease caregiver burden. Therefore, it is vital for further research on dementia caregiver support and interventions to be completed, disseminated, and utilized.

There are numerous tasks involved with caregiving. A caregiver may need to bathe the individual, turn him or her in bed, assist in feeding, and may even need to lift the individual if bedridden (Alzheimer’s Association, 2017). A caregiver may also need to handle finances for the individual, run errands, and provide transportation (Bastawrous, 2013; Bouldin et al., 2017). Healthcare tasks, such as giving shots, administering medications, changing dressings, and managing intravenous tubes, may also be routine tasks carried out by caregivers (Ducharme et al., 2011). Caregivers also need to provide emotional support, as the loss of independence is emotionally draining for the care recipient (Bouldin et al., 2017; Ducharme et al., 2011). Numerous roles and tasks are required to care for an individual and are burdening to the caregiver according to numerous studies reported previously.

Assorted studies report tasks of caregiving that can be burdening to the caregiver and often lead to negative health outcomes including feelings of guilt, depression, added stress, financial burden, elevated blood pressure, lowered immunity, back pain, decline in self-care habits, and limited time for oneself, family, and friends (AANAC, 2014; Alzheimer's Association, 2017; Chiu et al., 2013; Ducharme et al., 2011). Dementia caregivers report worse sleep (82%), worse eating habits (63%), worse exercise habits (58%), and significantly increased emotional stress (35%) (Alzheimer's Association, 2017).

Caregivers spend most of their time taking care of others and often forget to take care of their own health. Caregivers are 40% less likely to go to regular visits with their primary care provider as compared to non-caregivers, resulting in decreased health maintenance, decreased problem identification, and decreased health outcomes (Zhu et al., 2015). Additionally, dementia caregivers have a higher reported rate of acute provider visits associated with lower rates of regular health maintenance and the stressors associated with caregiving (Zhu et al., 2015). With the added stress, caregivers may engage in less health promotion activities, which can lead to further detriments to their overall health and may even increase their risk for death and additional healthcare costs (Alzheimer's Association, 2017). Depression is one of the most frequently reported negative outcomes associated with caregiver burden (Bouldin et al., 2017; Ducharme et al., 2011). Overall, the burden associated with dementia caregiving is becoming more significant.

Compared with other caregivers, dementia caregivers provide care which is considered more physically demanding, more emotionally demanding, costlier, more time-consuming, and exerts a greater impact on one’s personal, family, and work life (Adelman et al., 2014; Ducharme et al., 2011). On average, an individual spends 80 hours per week carrying out caregiver roles, often beyond their daily tasks and job (Bouldin et al., 2017; Ducharme et al., 2011). This emphasizes the need to focus on caregiver well-being and burden reduction. Similarly, even though there are many potential negative outcomes of being a caregiver, studies note there are various interventions and services available to caregivers to assist in preventing and treating caregiver burden. However, caregivers often lack the access to information or necessary resources to reduce caregiver burden and enhance care provided to the dementia care recipient (Alzheimer’s Association, 2017; Chiu et al., 2013; Robinson, Buckwalter, & Reed, 2013).

Several studies have discussed the relationship between formal dementia staff caregiver burden and behavior of the dementia residents (Cheng, 2017; Fearon & Nicol, 2011; Sprangers et al., 2015). Dementia recipients requiring higher levels of care have a direct relationship to an elevated level of caregiver burden. Training formal dementia caregivers on coping mechanisms to combat burden is essential to support the healthcare team in providing quality care to residents and to help reduce burden (Juthberg, Eriksson, Norberg, & Sundin, 2010). Physicians and nurse practitioners must also be aware of dementia caregiver needs and burden to best understand the full clinical picture. Dementia caregivers have reported increased medical health issues associated with caregiving including mental illnesses, hypertension, and orthopedic injuries. Since dementia caregivers are 40% less likely to visit their primary care provider for regular health maintenance, it is important for providers and nursing home staff to encourage caregivers to focus on their own health (Zhu et al., 2015).

Literature Gap

After completing a literature review on dementia caregiver needs, it was evident there was very little data published in North Dakota regarding specific dementia caregiver needs. Also, most available information was related to general caregivers at the national level, rather than information specific to dementia caregivers. Publications and data were found regarding the ND aging population, increasing dementia prevalence, and increased caregiver demand. However, there was little published research found addressing the individual needs of the ND dementia caregiver.

Another gap noted was that most of the research studies and caregiver program interventions were intended for caregivers with experience, such as healthcare workers and caregivers hired by a healthcare agency. There was limited literature focused on outcomes and programs for the dementia caregiver. Since 2012, there has been an increase in the development and research of dementia caregiver training programs, however before 2012 limited research was available. During the fall of 2015, a needs assessment was completed by the co-investigator, which addressed the literature gap by focusing on dementia caregiver needs in Fargo, ND. Identification of priority need areas for local dementia caregivers inspired the proposed dementia caregiver training program.

Dementia Caregiver Needs Assessment

A dementia caregiver needs assessment was completed fall 2015 that identified the need for implementation of a dementia caregiver training program within the community. The needs assessment was conducted in the Fargo-Moorhead community. The purpose of the assessment was to identify top dementia caregiver needs in the community and identify interventions to best address those needs. After analyzing the data, the top three reported caregiver needs within the community were: financial assistance, dementia care education, and home care services. Figure 1 provides visualization of the identified top dementia caregiver needs. The mean reported caregiver stress level was 7.6/10, indicating high levels of caregiver burden.

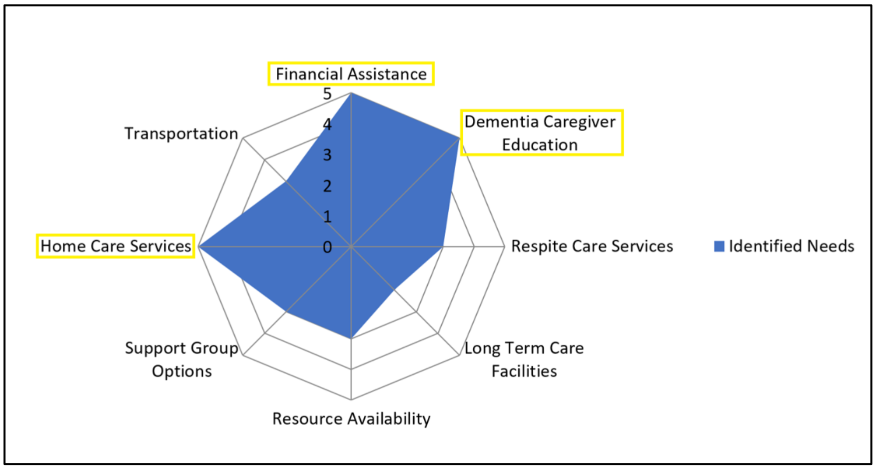


Figure 1. Community assessment dementia caregiver needs.

To determine the priority caregiver need for intervention development and implementation, various considerations were utilized. Interventions focused on the top three needs that were identified. Addressing the homecare service shortage and financial assistance would require more time, funding, community help, and partners than this co-investigator could provide within the scope of the project. Therefore, providing caregiver education was considered the most practical quality improvement project as the focus would be within the nursing scope of practice and costs would be less compared to the other two identified priorities. Based on practicality, scope of practice, detailed literature review, and a community needs assessment, a dementia caregiver training program was chosen as the priority dementia caregiver need and project focus.

CHAPTER THREE. THEORETICAL FRAMEWORK

Utilization of evidence-based practice (EBP) is the foundation for completing a successful practice improvement project. EBP is the “integration of best research evidence with clinical expertise to improve patient care and outcomes” (DiCenso, Gyatt, & Ciliska, 2014, p. 4). EBP is the expectation in clinical practice to enhance outcomes through utilization of the best available up-to-date evidence (Wallace & Vanhook, 2015). There are currently 47 identified EBP models in the literature to help guide project development, implementation, and evaluation (Wallace & Vanhook, 2015). The Iowa model of EBP and the Transitions Theory were chosen to provide a sound foundation for the project and provide guidance.

The Iowa Model of Evidence-Based Practice

Identifying a theoretical framework is considered an essential step for development of a strong EBP project. The Iowa model was chosen to guide the dementia caregiver training program and provide the project a strong EBP foundation. Marita G. Titler and colleagues are the developers of the Iowa model (White & Spruce, 2015). The model provides a very straight-forward, concise, yet comprehensive design to help guide an EBP project (Melnyk & Fineout-Overholt, 2015). See Appendix B for the Iowa model. The model clearly outlines a multistep process of implementing a change project with continuous feedback loops for evaluation and project improvement (Iowa Model Collaborative, 2017).

Once a topic area is identified and support has been established, a detailed literature review must be obtained to identify evidence-based research to guide the dementia caregiver project development (White & Spruce, 2015). After completion of a detailed literature review and analysis of evidence-based research, development of the dementia caregiver training program was initiated. Following development, implementation of the dementia caregiver training program took place. The implemented project was then evaluated. The Iowa model provided a guide and a strong EBP foundation for the dementia caregiver training program and will be used throughout the practice improvement project. Permission to utilize the Iowa model to guide the dementia caregiver training program was granted by the developers at the University of Iowa Hospitals and Clinics (APPENDIX C.).

Topic Selection

Several factors must be considered when choosing a topic for a practice improvement project. These include the priority of the problem, practicality of the topic, literature review support, and partner agency support. The topic of dementia caregiver burden was supported through a detailed literature review. Dementia caregivers experience increased levels of burden associated with increased physical, mental, and emotional demands of caregiving (AANAC, 2014; Alzheimer's Association, 2017; Cheng, 2017; Chiu et al., 2013; Ducharme et al., 2011). Caregiver burden is associated with numerous negative outcomes including increased health issues, decreased quality of care to care recipient, increased organizational costs, and increased turnover rates (Cheng, 2017; Fearon & Nicol, 2011; HHS, 2016; Juthberg et al., 2010). Caregivers hold the foundation to our nations long-term healthcare organization (Sprangers et al., 2015). Therefore, interventions targeted at decreasing dementia caregiver burden are vital. Evidence-based research supports dementia caregiver education as a successful way to reduce caregiver burden and enhance outcomes (AANAC, 2014; Adelman et al., 2014; Alzheimer's Association, 2017).

Next, the Iowa model emphasizes the importance of identifying triggers and organizational priorities to best guide one to a topic of interest and support (Melnyk & Fineout-Overholt, 2015). Identification of organizational priorities was completed by communicating with various dementia caregivers at the implementation agency. Discussion with agency caregivers enhanced support of the training program and enhanced development of the project by determining educational needs. Prior to program development, a questionnaire was provided for local long-term care agency caregivers to complete. The questionnaire helped determine local long-term care agency caregiver educational needs.

Forming a Team

After topic selection was completed and support for project obtained, a team was formed (Melnyk & Fineout-Overholt, 2015). Forming a team of stakeholders helped maintain support and enhanced development, implementation, and evaluation of the practice improvement project (White & Spruce, 2015). Stakeholders can be anyone who will make a positive contribution to the project including nurses, advanced practice providers, physicians, interdisciplinary colleagues, long-term care support staff, and topic experts. Committee members for the dementia training program project were chosen based on these criteria and include: Dean Gross, PhD, FNP-BC, committee chairperson; Kelly Buettner-Schmidt, PhD, RN; Paul Rokke, PhD; and Sarah Matcha, FNP-BC, RN. Additional team members include the agency dementia caregivers and agency support staff.

Evidence Retrieval

Following topic selection and team formation, retrieval of research-based evidence was completed to best develop the practice improvement project (White & Spruce, 2015). A detailed discussion of evidence retrieval is provided in the literature review section above. Evidence gathered for the dementia caregiver project includes the aging populating, caregiver demand, caregiver burden, turnover rates, and interventions aimed at reducing dementia caregiver burden. Various electronic databases were utilized to retrieve the evidence including Cochrane, CINAHL, Medline, and the NDSU online ejournal database. Textbooks and collaboration with other expert healthcare providers also contributed to evidence collection.

Grading the Evidence

To create a successful practice improvement project with an EBP foundation, evidence synthesis and analysis was completed (White & Spruce, 2015). The data gathered throughout the literature review and community needs assessment were sufficient to address both dementia caregiver burden and training programs focused on decreasing caregiver burden. Analysis of evidence is further detailed in the literature review section above. Critical appraisals of identified research and a data synthesis table were completed to grade the evidence and provide an EBP base for project development.

EBP Standard Development

Following literature review and analysis, team members collaborated to develop recommendations for practice. Recommendations aim to enhance practice, guidelines, treatment, education, and future research (White & Spruce, 2015). Objectives for this project focused on increasing caregiver knowledge and decreasing dementia caregiver burden at a local long-term care agency. Collaboration with a dementia caregiver expert and nurse practitioner (NP), enhanced the caregiver training program development. She has provided numerous education classes for dementia caregivers about burden and care techniques. She has also previously developed educational presentations for dementia caregivers, which have been provided to the co-investigator to utilize for the development of the dementia caregiver training program.

EBP Implementation

Implementation of a developed project occurs during a specified time frame and in coordination with the partnered agency and key stakeholders (Melnyk & Fineout-Overholt, 2015). Agency support is crucial to enhance project effectiveness and outcomes. Support was obtained from the local long-term care agency (APPENDIX D.) and implementation of the dementia caregiver training program was initiated June 2017.

Evaluation

Evaluation is an integral step of a practice improvement project. Evaluation should be completed at different periods during and following project implementation. EBP improvement projects need continuous evaluation to enhance outcomes and enhance change integration (White & Spruce, 2015). Without evaluation, no further practice recommendations and suggestions would be published, halting evidenced-based research and practice change (Melnyk & Fineout-Overholt, 2015). Statistical analysis of pre and post-questionnaires and scales were the core evaluation methods for the dementia caregiver training program.

Summary

The Iowa model enhanced structure and guidance during development of the dementia caregiver training program and provided the project with a solid EBP foundation. Also, the Iowa model helped guide the chosen EBP improvement project, form a team of key stakeholders, develop the dementia caregiver training program, and evaluate the implemented project.

Transitions Theory

The Transitions Theory is a middle range nursing theory developed by Afaf I. Meleis and colleagues throughout three decades of research in the late twentieth century (Parker & Smith, 2015). The theory was developed with two main goals: to prepare individuals for developmental, situational, and health illness transitions, and to care for them during the transition, enhancing outcomes (Alligood, 2017). Transitions influence everyone and can greatly impact numerous areas including health status, relationships, stress, and role status. Therefore, the Transitions

Theory is applicable to the nursing discipline as nursing involves taking care of individuals who may be experiencing transitions from graduating, giving birth, divorce, new cancer diagnosis, starting a new career, or preparing for surgery. Furthermore, Transitions Theory is directly applicable to the dementia caregiver population since caregivers all go through a transition while integrating to the caregiver role and while providing care daily for recipients who have differing needs. The theory focuses on understanding the change response, supporting the experience, and helping one to remain healthy before, during, and after the transition event (as cited in Parker & Smith, 2015).

The Transitions Theory can enhance nursing care for the dementia caregiver before, during, and after the transition event (as cited in Parker & Smith, 2015). The main purpose of the theory is to identify and predict individuals experiencing life changes and then assisting these individuals in terms of health promotion (Meleis, 2010). The Transitions Theory will enhance dementia caregiver project outcomes since focus will be directed at assisting caregivers to transition through their various experiences in a healthy way. The theory describes transitions, explains transitions, predicts transitions, and identifies applicable interventions for the transition experienced (Alligood, 2017).

The six major concepts of the Transitions Theory include: "types and patterns of transitions, properties of transition experiences, transition conditions, process indicators, outcome indicators, and nursing therapeutics" (Meleis, 2010, p. 382). The Transitions Theory includes five outcome response patterns which help to predict the overall outcome from the transition event experienced by the individual (as cited in Parker & Smith, 2015). The five outcome response patterns are: "mastery, fluid integrative identities, resourcefulness, healthy interactions, and perceived well-being" (as cited in Parker & Smith, 2015, p. 367). The theory provides a framework which guides care prior to, during, and after the transition event (Alligood, 2017). Additionally, Transitions Theory can be broken down into two main concept areas: understanding the transition event and interventions to facilitate fluid transition (Parker & Smith, 2015). The co-investigator's project utilized three of the Transitions Theory interventions during the training program to enhance program effectiveness. The three intervention concepts, clarifying meanings, mobilizing support, and debriefing will be discussed next (Parker & Smith, 2015).

Clarifying Meanings

The first intervention concept is clarifying roles, competencies, and meanings (Parker & Smith, 2015). The theory emphasizes the importance of ensuring caregivers are knowledgeable about their roles and have the education needed to succeed (Parker & Smith, 2015). The project encompassed this concept by providing education to caregivers focused on enhancing their knowledge and increasing their confidence in caring for individuals with dementia.

Mobilizing Support

The next intervention concept emphasizes the importance of providing support to caregivers to enhance transition through an event, enhance outcomes, and decrease burden (Parker & Smith, 2015). Implementation of a caregiver training program aimed to provide caregivers with a support group to talk about their experiences and share resources. The training program provided additional resources to increase knowledge and decrease burden.

Debriefing

The final intervention from the transition theory which was utilized during project implementation is debriefing (Parker & Smith, 2015). Debriefing is a "process of communicating to others the experiences that a person or group encountered around an event" (Parker & Smith, 2015, p. 369). During the training program, caregivers will be encouraged to share their challenging, difficult, and life-changing experiences associated with caregiving to help the caregivers come to terms with their experiences along with helping attain psychological well-being (Parker & Smith, 2015).

Summary

The Transitions Theory provided a strong framework for development of the educational material provided to the dementia caregivers during the training program. Utilizing the intervention concepts, clarifying meanings, mobilizing support, and debriefing, from the Transitions Theory enhanced project development by focusing on fluid transition through events with the goal of decreasing burden.

CHAPTER FOUR. PROJECT DESCRIPTION

Project Objectives

Project objectives were developed to support successful implementation of this dissertation. Creating a training program, educating caregivers, and caregiver burden reduction were the main project objectives. Objectives included:

1) Develop and implement an educational dementia caregiver training program at a local long-term care agency.
2) Increase dementia caregiver knowledge about dementia and behavior modification, following the training program.
3) Increase dementia caregiver knowledge about ways to reduce burden, following the training program
4) Decrease dementia caregiver burden, two months following the training program.

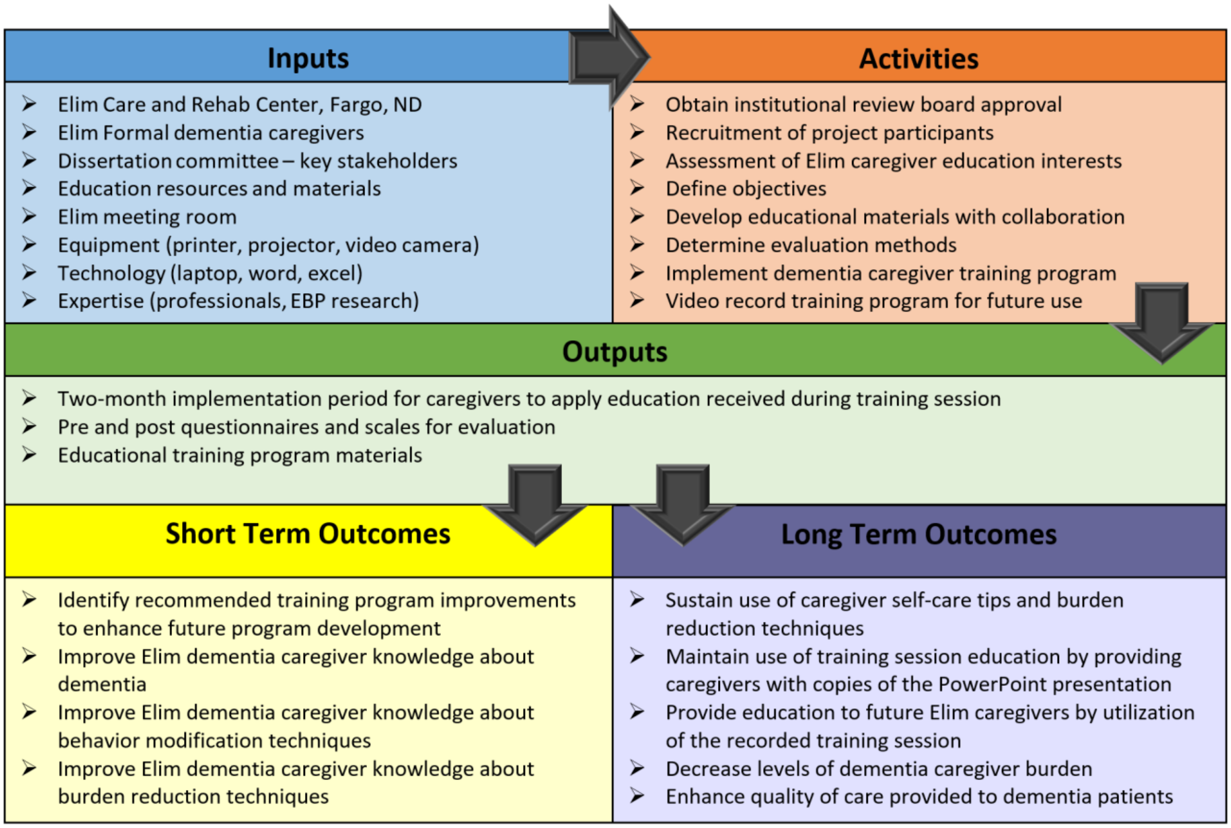
Project Evaluation

Evaluation of the training program was vital to assess if the developed objectives were met. An evaluation logic model was developed and utilized to help with visualization and understanding of the training program. Additionally, a consulting statistician, was utilized to further assist with data analysis and development of descriptive statistics. Utilizing an expert in data analysis helped ensure accuracy of data analysis and development of reliable and valid outcome measures. Evaluation methods for each project objective are discussed below.

Objective One

- Develop and implement an evidenced-based educational dementia caregiver training program at a local long-term care agency.

The development and implementation of the training program is shown below. Evaluation of this objective was developed using the detailed literature review, the theoretical framework, and guided by a logic model as developed by the co-investigator (Figure 2). Evaluation of the training program included the outputs and outcomes presented in the logic model. Evaluation of the training program was completed via analysis of pre-post questionnaires and scales. Open-ended questions were included in the knowledge questionnaires to assess training program effectiveness and to obtain suggestions for program improvement.



Inputs

- Elim Care and Rehab Center, Fargo, ND
- Elim Formal dementia caregivers
- Dissertation committee – key stakeholders
- Education resources and materials
- Elim meeting room
- Equipment (printer, projector, video camera)
- Technology (laptop, word, excel)
- Expertise (professionals, EBP research)

Activities

- Obtain institutional review board approval
- Recruitment of project participants
- Assessment of Elim caregiver education interests
- Define objectives
- Develop educational materials with collaboration
- Determine evaluation methods
- Implement dementia caregiver training program
- Video record training program for future use

Outputs

- Two-month implementation period for caregivers to apply education received during training session
- Pre and post questionnaires and scales for evaluation
- Educational training program materials

Short Term Outcomes

- Identify recommended training program improvements to enhance future program development
- Improve Elim dementia caregiver knowledge about dementia
- Improve Elim dementia caregiver knowledge about behavior modification techniques
- Improve Elim dementia caregiver knowledge about burden reduction techniques

Long Term Outcomes

- Sustain use of caregiver self-care tips and burden reduction techniques
- Maintain use of training session education by providing caregivers with copies of the PowerPoint presentation
- Provide education to future Elim caregivers by utilization of the recorded training session
- Decrease levels of dementia caregiver burden
- Enhance quality of care provided to dementia patients

Figure 2. Logic model for developed practice improvement project objectives

Objective Two

- Increase dementia caregiver knowledge about dementia and behavior modification, following the training program.

Education provided to the caregivers during the training session was focused on dementia and behavior modification. Participants were also provided with the PowerPoint handout to enhance information retention. Increased knowledge evaluation was based on analysis of the pre-education knowledge questionnaire (APPENDIX K.), post-education knowledge questionnaire (APPENDIX M.), and the two-month post-education knowledge questionnaire (APPENDIX O.). The questionnaires were developed by the co-investigator. The pre-education knowledge questionnaire was completed during the training program introduction. The post-education knowledge questionnaire was completed during the training program conclusion. The two-month post-education knowledge questionnaire was completed two-months following program completion. Completion of questionnaires were voluntary. Analysis of the pre-post knowledge questionnaires measured caregiver education levels before and after the training program and enhanced analysis of this objective. Most questions utilized a five-point Likert scale to address caregiver knowledge.

Objective Three

- Increase dementia caregiver knowledge about ways to reduce burden, following the training program

In addition to providing education to caregivers about behavior modification, the training program focused on caregiver self-care and caregiver burden. Education was provided about ways to reduce burden. The same knowledge questionnaire was utilized for evaluation of this objective as was utilized for objective two. Increased knowledge evaluation was based on analysis of the pre-education knowledge questionnaire (APPENDIX K.), post-education knowledge questionnaire (APPENDIX M.), and the two-month post-education knowledge questionnaire (APPENDIX O.). Questionnaire completion was voluntary. Questions utilized the five-point Likert scale to address caregiver knowledge about ways to reduce burden.

Objective Four

- Decrease dementia caregiver burden, two months following the training program.

The training program focused on providing education to caregivers about ways to decrease burden. Handouts were provided as a resource to utilize after class completion. Evaluation of this objective was completed through use of both the knowledge questionnaire discussed above and the Professional Care Team Burden (PCTB) Scale. The clinically developed PCTB Scale has a Cronbach's alpha of 0.785% and, therefore, is a reliable instrument to measure formal caregivers' burden (Auer et al., 2015). The formal title for the developed scale is the Professional Care Team Burden Scale. However, for ease of understanding, the scale is referred to as the burden scale throughout this project.

Utilizing the previously developed burden scale helped quantify data and enhanced validity and reliability of data measurement. The developed burden scale provided a score for the level of caregiver burden. The caregivers completed the pre-education burden scale (APPENDIX L.) during training program introduction. The post-education burden scale (APPENDIX N.) was completed during the training program conclusion. The two-month post-education burden scale (APPENDIX P.) was completed two-months following the training program. Scale completion was voluntary. Analyzing burden scores of dementia caregivers at baseline, completion of the program, and two months post-implementation helped to evaluate this objective. Permission for utilization of the caregiver burden scale was obtained (APPENDIX Q.).

Congruence of the Project to the Organization’s Strategic Plan

The practice improvement project was implemented at a local long-term care agency. More specifically, the staff of the memory care unit at the local long-term care agency, were the individuals who received the education developed for the training program. The project aligned with the mission of the local long-term care agency which is to provide high quality healthcare to individuals with memory loss. The dementia training program provided staff with education to further enhance caregiving abilities. The local long-term care agency also strives to ensure staff members receive special training to care for those with memory loss and are provided with resources needed to succeed. The training program provided staff with additional resources to increase knowledge and enhance outcomes. Furthermore, local long-term agency staff reported they receive quarterly education. However, the education is rarely focused on caregiver burden or techniques to handle various dementia behaviors. The training program provided the agency’s caregivers with additional education on caregiver burden and dementia behavior modification.

Project Design

The practice improvement project design was focused on increasing caregiver knowledge and decreasing levels of burden through implementation of the dementia caregiver training program at a local long-term care agency. Direct contact was made with the agency to determine organizational priorities. The agency was interested and enthusiastic about partnering in development of the dementia caregiver training program. Approval from the agency was granted for implementation of the project (APPENDIX D.). Numerous educational topics associated with dementia caregiver burden could be provided to the caregivers including: self-care, caregiver burden, communication techniques, types of dementia, dementia behavior management, and managing end of life issues. However, due to limited training session time, a caregiver education needs survey was conducted prior to program development. After obtaining approval for project implementation at the agency, determination of dementia caregiver educational needs was addressed.

Local Long-Term Care Agency Caregiver Educational Needs

Integrating evidence with clinical expertise and participant preferences is the ideal project development model to enhance collaboration and project outcomes (Melnyk & Fineout-Overholt, 2015). Additionally, there are numerous educational topics applicable to dementia caregiver burden. However, to develop a pertinent and successful training program it was important to identify agency dementia caregiver educational needs and interests. One could implement a highly rated dementia caregiver training program based on research, but without collaboration, one would be unable to enhance participation and project outcomes. To determine the caregiver educational needs, an educational needs survey was developed and distributed to the dementia caregivers by the co-investigator (APPENDIX E.). Survey questions addressed educational topics of interest, knowledge needs, and learning style preferences.

Prior to making any contact with agency caregivers, project approval was received (APPENDIX F.) from the NDSU Institutional Review Board (IRB). Once IRB approval was received, the educational needs survey was conducted by the co-investigator at three separate times on the same day to increase participation. Survey participation was voluntary. Eight surveys were completed and collected. Analysis of the survey data revealed three top priority educational interest areas of caregivers at a local long-term care agency: caregiver burden, dementia communication techniques with dementia residents, and coping with behaviors associated with dementia such as aggression, sundowning, hallucinations, and delusions. The preferred learning style was split between group discussion and PowerPoint presentation. Based on the information from the educational needs survey, development of the training program began.

Development of Training Content

An interactive PowerPoint presentation was created for the dementia caregiver training program. The presentation focused on the top three educational needs identified from the educational needs survey: caregiver burden, communication techniques, and coping with dementia behaviors. Development of training materials was done in collaboration with a neurology NP who works with numerous dementia patients and dementia caregivers. The NP provided expertise and knowledge to the developed training program. The NP has developed numerous PowerPoint presentations for the agency's dementia caregivers and has taught numerous education classes for dementia caregivers. For the education classes, she has also developed various PowerPoint presentations on dementia caregiver topics including the identified top three educational needs. The co-investigator was given approval by the neurology NP to utilize and adapt her previously developed PowerPoint presentations. The dementia caregiver training material was developed by the NP and adapted by the co-investigator to meet the objectives of the project and the education interests of agency caregivers. Refer to Appendix G, for the slides of the PowerPoint presentation utilized during the dementia caregiving training program.

Training Program Design

Once the dementia caregiver training program was developed, implementation took place at the agency. The dementia caregiver training program was conducted at the most convenient time of the day and the most convenient day of the week for the dementia caregivers. The co-investigator hosted two, one-hour training sessions to implement the dementia caregiver training program. The training focused on the three caregiver educational interests: caregiver burden, communication techniques, and coping with dementia associated behaviors. Also, since learning preferences were split between group discussion and PowerPoint presentation, the training program utilized both styles.

During the one-hour training program, the co-investigator provided training to the caregivers through PowerPoint presentation and encouraged group discussion. The interactive PowerPoint presentation was adapted from previously developed dementia caregiver educational content provided by the neurology NP. For those who preferred educational handouts, a copy of the PowerPoint presentation was provided to all participants at the beginning of the training program. The agency requested to record the co-investigator during the training program for utilization of education for new hires and future mandatory education. The agency provided a video camera and a technology support staff member to organize and record the training session. The recording did not show any participants. Instead, the video recording was focused only on the PowerPoint presentation and co-investigator leading the training program.

Participants

The training program was voluntary and made available to all formal agency dementia caregivers who spent any amount of time working on the memory care unit. The caregivers had various job titles including: nurses, certified nursing assistants, housekeepers, case managers, restorative aids, Chaplin, activity staff, and dietary staff. The training program was a recommended option to fulfill their mandated quarterly dementia training. Staff were not penalized for missing the training program. However, they would need to fulfill their quarterly dementia training requirements by completing one-hour of continuing education modules or watching the co-investigators recorded one-hour training program.

To notify staff of the training program, the agency nurse manager encouraged staff attendance by utilization of posters and email. The manager also worked with staffing to ensure extra staff were scheduled for the day of training to enhance attendance. The co-investigator developed a poster (APPENDIX H.) and email (APPENDIX I.) to notify staff of the recommended training. The co-investigator placed numerous posters throughout the unit and breakroom and the manager forwarded the email to all dementia caregiver staff. The email was sent one month, two weeks, and one week prior to training to enhance awareness and participation.

Training Program Outline

Each one-hour training program was broken down into three main sections: introduction, training content, and conclusion. Ten minutes of the program was spent on the introduction which included: oral consent (APPENDIX J.) and voluntary completion of a pre-education knowledge questionnaire (APPENDIX K.) and pre-education burden scale (APPENDIX L.). Five minutes of the program was spent on the conclusion which consisted of voluntary completion of the post-education knowledge questionnaire (APPENDIX M.) and post-education burden scale (APPENDIX N.). The questionnaires and scales are explained in the project evaluation section above. The other forty-five minutes of the program provided the dementia caregivers with education on burden, self-care tips, communication, and managing dementia associated behaviors. The three intervention concepts from the Transitions Theory provided structure to the training session. The three interventions are clarifying caregiver competencies and providing education, providing resources, and debriefing.

Following completion of the training program, caregivers were encouraged to take the presentation printout with them for reference and begin to utilize and apply the training they received over the next two months. Two-months following program completion, the co-investigator returned to the agency to distribute a two-month post-education knowledge questionnaire (APPENDIX O.) and two-month post-education burden scale (APPENDIX P.). Returning two months post project implementation allowed for analysis of program effectiveness and caregiver knowledge retention. Questionnaires and scales assisted with evaluation of developed objectives by using five-point Likert scale formatted questions along with qualitative questions. Scale questions addressed dementia caregiver burden levels. The questionnaire focused on caregiver demographics, knowledge level, self-care, and program improvement suggestions.

Protection of Human Subjects

Careful review of the dementia caregiver training program helped ensure safety, protection of participants, determination of risks and benefits, and formulation of an oral consent for the training program. The participants of the training program were agency dementia caregivers including nurses, nursing assistants, case managers, activity staff, and dietary staff. All participants were male or female and age eighteen or older (APPENDIX D.). Since the project did not involve invasive testing, monitoring, medications, or activities that could result in injury there were few risks associated with implementation. The potential risks to the participants included possible sharing of personal and sensitive information in questionnaires. Risks were minimized by oral consent and data protection.

Oral consent was obtained at the beginning of the training session (APPENDIX J.). Training program participation was voluntary as was completion of questionnaires and scales. The co-investigator and participants were the only individuals in the training room. Only the co-investigator had access to the questionnaires and burden scales. The following personally identifiable information was collected on the surveys and questionnaires: name, age, gender, and job title. The original questionnaire and scale data were maintained on paper. Analysis of original data were transferred to computer, excel and word format, during data analysis. No electronic data have identifiers. The original data will be stored at the NDSU School of Nursing, in a locked file cabinet for 3 years, and then will be destroyed. Electronic files of summarized results, with de-identified information, will be stored on the co-investigators personal strong-password protected laptop. The potential benefits of the training program included increasing caregiver confidence, decreasing caregiver burden, increasing level of caregiver education, and gaining support from other participants.

Project Resources

Recourses required to conduct this practice improvement project included time, an implementation agency, agency dementia caregivers and other support staff, technology, training materials, and key stakeholders. Forming a team of key stakeholders (dementia caregivers, nurses, case managers, social workers, providers, nursing home staff, and respite care staff) helped maintain support and enhanced effectiveness of the implemented EBP improvement project. The neurology NP was a vital contributor to project development. The provider offered her expert knowledge and resources to the co-investigator. Training materials were developed by the NP and adapted by the co-investigator to meet the needs of the agency caregivers. The nursing manager, was also a vital resource for program development and implementation. She was the agency point of contact for the co-investigator, answered all questions, and provided continued motivation for project completion.

The agency provided the following resources: meeting room, projector screen, video camera, dementia caregivers, and printer (APPENDIX D.). Thirty color copies of the PowerPoint presentation were printed and provided to the participants for reference. Additionally, the co-investigator provided participants with snacks during the training sessions to enhance attendance. Funding for this project included costs of printing, miscellaneous office supplies, and snacks provided to the participants. The total costs for all required materials and resources was minimal.

CHAPTER FIVE. RESULTS

Implementation of the quality improvement project described above was started on June 9th, 2017 and concluded August 9th, 2017 at the agency. The project population included only formal dementia caregivers, who worked on the memory care unit. A total of 42 agency dementia caregivers were encouraged to attend the training program. Of the 42 agency dementia caregivers, 26 (61.9%) caregivers attended the training program. There were 15 (57.7%) participants who completed the training on June 9th, 2017 and 11 (42.3%) participants completed the training on June 10th, 2017. Of the total 26 participants, 22 (84.6%) completed the pre-post questionnaire and burden scale, which was administered right before the training session and right after the training session. The questionnaire and burden scale were then again administered on August 9th, after the two-month implementation window. Twelve (46.2%) participants completed the two-month post-questionnaire and burden scale. Questionnaire and burden scale completion was voluntary for all training session participants.

Project Demographics

Most of the training session participants were female dementia caregivers employed by the agency. There were 21 (80.8%) female participants and five (19.2%) male participants. Dementia caregivers included any individual who provided care to someone with dementia. Therefore, there were numerous job titles and roles of the training session participants including: seven certified nursing assistants, six licensed practical nurses, five registered nurses, two case managers, two dieticians, two housekeepers, one unit manager, and one chaplain. The work experience among participants ranged from less than one year to 38 years. The participants had an average of 13.1 years of experience working as a dementia caregiver, with a median of 11.5 years of experience. The age among participants ranged from 21 to 74, with an average age of 38 and a median age of 35. Figure 3 is included to help visualize the various dementia caregiver roles.

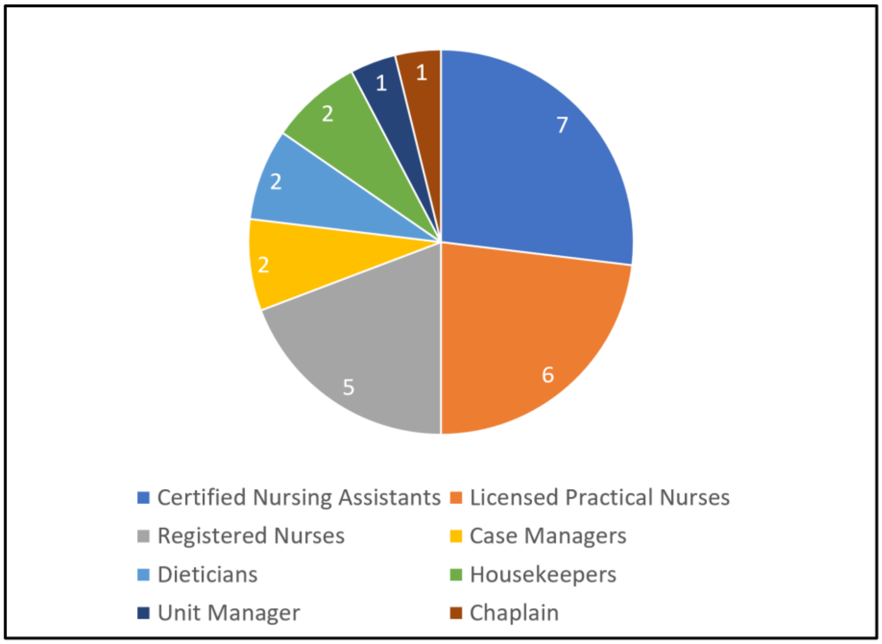


Figure 3. Demographics

The original questionnaire and scale data were maintained on paper and will be stored at the NDSU School of Nursing, in a locked file cabinet for three years, and then destroyed. Analysis of original data were transferred to a computer, utilizing Excel, during data analysis. No electronic data have identifiers. The questionnaires and burden scales were completed on paper right before training, right after training, and two-months post-training. Collection of completed questionnaires and scales was done immediately after completion to ensure maintenance of confidentiality. Only the co-investigator has access to the original paper data. Reports were generated in Excel to enhance data analysis and include graphs, charts, and averages.

Data Results

To review, the practice improvement project objectives included 1) develop and implement an educational dementia caregiver training program at a local long-term care agency;

2) increase dementia caregiver knowledge about dementia and behavior modification, following the training program; 3) increase dementia caregiver knowledge about ways to reduce burden, following the training program; and 4) decrease dementia caregiver burden, two months following the training program.

Burden Scale Data Results

The burden scale data were quantitative in nature and included a five-point Likert scale with response choices of *strongly disagree, disagree, neutral, agree, and strongly agree.* A total of 10 Likert scale questions were asked on the burden scale. The responses were associated with a numerical value with strongly disagree worth four points and strongly agree worth zero points. The total points for all ten burden scale questions were totaled up for each participant, resulting in a quantitative burden score for each participant. Higher burden scale scores correlate with higher levels of burden. The highest possible burden score is 40/40, indicating high levels of burden. The lowest possible burden score is 0/0, indicating minimal levels of burden. Twenty-two (84.6%) out of the 26 participants fully completed the pre-education burden scale and the post-education burden scale, while 12 (46.2%) out of 26 participants fully completed the two-month post-education burden scale. The two-month post-education burden scale data were weighted to equal 22 respondents instead of the 12 respondents, to allow for enhanced data analysis. Therefore, data result descriptions below will include all 22 respondents.

Pre-post and two-month post comparison of all ten individual Likert burden scale questions are depicted in graphs to enhance visualization of data results. Answers to each of the 10 individual Likert burden scale questions have been summarized in graphs to enhance visualization of data results, refer to Appendix R. The average pre-education burden scale score for the 22 participants was 16/40. The average post-education burden scale score for the 22 participants was 12.1/40. Additionally, the average two-month post-education burden scale score for the 12 respondents was 11.1/40. Figure 4 provides a visualization of the average burden scale score changes from prior to the training session to two-months after the implementation window.

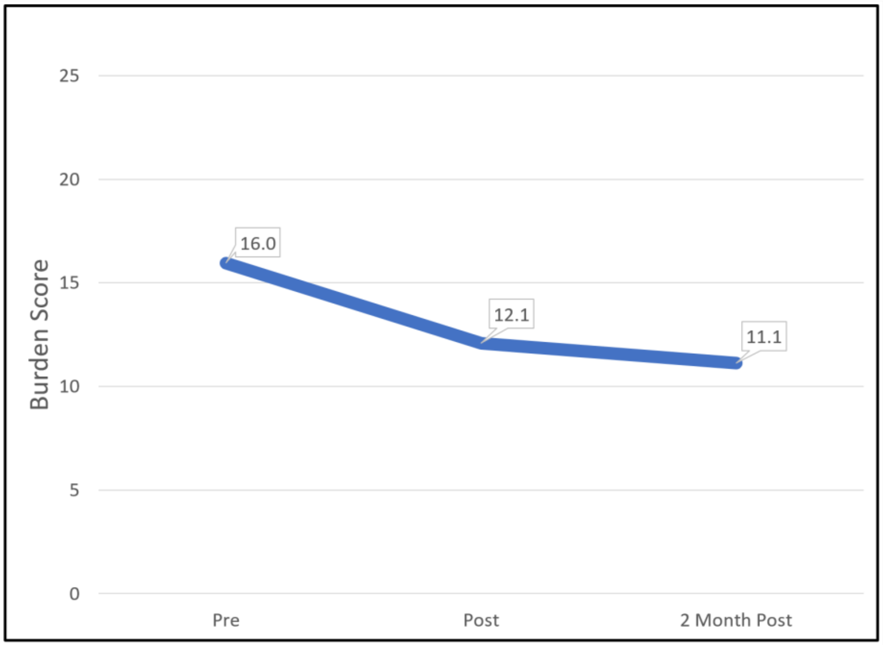


Figure 4. Average burden scale scores

Knowledge Questionnaire Data Results

The knowledge questionnaire data were primarily quantitative and included a total of seven questions, with six of the seven being quantitative five-point Likert style questions and one being a qualitative question. Four of the seven questions utilized a five-point Likert scale with response choices of *not at all, slightly, moderately, very, and extremely*. The other two quantitative questions also utilized a five-point Likert scale, but with response choices of *very important, important, moderately important, slightly important, and not important*. The knowledge questionnaire concluded with a qualitative question asking the participant what was most helpful during the training and suggestions for improvement.

Twenty-two (84.6%) out of the 26 participants fully completed the pre-education knowledge questionnaire and the post-education knowledge questionnaire, while 12 (46.2%) out of 26 participants fully completed the two-month post-education knowledge questionnaire. The two-month post-education knowledge questionnaire data were also weighted to equal 22 respondents instead of the 12 respondents, to allow for data analysis of the data at the pre-post and two-month post-education questionnaires. Graphs have been included within the paper below to represent the data obtained from the knowledge questionnaires.

For each of the six quantitative five-point Likert style questions, average scores were generated to enhance data analysis. The response options for four of the questions were *not at all, slightly, moderately, very, and extremely* and all were assigned a numerical value zero through four. Zero was assigned to not at all and four was assigned to extremely. The response options for the other two quantitative five-point Likert style questions were *very important, important, moderately important, slightly important, and not important*, and were also assigned a numerical value zero through four. Zero was assigned to not important and four was assigned to very important. A total of 4 points could be received per question for each respondent. The higher the score the higher the importance rating, knowledge level, or comfort level. The highest possible score is 4/4, indicating higher importance ratings, knowledge levels, or comfort levels. The lowest possible score is 0/0, indicated low importance ratings, knowledge levels, or comfort levels. The average question scores will be detailed below under each objective and in chapter six.

Question One

How comfortable do you feel with providing care to dementia patients? This question was created to establish a baseline knowledge level for providing care to dementia patients. The baseline participant knowledge level provides a means to compare changes from baseline, to right after the training session, and then two-months later.

On the pre-education knowledge questionnaire, two (9.1%) responded not at all comfortable and five (22.7%) responded slightly comfortable. However, zero (0%) responded not at all and slightly on the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Eight (36.3%) responded very comfortable on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 14 (63.6%) responded very comfortable and where 16 (72.7%) responded very comfortable on the two-month post-education knowledge questionnaire. Additionally, an average score for question one was generated. The average pre-education knowledge questionnaire score for the 22 participants was 2.32/4. The average post-education knowledge questionnaire score for the 22 participants was 3.27/4. Additionally, the average two-month post-education knowledge questionnaire score for the 12 respondents was 3.09/4.

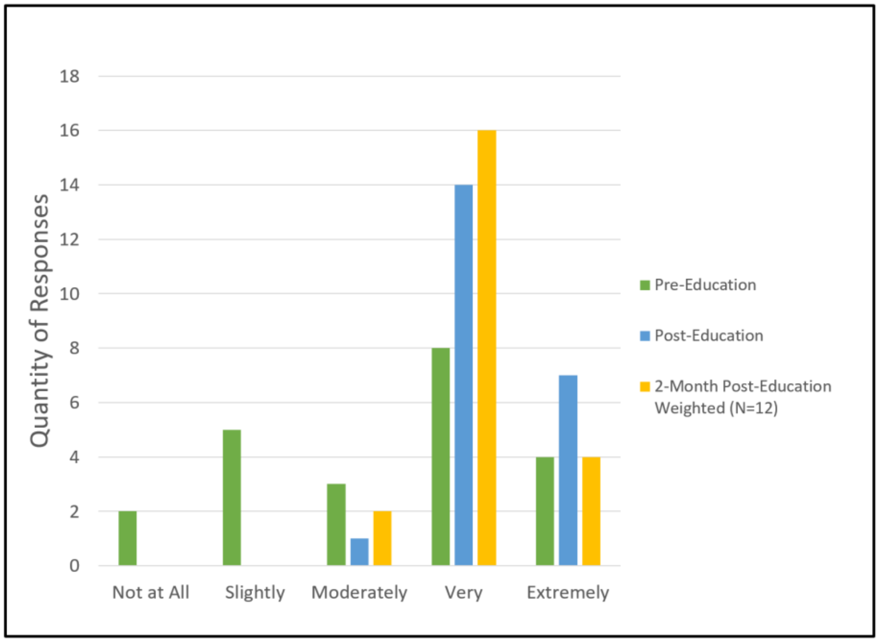


Figure 5. Knowledge question one

Question Two

How knowledgeable do you feel about communicating effectively with dementia patients? Question two was designed with similar intentions as question one. Question two was created to establish a baseline knowledge level about communication techniques with dementia patients. The participant baseline knowledge level will allow for analysis of knowledge level changes from baseline, to right after the training program, and then two-months after the training session.

On the pre-education knowledge questionnaire, one (4.5%) responded not at all knowledgeable and three (13.6%) responded slightly knowledgeable. Zero (0%) responded not at all and slightly on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Eight (36.4%) responded very knowledgeable on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 12 (54.5%) responded very knowledgeable and 16 (72.7%) responded very knowledgeable on the two-month post-education knowledge questionnaire.

Additionally, an average score for question two was generated. The average pre-education questionnaire score for the 22 participants was 2.41/4. The average post-education questionnaire score for the 22 participants was 3.0/4. The average two-month post-education questionnaire score for the 12 respondents was 2.91/4.

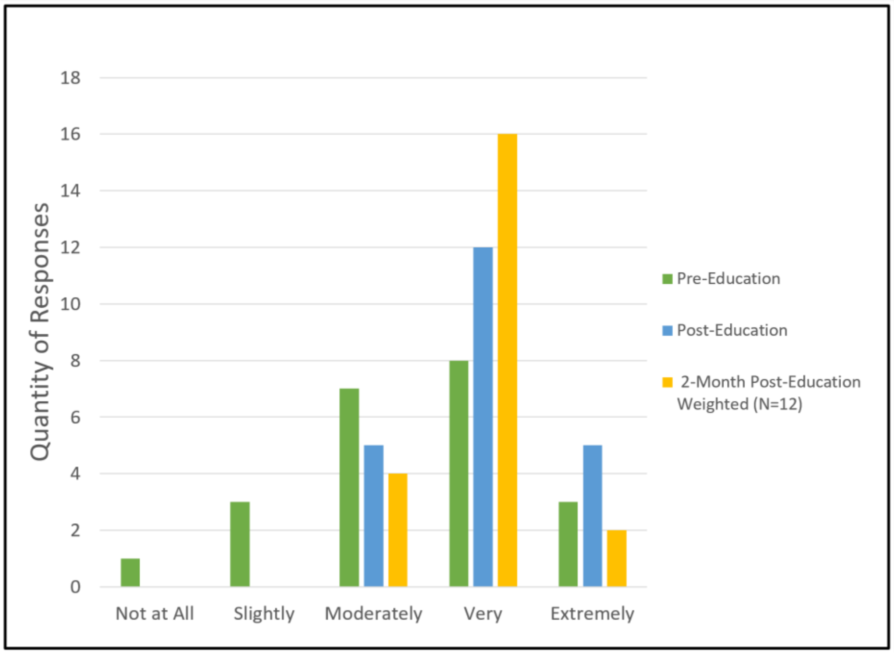


Figure 6. Knowledge question two

Question Three

How knowledgeable do you feel about handling agitation and behavior issues in those with dementia? Question three was also designed for similar purposes as question one and two, to determine a baseline knowledge level about dementia behavior management. The baseline knowledge level will allow for comparison from prior to the training to two months after the training. On the pre-education knowledge questionnaire, one (4.5%) responded not at all knowledgeable and six (27.2%) responded slightly knowledgeable. However, zero (0%) responded not at all and slightly on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Three (13.6%) responded very knowledgeable on the pre-education knowledge questionnaire, compared to the 12 (54.5%) very knowledgeable responses received on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire.

Additionally, an average score for question three was generated. The average pre-education questionnaire score for the 22 participants was 1.95/4. The average post-education questionnaire score for the 22 participants was 2.86/4. The average two-month post-education questionnaire score for the 12 respondents was 2.77/4.

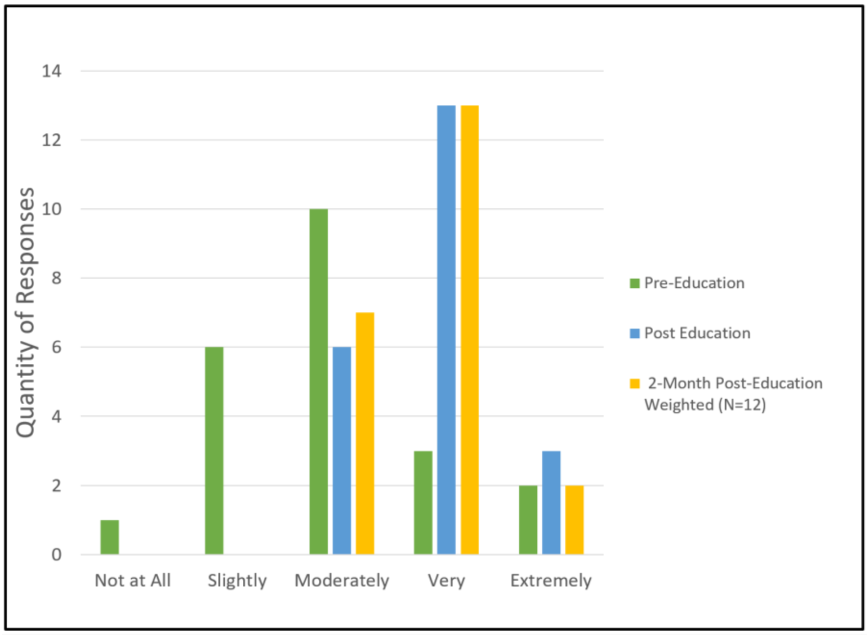


Figure 7. Knowledge question three

Question Four

How knowledgeable do you feel about ways to decrease caregiver burden? Question four was also developed with the intent to determine a baseline knowledge level about techniques to help decrease caregiver burden. Improvement in education level would indicate increased knowledge about ways to decrease caregiver burden. Utilizing this question allowed for comparison of participant knowledge levels on decreasing caregiver burden.

On the pre-education knowledge questionnaire, one (4.5%) responded not at all knowledgeable and five (22.7%) responded slightly knowledgeable. However, zero (0%) responded not at all and slightly on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Six (27.3%) responded very knowledgeable on the pre-knowledge questionnaire, compared to the two-month post-education knowledge questionnaire where nine (40.9%) responded very knowledgeable and 12 (54.5%) responded very knowledgeable on the post-education knowledge questionnaire.

Additionally, an average score for question four was generated. The average pre-education questionnaire score for the 22 participants was 2.14/4. The average post-education questionnaire score for the 22 participants was 3.0/4. The average two-month post-education questionnaire score for the 12 respondents was 2.59/4.

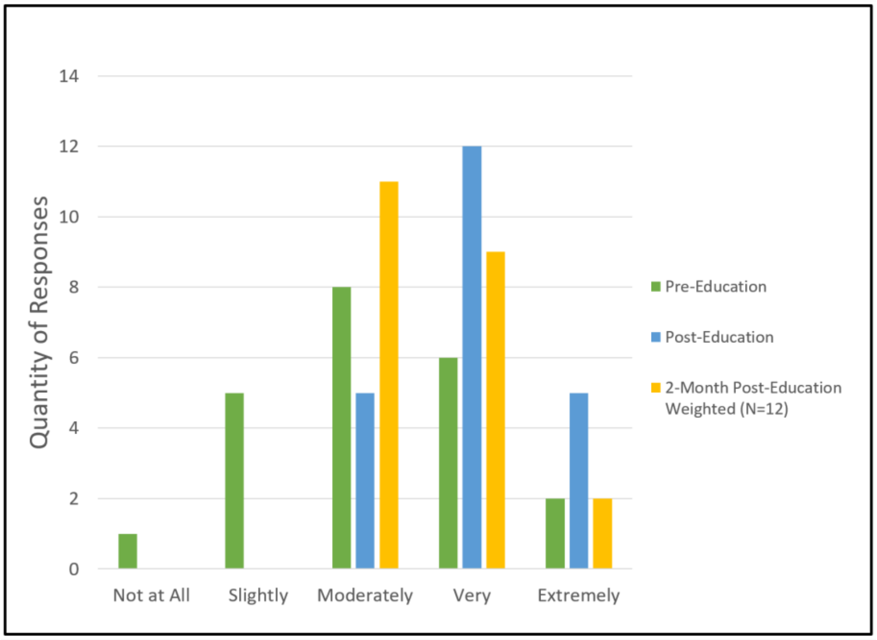


Figure 8. Knowledge question four

Question Five

How would you rate the importance of taking care of yourself? Intention of this question was to determine how important the participants felt it was to take care of their own self and to then compare how they rate the importance from prior to the training, to after the training, and then two-months post-training.

Zero (0%) responders chose not important or slightly important on all three questionnaires about how important they rate taking care of themselves. Eleven (50%) responded very important on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 12 (54.5) responded very important and the two-month post-education knowledge questionnaire where 18 (81.8%) responded very important.

Additionally, an average score for question five was generated. The average pre-education questionnaire score for the 22 participants was 3.41/4. The average post-education questionnaire score for the 22 participants was 3.36/4. Additionally, the average two-month post-education questionnaire score for the 12 respondents was 3.82/4.

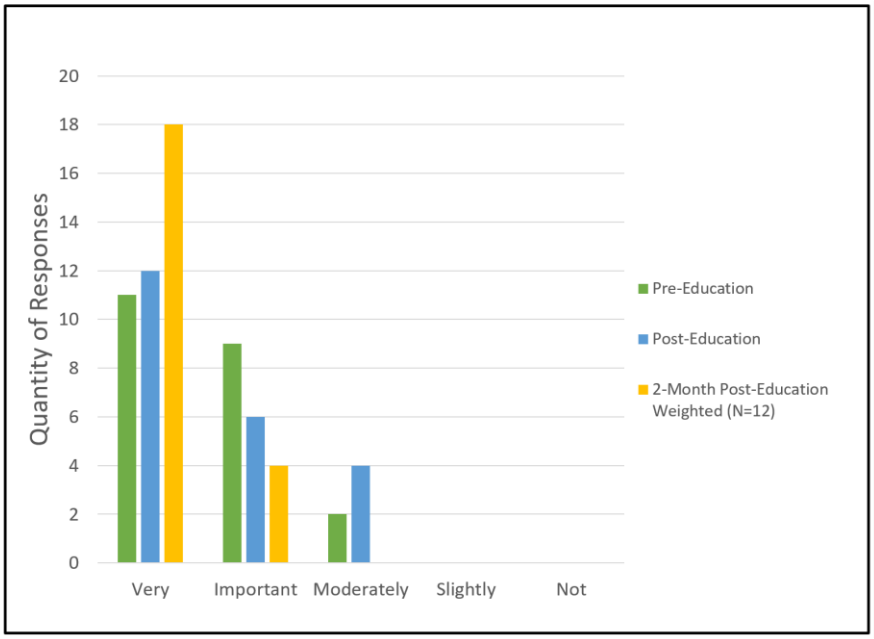


Figure 9. Knowledge question five

Question Six

How important is it for you to go to your healthcare provider for a yearly physical? Question six was included to determine how important caregivers felt it was to take care of oneself by visiting their primary for regular health maintenance. On the pre-education knowledge questionnaire, five (22.7%) responded not important and six (27.2%) responded slightly important when answering how important it is to them to go to their healthcare provider. However, zero (0%) responded not and slightly on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Three (13.6%) responded important on the pre-education knowledge questionnaire, compared to eight (36.4%) responses received on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Four (18.2%) responded very important on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where eight (36.4%) responded very important and 11 (50%) responded very important on the two-month post-knowledge questionnaire. Additionally, an average score for question six was generated. The average pre-education questionnaire score for the 22 participants was 1.77/4. The average post-education questionnaire score for the 22 participants was 3.14/4. Additionally, the average two-month post-education questionnaire score for the 12 respondents was 3.41/4.

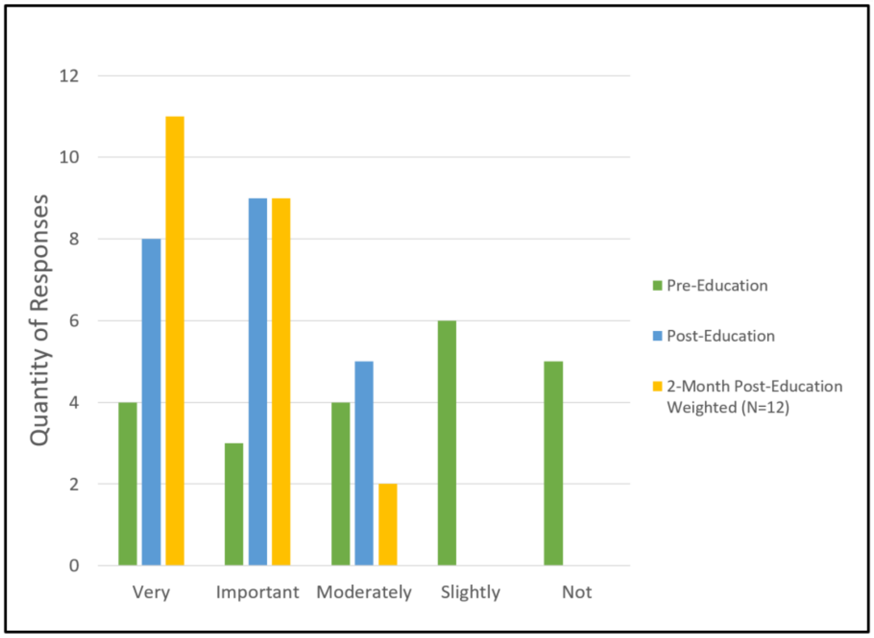


Figure 10. Knowledge question six

Question Seven

What aspects of the training session were most helpful to you and do you have any feedback or suggestions to improve the training? Question seven was developed to allow for participant feedback and identification of program enhancements. Some suggestions for program improvement included: “A two-day training session or just more time would have been helpful since there was so much good information included” and “I think role-playing of various dementia behaviors would help us apply all the valuable information you provided!” Some other general comments included: “This training program was great! It made me feel like my health and well-being were valued, training is always focused on the residents and never my health” and “Such useful information, great education, just wish the class was longer as I enjoyed it so much!” For reference, a qualitative data table was created, which lists all qualitative responses from the respondents on the knowledge questionnaires (APPENDIX S.).

CHAPTER SIX. DISCUSSION AND RECOMMENDATIONS

The objectives of this project were to 1) develop and implement an educational dementia caregiver training program at a local long-term care agency; 2) increase dementia caregiver knowledge about dementia and behavior modification, following the training program; 3) increase dementia caregiver knowledge about ways to reduce burden, following the training program; and 4) decrease dementia caregiver burden, two months following the training program. This chapter offers an interpretation of the dementia caregiver training program results, project limitations, and recommendations. Implications for practice and implications for future research are also discussed below.

Quantitative Results and Interpretations

All four objectives of the practice improvement project were achieved. The dementia training program was successfully implemented and gains in knowledge and burden reduction were observed. Overall, the dementia caregiver burden training program appeared to be an effective training method for participants.

Analysis of Knowledge Retention Rates

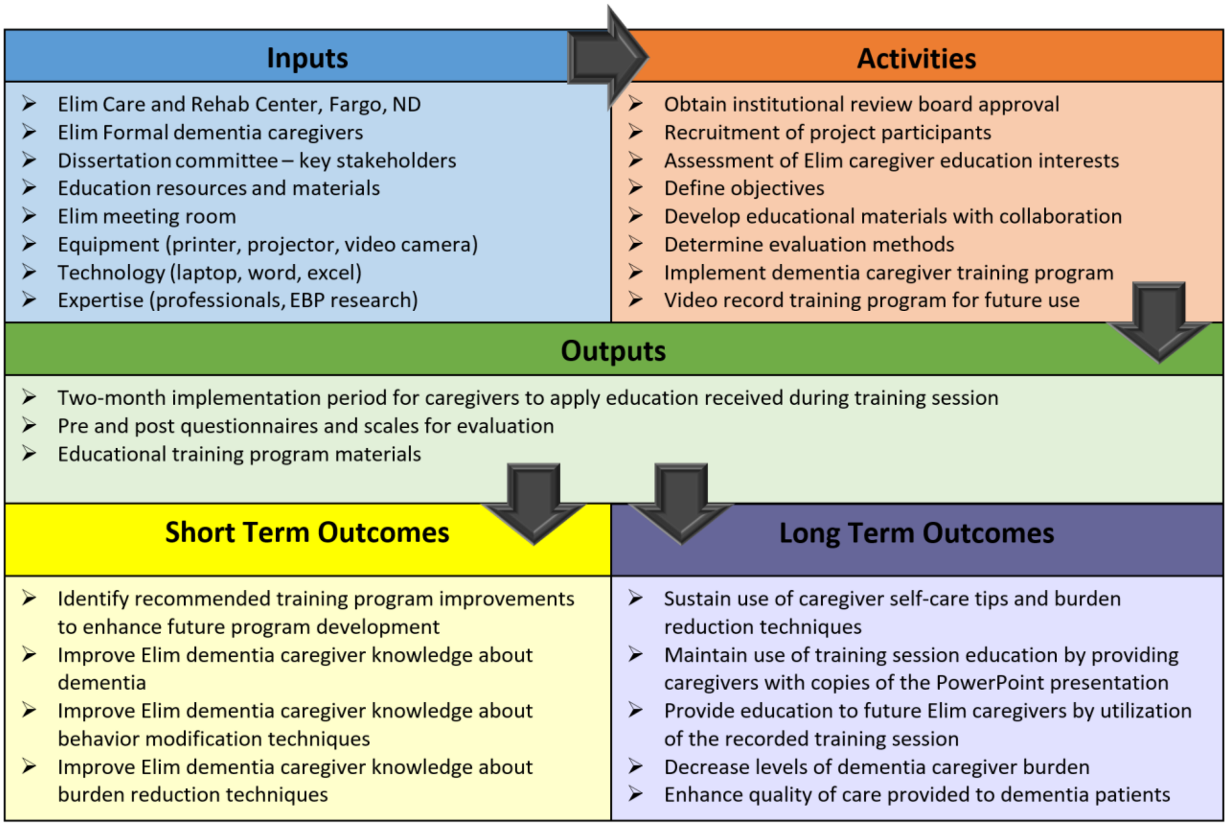
Literature suggests a slight decline in content retention should be expected from post-evaluation to the two-month evaluation window (Mahramus et al., 2014). Questions one through four on the knowledge questionnaire were utilized to determine knowledge levels and retention at the pre-post and two-month post training periods. For all four questions, increased knowledge levels were noted from the pre-evaluation to the post-evaluation periods indicating increased knowledge. Enhanced knowledge levels were expected post training, since information is remembered best within the first hour following training (Hone & El Said, 2016).

However, for all questions, one through four, a slight decrease in knowledge retention were noted when comparing levels from the post-evaluation period to the two-month post-evaluation period. A slight decline at the two-month post-evaluation window were expected as literature suggests learners forget 58% of training content within four hours following the training session (Mahramus et al., 2014). However, knowledge levels were still higher at the two-month post-evaluation period compared to baseline for all for questions, suggesting content retention and increased participant knowledge levels. Learner retention and knowledge levels can be enhanced by utilizing the following knowledge application methods during training: teach back method, role-play, case studies, and group discussion (Hone & El Said, 2016; Mahramus et al., 2014).

Objective One

The first objective of this project was to develop and implement a dementia caregiver training program at a local long-term care agency. Since this objective was the co-investigator's responsibility to complete, there were no direct data collected for this objective. Even without obtaining direct data pertaining to the training program, qualitative and quantitative data suggests the implemented training program served as a strong resource for dementia caregivers.

Numerous questionnaire feedback responses indicated caregiver satisfaction with the training program. Refer to Appendix S for all feedback responses received. The dementia caregiver training program evaluation was guided by a logic model as developed by the co-investigator and was discussed in further detail in the project evaluation section above. Evaluation of the training program included the outputs and outcomes presented in the logic model, Figure 11.



Inputs

- Elim Care and Rehab Center, Fargo, ND
- Elim Formal dementia caregivers
- Dissertation committee – key stakeholders
- Education resources and materials
- Elim meeting room
- Equipment (printer, projector, video camera)
- Technology (laptop, word, excel)
- Expertise (professionals, EBP research)

Activities

- Obtain institutional review board approval
- Recruitment of project participants
- Assessment of Elim caregiver education interests
- Define objectives
- Develop educational materials with collaboration
- Determine evaluation methods
- Implement dementia caregiver training program
- Video record training program for future use

Outputs

- Two-month implementation period for caregivers to apply education received during training session
- Pre and post questionnaires and scales for evaluation
- Educational training program materials

Short Term Outcomes

- Identify recommended training program improvements to enhance future program development
- Improve Elim dementia caregiver knowledge about dementia
- Improve Elim dementia caregiver knowledge about behavior modification techniques
- Improve Elim dementia caregiver knowledge about burden reduction techniques

Long Term Outcomes

- Sustain use of caregiver self-care tips and burden reduction techniques
- Maintain use of training session education by providing caregivers with copies of the PowerPoint presentation
- Provide education to future Elim caregivers by utilization of the recorded training session
- Decrease levels of dementia caregiver burden
- Enhance quality of care provided to dementia patients

Figure 11. Logic model

A total of 42 agency dementia caregivers were encouraged to attend the training program. Of the 42 agency dementia caregivers, 26 (61.9%) caregivers attended the training program. There were 15 participants who completed the training on June 9th, 2017 and 11 participants who completed the training on June 10th, 2017. Twenty-two (84.6%) participants fully responded to the pre-post knowledge questionnaire and burden scale. Twelve participants (46.2%) completed the two-month post-education knowledge questionnaire and burden scale. The questionnaire and burden scale were then again administered on August 9th, 2017, following the two-month implementation window, concluding implementation of the training program. Therefore, objective one was completed August 9th, 2017. Short term outcomes are discussed in each of the three objectives below.

Objective Two

The second objective of this project was to increase the participants' knowledge level about dementia and behavior modification including communication strategies. To interpret the results of objective two, questions from the knowledge questionnaire were analyzed at the pre-post and two-month post implementation periods. Questions one, two, and three from the knowledge questionnaire assisted with objective two interpretation.

Pre-knowledge question one

How comfortable do you feel with providing care to dementia patients? Further analysis of question one is provided here, building off the data reported in the results section above. Eight (36.3%) responded very comfortable on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 14 (63.6%) responded very comfortable and where 16 (72.7%) responded very comfortable on the two-month post-education knowledge questionnaire. Therefore, a 36.4% increased comfort level from the pre to two-months post was noted based on the very comfortable responses.

Additionally, there was a 0.77-point elevation noted when comparing the pre-questionnaire scores for question one and the two-month post-questionnaire scores for question one. A 19.25% increase in respondent comfort level was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores. Therefore, based on analysis of question one, participants increased their comfort level with providing care indicating increased knowledge levels, which helps to support completion of objective two. Refer to Figure 12 below for visualization of the increased comfort level from before to two-months after the training session.

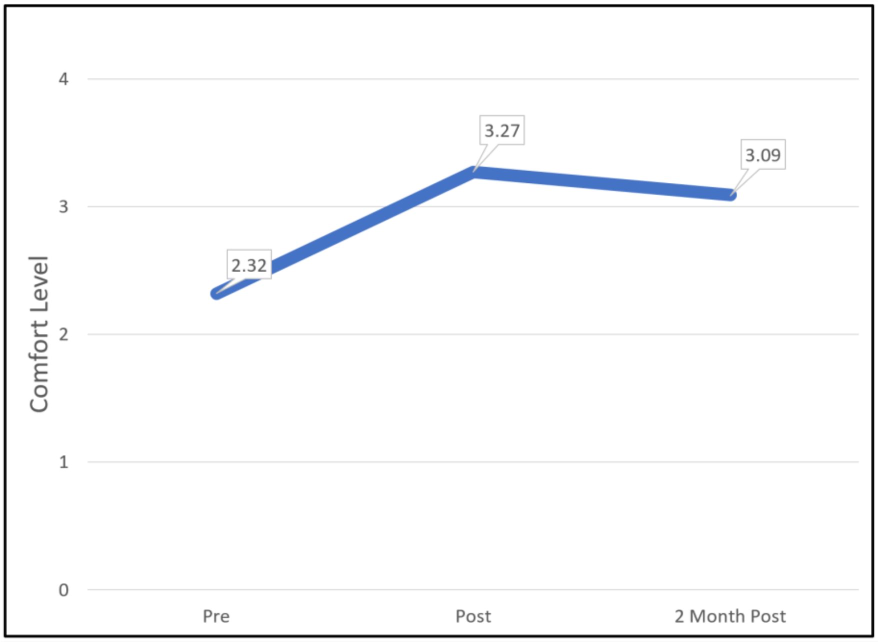


Figure 12. Question one average scores

Pre-knowledge question two

How knowledgeable do you feel about communicating effectively with dementia patients? Further analysis of question two is provided here, building off the data reported in the results section above. Eight (36.4%) responded very knowledgeable on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 12 (54.5%) responded very knowledgeable and 16 (72.7%) responded very knowledgeable on the two-month post-education knowledge questionnaire. Therefore, a 35.8% increased knowledge level from the pre to two-months post-education knowledge questionnaire was noted based on the very knowledgeable responses, indicating enhanced knowledge.

Additionally, there was a 0.5-point elevation noted when comparing the pre-questionnaire scores for question two and the two-month post-questionnaire scores for question two. A 12.5% increased knowledge level of communication techniques was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores for question two. Therefore, based on analysis of question two, participants increased their knowledge about communication techniques with dementia patients, which supports completion of objective two. Refer to Figure 13 below for visualization of the increased knowledge level from before to two-months after the training session.

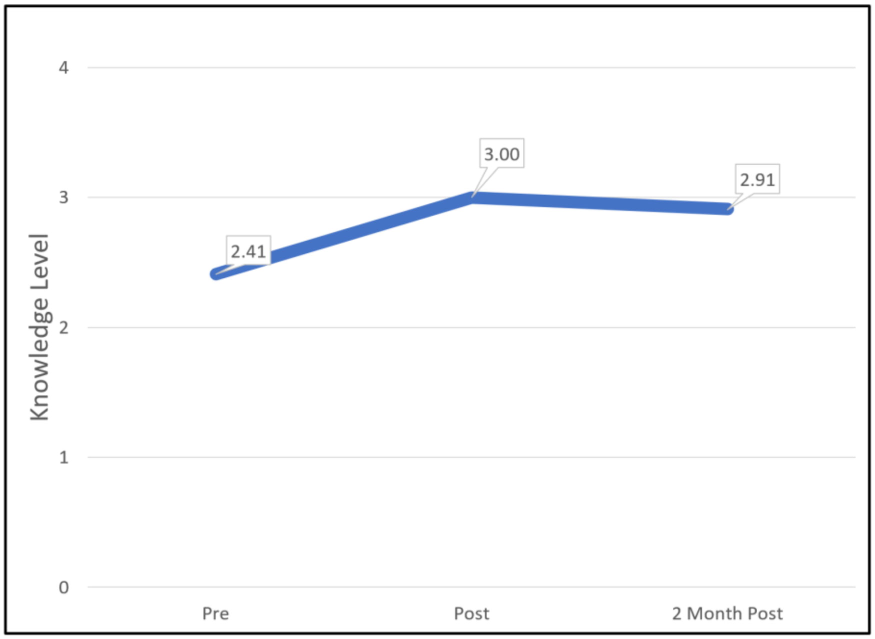


Figure 13. Question two average scores

Pre-knowledge question three

How knowledgeable do you feel about handling agitation and behavior issues in those with dementia? Further analysis of question three is provided here, building off the data reported in the results section above. Three (13.6%) responded very knowledgeable on the pre-education knowledge questionnaire, compared to the 12 (54.5%) very knowledgeable responses received on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Therefore, a 40.8% increased knowledge level from the pre to two-month post-education knowledge questionnaire was noted based on the very knowledgeable responses, indicating enhanced knowledge.

Additionally, there was a 0.82-point elevation noted when comparing the pre-education questionnaire scores for question three and the two-month post-education questionnaire scores for question three. A 20.5% increased knowledge level about managing dementia behaviors and agitation was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores for question three. Therefore, based on analysis of question three, participants increased their knowledge about dementia behavior management, which directly supports completion of objective two. Refer to Figure 14 below for visualization of the increased knowledge level from before to two-months after the training session.

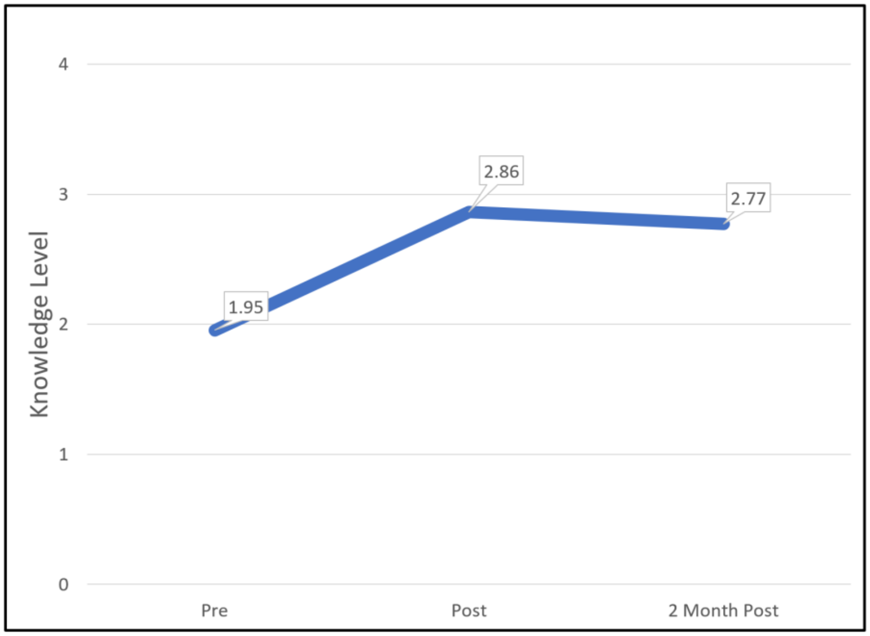


Figure 14. Question three average scores

Summary of objective two

Analysis of the three questions, from the pre-post and two-month post education data, indicated increased comfort level, increased knowledge about communication techniques, dementia, and dementia behavior management at both the post and two-month post-evaluation periods. Questions one, two, and three all showed a slight decrease in knowledge and comfort levels from post to two-months post training, which was expected based on literature reports of decreased retention rates following training (Hone & El Said, 2016; Mahramus et al., 2014). Learners forget 58% of training content within four hours following training, explaining the slight decrease in knowledge levels from post to two-months post training (Mahramus et al., 2014). However, knowledge levels were still higher at two-months compared to baseline, indicating an increase in dementia caregiver knowledge levels. Thus, objective two was fully met based on analysis of questions one, two, and three of the knowledge questionnaire.

Objective Three

The third objective of this project was to increase the participants' knowledge level about ways to reduce burden. To interpret the results of objective three, questions from the knowledge questionnaire were analyzed from the pre-post and two-month post implementation periods. Questions four, five, and six from the knowledge questionnaire assisted with objective three analysis. Figures are provided below to visualize the average individual question scores from prior to the training session to two-months after the implementation window.

Pre-knowledge question four

How knowledgeable do you feel about ways to decrease caregiver burden? Further analysis of question four is provided here, building off the data reported in the results section above. Six (27.3%) responded very knowledgeable on the pre-education knowledge questionnaire, compared to the two-month post-education knowledge questionnaire where nine (40.9%) responded very knowledgeable and 12 (54.5%) responded very knowledgeable on the post-knowledge questionnaire. Therefore, a 13.6% increased knowledge level from the pre to two-months post-education knowledge questionnaire was noted based on the very knowledgeable responses, indicating enhanced knowledge.

Additionally, there was a 0.45-point elevation noted when comparing the pre-questionnaire scores for question four and the two-month post-questionnaire scores for question four. An 11.25% increased knowledge level was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores for question four. Therefore, based on analysis of question four, participants increased their knowledge level about ways to decrease caregiver burden, which directly supports completion of objective three. Refer to the Figure 15 for visualization of the increased knowledge level from before to two-months after the training session.

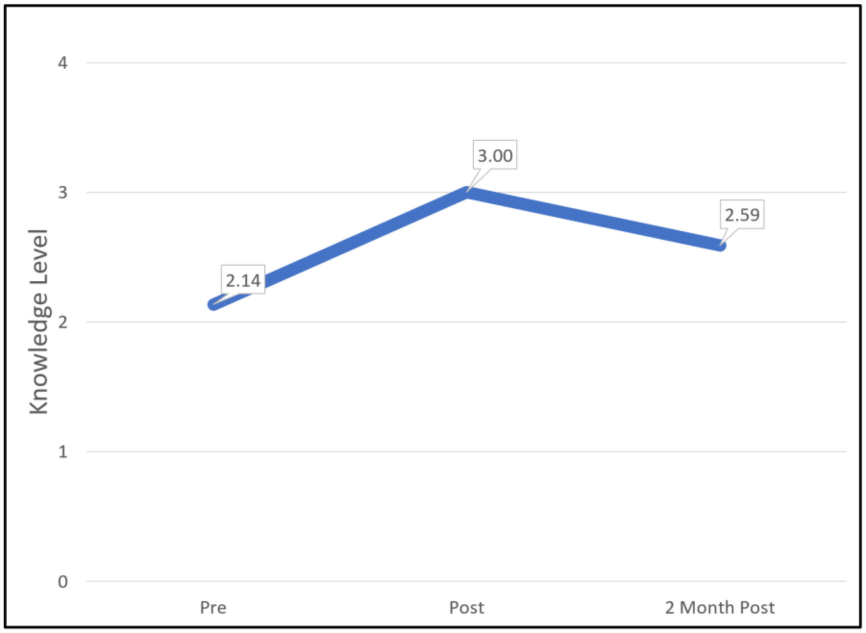


Figure 15. Question four average scores

Pre-knowledge question five

How would you rate the importance of taking care of yourself? Further analysis of question five is provided here, building off the data reported in the results section above. Eleven (50%) responded very important on the pre-education knowledge questionnaire, compared to the post-education knowledge questionnaire where 12 (54.5) responded very important and the two-month post-education knowledge questionnaire where 18 (81.8%) responded very important.

Therefore, a 31.8% increased importance rating from the pre to two-months post-education knowledge questionnaire was noted based on the very important responses, indicating enhanced importance ratings.

Additionally, there was a 0.41-point elevation noted when comparing the pre-education questionnaire scores for question five and the two-month post-questionnaire scores for question five. A 10.25% increased importance rating was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores for question five. Therefore, based on analysis of question five, participants increased their importance rating of taking care of themselves indicating increased knowledge on ways to reduce burden, which directly supports completion of objective three. Refer to Figure 16 for visualization of the increased importance rating from before to two-months after the training session.

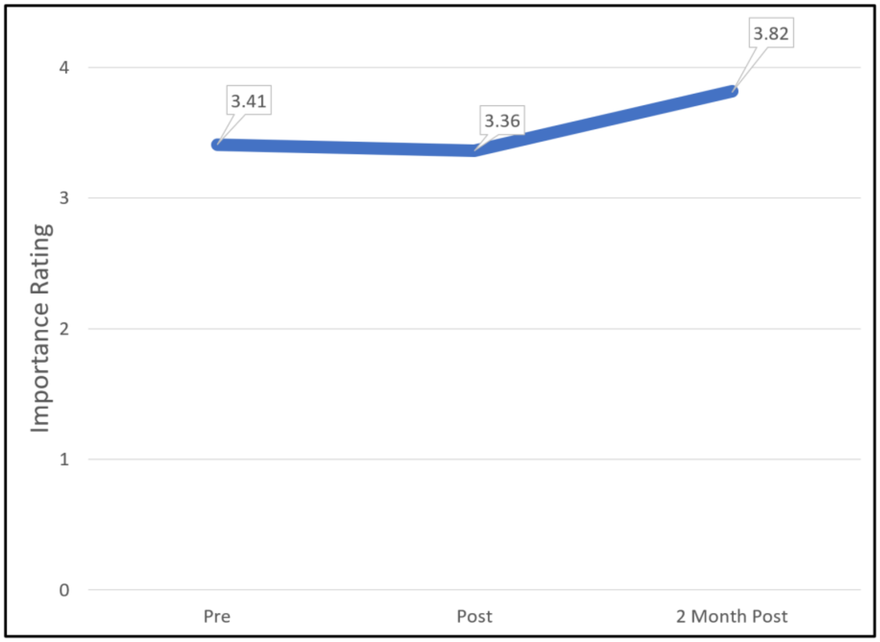


Figure 16. Question five average scores

Pre-knowledge question six

How important is it for you to go to your healthcare provider for a yearly physical? Further analysis of question six is provided here, building off the data reported in the results section above. Research indicates caregivers are 40% less likely to visit a provider for regular health maintenance (Zhu et al., 2015). Therefore, this question aims to determine how important participants rate taking care of oneself by going to a healthcare provider regularly. Analysis of data allowed for comparison of their importance rating from beginning to the end of the two-month implementation window. A 22.8% increase was noted when comparing the pre-education knowledge questionnaire to the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire for the response of important. Three (13.6%) responded important on the pre-education knowledge questionnaire, compared to eight (36.4%) responses received on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire.

Additionally, there was a 1.64-point elevation noted when comparing the pre-questionnaire scores for question six and the two-month post-questionnaire scores for question six. A 41% increased importance rating was noted when comparing pre-questionnaire scores with the two-month post-questionnaire scores for question six. Therefore, based on analysis of question six, participants increased their importance rating of taking care of their own health by going to a healthcare provider regularly, indicating increased understanding and knowledge about ways to enhance self-care and reduce burden. Thus, data results of question six directly support completion of objective three. Refer to Figure 17 for visualization of the increased importance rating from before to two-months after the training session.

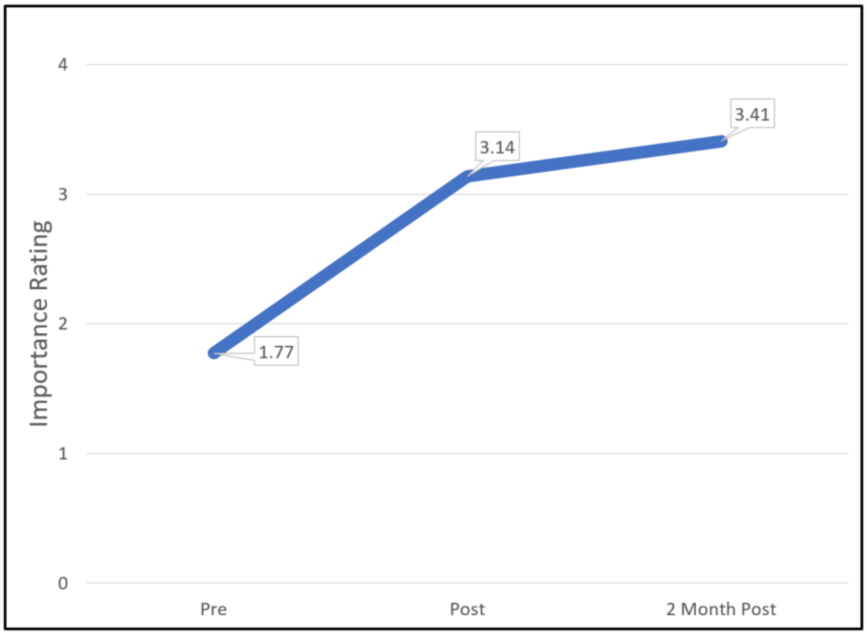


Figure 17. Question six average scores

Summary of objective three

Pre-post and two-month post data analysis of the three questions indicated increased knowledge about ways to decrease caregiver burden, increased importance ratings of self-care, and increased importance ratings of visiting a healthcare provider regularly to enhance self-care and health maintenance. Thus, objective three was fully met based on analysis of questions four, five, and six of the knowledge questionnaire. Additionally, Figure 18 provides a results comparison of questions one through six to enhance visualization of changes before training, after training, and two-months after training.

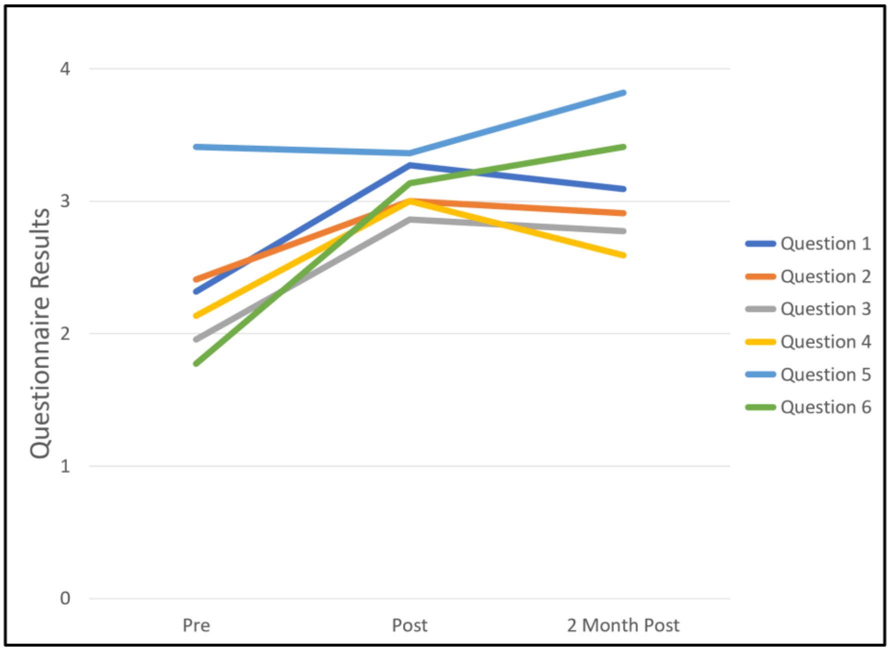


Figure 18. Comparison of questionnaire results

Objective Four

The fourth objective of this project was to indicate decreased dementia caregiver burden levels at the two-month post-education burden scale completion. To interpret the results of objective four, questions from the pre-education burden scale, post-education burden scale, and two-month post-education burden scale were analyzed. As discussed in the results section above, the average pre-education burden scale score was 16/40. The average post-education burden scale score was 12.1/40 and the average two-month post-education burden scale score was 11.1/40. There was a 4.9-point reduction noted from beginning to end of implementation. Therefore, a 12.25% dementia caregiver burden reduction was noted from beginning to end. Based on the burden reduction noted though analysis of the burden scores, objective four was fully met. Figure 18 is provided below to visualize the average burden score changes from prior to the training session to two-months after the implementation window.

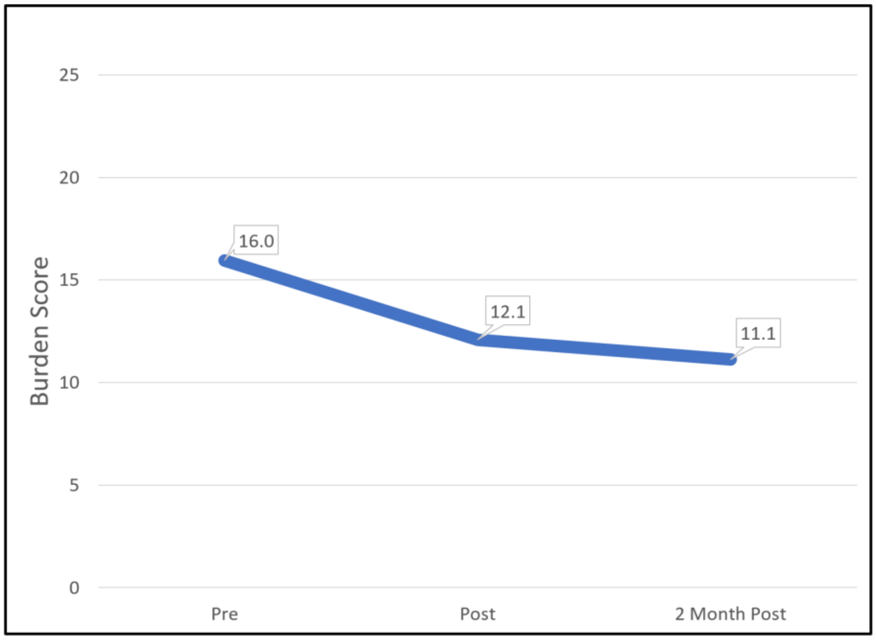


Figure 19. Average burden scores

Qualitative Results and Interpretations

Participants were asked about what was most helpful and suggestions for training program enhancement on both the post-education knowledge questionnaire and the two-month post-education knowledge questionnaire. Inclusion of this open-ended qualitative question was to determine recommendations for future program improvement and to determine participant satisfaction. Appendix S provides a compilation of all responses received. The feedback received was all positive, participants were satisfied, and many indicated they enjoyed the training. The participants found the following education topics most helpful: self-care, burden reduction, communication techniques, and dealing with various dementia behaviors. A few top recommendations for training program enhancement included: longer class time and inclusion of interactive role-play to allow for knowledge application. The qualitative data helped support dementia caregiver training program effectiveness, relevance, and helpfulness along with recommendations to enhance the training program. Project results are consistent with literature findings, since literature reports dementia caregiver training programs to be an effective method to improve staff satisfaction, increase education levels, and decrease caregiver burden (Adelman et al., 2014; Cheng, 2017; NCC, 2016).

Project Limitations

Several limitations of the practice improvement project were identified through analysis. The small convenience sample size was a major limitation for data analysis. A larger sample size would have enhanced accuracy of results. The training program participants were primarily day shift staff since training was offered in the afternoon. Very few staff from the evening and night shift were able to attend since the session times were not conducive to their work schedules, resulting in a much lower participant pool.

Twenty-six formal agency dementia caregivers completed the one-hour training session with completion of 22 (84.6%) pre-post questionnaires and burden scales and completion of 12 (46.2%) two-month post-questionnaires and burden scales. Demographic analysis was completed to determine any identifiable factors for lower completion rates of the two-month post-education knowledge questionnaire and burden scale. Analysis of demographic results did not identify any overarching participant themes. Therefore, lower completion rates of the two-month post-education questionnaire and burden scale is likely related to varying shift times, time constraints, survey burden, and a lack of advertising (McPeake, Bateson, & O’Neill, 2016). Furthermore, lower completion rates for the two-month follow-up surveys were expected as literature suggests lower completion rates for surveys completed on respondents’ personal time (Cunningham et al., 2015). Completion rates are reported higher at 67%, when conducted in-person during a 15-minute to 30-minute pre-scheduled time, compared to a response rate of 27% when respondents are expected to complete the survey on their own time (Cunningham et al., 2015).

Frequently low response rates in the healthcare field, between 10%-34%, are reported related to many factors including survey burden, time constraints, no monetary incentives, no advertising, and no personal contact (Cunningham et al., 2015; Pit, Vo, & Pyakurel, 2014). Favorable project survey completion rates (46.2% and 86.2%) were noted related to personal contact with the dementia caregivers, pre-post survey advertising, survey completion done during a pre-scheduled time during the training session, and a short concise survey design (Pit et al., 2014). The two-month questionnaire and scale implementation were not carried out during a pre-scheduled time, due to caregiver time constraints and staffing ratios. Since a pre-scheduled meeting time was not set for the two-month post-surveys, a lower response rate of 46.2% was noted compared to an 86.2% response rate for the pre-scheduled surveys at the pre-post completion time.

Another limitation was associated with the small convenience sample. All participants were formal dementia caregivers from the partnered agency. Informal caregivers were not included in this practice improvement project. At the beginning of the practice improvement project, the co-investigator had focused on the informal dementia caregiver population, since informal caregivers often need additional education and support related to a lack of training and assistance within the home (Sprangers et al., 2015).

However, the co-investigator was unable to secure informal caregiver participants for the training program. Development of the practice improvement project was then moved to focus on formal dementia caregivers, whom also need education and additional support to best maintain their health, reduce burden levels, and reduce turnover rates (Bouldin et al., 2017; Broughton, 2011). Even though the initial intended informal population was not obtained for the practice improvement project, a successful project was implemented and completed resulting in positive outcomes for formal dementia caregivers.

The last limitation was associated with the length of the dementia caregiver training session. Participants attended a one-hour training session. One-hour did not provide adequate time for completion of surveys, introduction, conclusion, presentation of knowledge content, and class discussion. As many participants reported, a longer class time would have been beneficial (Appendix S.). However, due to time constraints and staffing ratios, the co-investigator was allocated a one-hour window to implement the training session. Time constraints resulted in decreased participant class discussion and decreased time for questionnaire and scale completion. All of which may have decreased training program outcomes and skewed survey results due to inadequate completion time.

Recommendations

The training program is supported as a recommendation to formal dementia caregivers based on positive project outcomes and current literature support of dementia caregiver education. Project results are consistent with literature reports of decreased dementia caregiver burden and increased knowledge levels following educational training programs (Adelman et al., 2014; Cheng, 2017; Sprangers et al., 2015). Continued implementation of the developed dementia caregiver training program is suggested based on positive outcomes. The co-investigator anticipates continuing the dementia caregiver training program as a part of continued professional development, continuing education, and community service.

One of the training sessions was recorded by the agency’s technology department. New hires and all other dementia caregivers could be offered the opportunity to view the training session to further enhance caregiver knowledge and burden reduction. Since the recorded training session has not been utilized or evaluated prior to this project, evaluation of the video training program is recommended to ensure caregiver satisfaction and evaluation of effectiveness (Gitlin, Mark, Stanley, & Hodgson, 2015). Future evaluation of the video training program could include interviews and pre-post questionnaires (Gaugler, Hobday, Robbins, & Barclay, 2016; Gitlin et al., 2015). Evaluation will provide insight on effectiveness, satisfaction, and areas for improvement (Gaugler et al., 2016; Gitlin et al., 2015). Furthermore, expansion of the training program to other nursing home memory care units would be beneficial to reach additional formal caregivers to help enhance their knowledge and reduce their burden.

According to literature, coordination of a scheduled 15-minute to 30-minute meeting time with the dementia caregivers at the two-month post-questionnaire and burden scale implementation could enhance survey completion and enhance data analysis with a larger response pool (McPeake et al., 2016). Additional reasons for lower survey response rates could have been due to: time constraints, lack of personal benefit, and survey burden with surveys consisting of more than ten questions (Brown, Craig, Watson, & Wendy, 2016). Therefore, to enhance questionnaire and scale responses in the future, scheduling a brief formal meeting with the caregivers and revising surveys to ensure conciseness could decrease survey burden and enhance survey response rates.

Other improvements to the practice improvement project could be made including methods to increase the number of dementia training program participants. Most participants were from the day shift, related to schedule conflicts with the night and evening staff. Following graduation, the co-investigator will add a training session to match evening and night shift schedules to help increase the number of training program participants.

Expansion of the convenience sample of formal dementia caregivers would further enhance caregiver outcomes. Expanding dementia caregiver training to informal caregivers would further enhance community caregiver knowledge levels with the intent to further reduce burden levels. Informal caregivers often need more support and education since they are often untrained and unpaid and have little to no support at home (Cheng, 2017). Expansion of the training program to include classes for informal caregivers within the community would be of benefit to enhance caregiver and care recipient outcomes, since education is also a top need identified for informal dementia caregivers (AARP, 2015; Adelman et al., 2014; Bouldin et al., 2017). Collaboration with interested providers, nurse educators, and respite care facilities, could help support and maintain training program development and implementation. Literature supports an interdisciplinary approach to enhance program effectiveness and maintain continued implementation (Gerolimatos, Page, Balestracci, & Hinrichs, 2018). Collaboration with other disciplines will provide additional individuals to enhance training content and carry out the dementia caregiver training program (Gerolimatos et al., 2018).

To enhance education, a longer training program implementation time would be recommended. An increase from one to two hours of training would enhance outcomes, increase group discussion, and allow for group interaction and role-play. Also, to assist with time constraints, removal of the post-surveys could have been considered since there would still be pre-survey and two-month post survey data to analyze.

Implications for Practice

The results of the practice improvement project support the need for increased burden management and education among formal dementia caregivers. Healthcare professionals who have contact with dementia caregivers need to ensure they provide caregivers with education and support. Furthermore, healthcare providers need to remember caregivers are 40% less likely to visit a primary care provider for routine health maintenance (Zhu et al., 2015). Therefore, when a caregiver does come to an appointment, the healthcare professional must focus on education, health maintenance, self-care tips, assess for burden, and other health issues associated with caregiving.

Healthcare professionals can also assist with enhancing caregiver education and support by assisting with dementia caregiver training within the community. Increased support and education provided to dementia caregivers can result in reduced burden, enhanced outcomes, and reduced turnover. Caregivers often put their health last. Burden rates are reported highest among dementia caregivers related to increased physical, mental, and emotional demands associated with caring for individuals with dementia (AANAC, 2014). Dementia caregivers are at risk for chronic health issues especially depression, anxiety, hypertension, and back injuries (AANAC, 2014). Additionally, North Dakota reported the highest Alzheimer’s death rate in America (ND Health, 2016). Therefore, healthcare professionals need to advocate for increased dementia caregiver support to enhance caregiver abilities and recipient outcomes. Healthcare professionals can encourage dementia caregivers to take charge of their health by providing education about self-care tips and burden reduction techniques. Additionally, awareness and knowledge of dementia caregiver needs can lead to enhanced caregiver health outcomes. Literature suggests primary care providers lack necessary education about dementia, caregiver burden, and caregiver needs (Kerns, 2018). When healthcare providers are more aware and knowledgeable about dementia caregiver needs and burden, they can better educate caregivers about ways to reduce burden and enhance outcomes.

Dissemination

After evaluation has been completed, dissemination of results is vital to ensure information is available to those interested to further enhance dementia caregiver outcomes and research (Melnyk & Fineout-Overholt, 2015). The practice improvement projects plan was presented at the NDSU College of Health Professions Poster Presentation in March 2017 and at the North Dakota Nurse Practitioner Association (NDNPA) Pharmacology Conference poster presentation in September 2017. Poster presentation approval was received prior to the NDNPA Pharmacology Conference by submission of an abstract for the proposed dementia caregiver poster presentation (APPENDIX T.). The results of the dementia caregiver training program will be presented at the NDSU College of Health Professions Poster Presentation in April 2018.

Further dissemination of the practice improvement project by the co-investigator are anticipated to be completed May 2018 to enhance community awareness, gain interest, and increase dementia caregiver research. Additional dissemination methods will include the development of a three-minute video about the projects significance and results. The three-minute video will present project results in a format that is interesting and understandable to a general audience. Additionally, roundtable presentations will allow dissemination of results and increase awareness of the dementia caregiver training program to specific facilities throughout the community (Melnyk & Fineout-Overholt, 2015). Roundtable presentations are anticipated to be conducted with key stakeholders at various facilities throughout the community such as respite care facilities, assisted living facilities, and nursing homes. At least one roundtable presentation will be completed. Time allowing, additional roundtables will be completed throughout the community.

Implication for Future Research

Additional research projects on dementia caregiver burden needs to focus on dementia caregiver burden and methods to best reduce caregiver burden. As discussed earlier, dementia caregivers are paramount to the healthcare system (AARP, 2015). With the aging society, increased caregiver demand, increased caregiver burden, and increased dementia prevalence, additional research on best methods to support dementia caregivers is vital (AARP, 2015; CDC, 2016; Sprangers et al., 2015). Caregivers who are provided with education and additional support have been shown to reduce burden levels, enhance health outcomes, and enhance care provided to the recipient (Chiu et al., 2013; Cook et al., 2012). Further research and evaluation must be completed on various dementia caregiver training programs to enhance further educational content development and caregiver outcomes. This project should be replicated in the future. Further dissemination of the dementia training program, after improvements have been made, could provide a means for future implementation of evidenced-based practice on the dementia caregiver training program outcomes.

As discussed earlier, a major literature gap identified during the literature review process was informal dementia caregiver burden and best methods to decrease informal caregiver burden. Since informal caregiver experience has just as much, if not more, burden than formal caregivers, it is vital for additional research to be carried out (Alzheimer’s Association, 2017; Cheng, 2017). There was limited research on training programs for formal and informal dementia caregivers. Additional research on dementia caregiver training programs will enhance abilities to increase knowledge, enhance caregiver outcomes, and decrease burden.

Application to Nurse Practitioner Role

Nurse practitioners (NPs), practicing in family healthcare and a variety of other healthcare settings, will likely provide care to informal and formal dementia caregivers on a regular basis. Family medicine NPs will often be the initial contact dementia caregivers have with the healthcare system. Therefore, NPs can identify dementia caregivers, assess for additional health issues associated with caregiving, and talk to the caregiver about how caregiving is influencing daily life. NPs have a unique emphasis on health promotion and health education and are widely recognized as great listeners and educators (American Association of Nurse Practitioners, 2017). NPs can provide dementia caregivers with education about health maintenance, burden reduction education, and support resources throughout the community. All in all, as healthcare providers, educators, mentors, researchers, and advocates, NP's can enhance health outcomes for dementia caregivers and reduce overall burden experienced by the caregiver.

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APPENDIX A. DATA SYNTHESIS TABLE

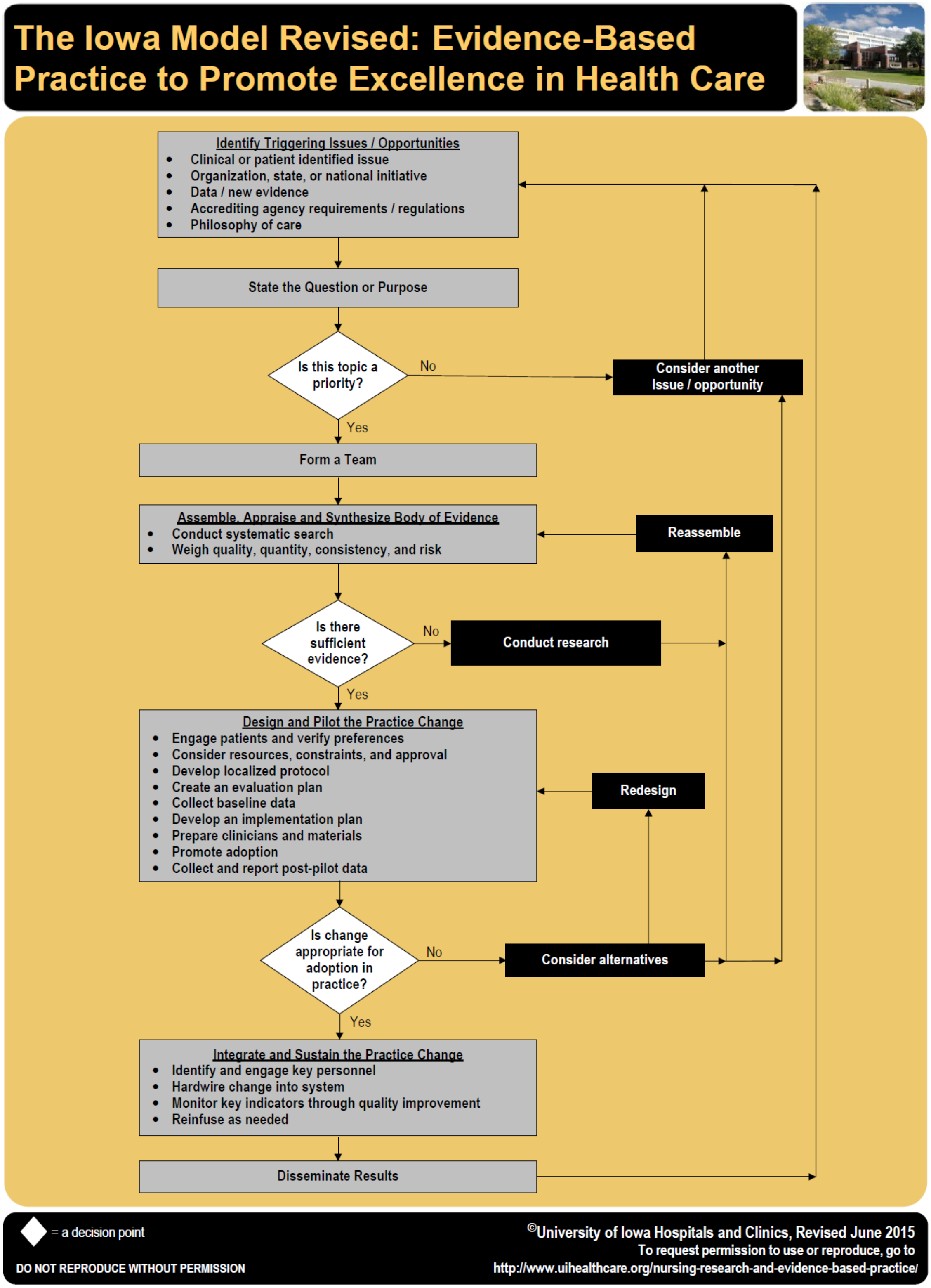
	Citation	Conceptual Framework	Design/ Method	Sample/ Setting	Major Variables Studied and Their Definitions	Measurement of Major Variables	Data Analysis	Study Findings	Strength of the Evidence
1	Cook, M., Swift, L., James, I, Malouf, R., Vugt, D., & Verhey, F. (2012). Functional analysis-based interventions for challenging behavior in dementia. *Cochrane Database of Systematic Reviews, 2*, No.: CD006929. doi: 10.1002/14651858.CD006929.pub2	Various based on studies in systematic review	Systematic Review Meta-analysis	Various studies in this article – all utilized dementia caregivers and dementia care recipients as the sample	Assess effects of functional analysis (FA) based interventions for people with dementia living in home setting	4 reviewers selected the trials. 2 reviewers worked indep. To extract data and analyze for review	18 articles included in the review.	+ effects noted at post-intervention for frequency of reported challenging behavior (not for incidence or severity) for caregiver reaction (but not burden or depression)	Provides a systemic review of literature 2012 and prior on my focused topic
2	Hermans, D., Htay, E. H., & Cooley, S. (2009). Non-pharmacologic interventions for wandering of people with dementia in the domestic setting. *Cochrane Database of Systematic Reviews, 1, No.:* CD005994. doi:10.1002/14651858. CD005994.pub2.	Various – based on studies in systematic review	Systematic Review Meta-analysis	Various studies – utilized dementia patients living in a domestic setting	Non-pharmacological interventions: light therapy, PT, music therapy, reality orientation, OT, therapeutic touch	Evaluate safety of non-pharm interventions to < wandering in domestic setting for dementia	Of the review no RCT on this topic were identified, so no conclusions on interventions we able to be made.	Great lack of RCT on wandering interventions for domestic settings. Numerous RCT for institutional settings. RCT on this study topic are urgently needed to help decrease wandering	Systematic review of literature 2009 and prior focused on non-pharm interventions for wandering in domestic setting.
3	Forbes, D., Blake, C. M., Thiessen, E. J., Peacock, S., * Hawranik, P. (2014). Light therapy for improving cognition, activities of daily living, sleep, challenging behavior, and psychiatric disturbances in dementia. *Cochrane Database of Systematic Reviews, 2,* No.:CD003946. doi: 10.1002/14651858. CD003946.pub4.	Various-based on studies in systematic review	Systematic Review – Metal-analysis	All sample participants were diagnosed with dementia. The setting was mixed between domestic and institutionalized.	Dementia patients and the influence of light therapy on overall cognition, ADLs, and behavior.	Examine/review 11 trials/studies effectiveness of light therapy in proving cognition, ADLs, sleep, challenging behavior, and psych symptoms assoc. with dementia	11 trials/studies met inclusion criteria 2 review author's indep. Assessed the articles and 4 author's indep. Compared intervention effects for each study	Found no effect of light therapy on cognitive function, sleep, challenging behavior, or psychiatric symptoms associated with dementia. Red. In dev. Of ADL limitations was reported in 1 study.	Systematic review of literature 2014 and prior on light therapy and dementia patients.
4	Chien, L. Y., Chu, H., Guo, J. L., Liao, Y. M., Chang, L. L., Chen, C. H., & Chou, K. R. (2011). Caregiver support groups in patients with dementia: A meta-analysis. *International Journal of Geriatric Psychiatry, 26*(10), 1089-1098. doi: 10.1002/gps.2660	Various – based on the studies included in the meta-analysis	Meta-analysis	Dementia caregivers who attend a support group focused on the caregiver	Support group use and characteristic of various support groups analyzed	Outcome indicators: psychological well-being, depression, burden, and social outcomes	30 quantitative journal articles that were true and quasi-experimental controlled trains on support groups of non-professional caregivers were analyzed	Support groups showed a significant + effect on caregivers' psychological well-being, depression, burden, and social outcomes. The length and intensity of group sessions has a significant impact on the effects.	Lit. review done on support groups for dementia caregivers from 1998-2009. Provides summarized information about support group and numerous references.
5	Chiu, M., Wesson, V., & Sadavoy, J. (2013). Improving caregiving competence, stress coping, and mental well-being in informal dementia careers. *World Journal of Psychiatry, 3*(3), 65-73.	Built upon recognition of the intense emotional challenge of caregiving, the susceptibility of carers to caregiver burden, and intention to guide them in dealing with impairments of the care recipients	Quasi-experimental pre-post treatment design	Dementia caregivers. The care recipient has to be living in the community, no in a long-term/short-term facility. 73 – caregivers participated	Coaching, Advocacy, Respite, Education, Relationship, and Simulation (CARERS) program -No control group, all received the intervention	Based on the CARERS developed program for dementia caregivers	Mean differences for measures were calculated. One-way ANOVA was used to determine if change in scores id depended on the respective baseline scores.	Improvement in careers' self-perception of competence, and significant reduction in emotion-focused coping, Geriatric Depression scale, and Pearlin's overload scale, upon completion of program. Also, carers with more compromised baseline scores benefited most from the intervention.	-Limitations: no control group -Strengths: provides a program which could provide a basis for dissertation project

6	Ducharme, D., Levesque, L. L., Lachance, L. M., Kergoat, M. J., Legault, A. J., Beaudet, L. M., & Zarit, S. H. (2011). Learning to become a family caregiver: Efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *The Gerontologist, 51*(4), 484-494. Doi:10.1093/geront/gnr014	Meleis and colleagues – role transition	Experimental design	Caregiver for a relative 65 or older diagnosed with dementia in the past 9 months -Caregivers already participating in support group were excluded 111 caregivers total participated	Psychoeducational individual program to facilitate transition to the caregiver role for experimental group Control group: usual care	Various scales were used: Self-efficacy scale, 8-item Preparedness for Caregiving Scale, Revised Scale for Caregiving Self-Efficacy, Planning for Future Care Needs scale, and Carers' Assessment of Managing Index	Descriptive statistics (means, SD, %'s) T-tests, ANCOVA	Caregivers in the experimental group more confident in dealing with caregiving situation, perceived themselves to be better prepared to provide care and more efficacious in caregiver role, better able to plan for future needs, increased knowledge of available services, and more freq. use of coping strategies.	-Strengths: provides a program which could provide a basis for dissertation project -Limitations: only studied caregivers who had been caregiving 9mo or less
7	Broughton, M., Smith, E. R., Baker, R., Angwin, A. J., Pachana, N. A., Copland, D. A., Humphreys, M. S., Gallois, C., Byrne, G. J., & Chenery, H. J. (2011). Evaluation of a caregiver education program to support memory and communication in dementia: A controlled pretest-posttest study with nursing home staff. *International Journal of Nursing Studies, 48*(11), 1436-1444. Doi:10.1016/j.ijnurstu. 2011.05.007	Unable to identify a theoretical framework	Controlled pretest-posttest	All nursing home staff were invited to participate. 68 participated, and of the 85, 52 completed the outcome measure at baseline and 3-month follow-up 64%: NA's 25%: RN's 11%: Other Staff	Utilizing a DVD-based training program entitled RECAPS and MESSAGE for nursing home staff	Had a training group and control group. Groups were compared on knowledge scores at baseline and 3-month follow-up.	Statistical analysis was conducted using Predictive Analytic Software (PASW Statistics 18). -Descriptive statistics, ANOVA	Training group showed a significant improvement in knowledge of support strategies from baseline to immediately post-training. > caregiver satisfaction, and viewed training as + and useful	Provides a developed program to help model my dissertation intervention/focus Limitation: will have to obtain the DVD program
8	Samia, L. W., Aboueissa, A. M., Halloran, J., & Hepburn, K. (2014). The Maine savvy caregiver project: Translating an evidence-based dementia family caregiver program within the re-aim framework. *Journal of Gerontological Social Work, 57*(6-7), 640-661. Doi:10.1080/ 01634372.2013.859201	RE-AIM framework	Quasi-experimental mixed-method guided by the RE-AIM framework	English speaking caregivers at least 18 years of age, resident of Maine. Care receiver could not reside in a long-term care facility N=676	Various scales: Caregiver competence scale, caregiver personal gain scale, caregiver management of situation, making positive comparisons scale. Implemented a caregiver education workshop to the experimental group	Control and experimental group. The control group was provided the intervention after study was completed to ensure all had equal care given	ANOVA, two-sample t-test analysis, descriptive statistics	Completing program resulted in > confident caregivers, who were better able to manage situation & expectations, & grew from experience. < depressed. < neg. reaction to the care receiver's behavior	Provides a developed program to help model my dissertation -Study does not make it clear as to what exactly the program consists of.

	Interventions	**Functional Analysis**	**Light Therapy**	**Music Therapy**	**PT/OT**	**Therapeutic Touch**	**Behavior Modification Programs**	**Support Groups**
Studies (per numbering in table above)								
1		X					X	
2			X	X	X	X	X	
3			X					
4							X	X
5		X					X	X
6		X					X	X
7							X	
8							X	

Legend: X indicates presence of the intervention in identified study

APPENDIX B. THE IOWA MODEL OF EBP



Used/Reprinted with permission from the University of Iowa Hospitals and Clinics, 2015

APPENDIX C. IOWA MODEL PERMISSION FOR UTILIZATION

UNIVERSITY OF IOWA
HOSPITALS & CLINICS
University of Iowa Health Care

Department of Nursing Services and Patient Care
Nursing Research, Evidence-Based Practice and Quality
200 Hawkins Drive, RM T100 GH
Iowa City, IA 52242
319-384-9098; 319-356-4348 (fax)
www.uihealthcare.com

MAGNET RECOGNIZED
AMERICAN NURSES CREDENTIALING CENTER

January 19, 2017

Kayla Weigel

RE: Permission to Use and/or Reproduce The Iowa Model (2015)

Dear Ms. Weigel:

As requested via email, you have permission to use the *2015 Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Healthcare Care* in your DNP project.

It is our understanding that you are developing a dementia caregiver training program for the Fargo, ND community. The program will be focused on enhancing confident, increasing caregiver knowledge, and decreasing overall caregiver burden.

Please be sure to include the following verbiage "Used with permission from the University of Iowa Hospitals and Clinics".

The 2015 *Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care* will be retained by the University of Iowa Hospitals and Clinics. Permission is limited to your DNP project.

In the future, if you wish to publish your DNP project, you will need to submit a new request at: https://uihc.org/nursing-research-and-evidence-based-practice.

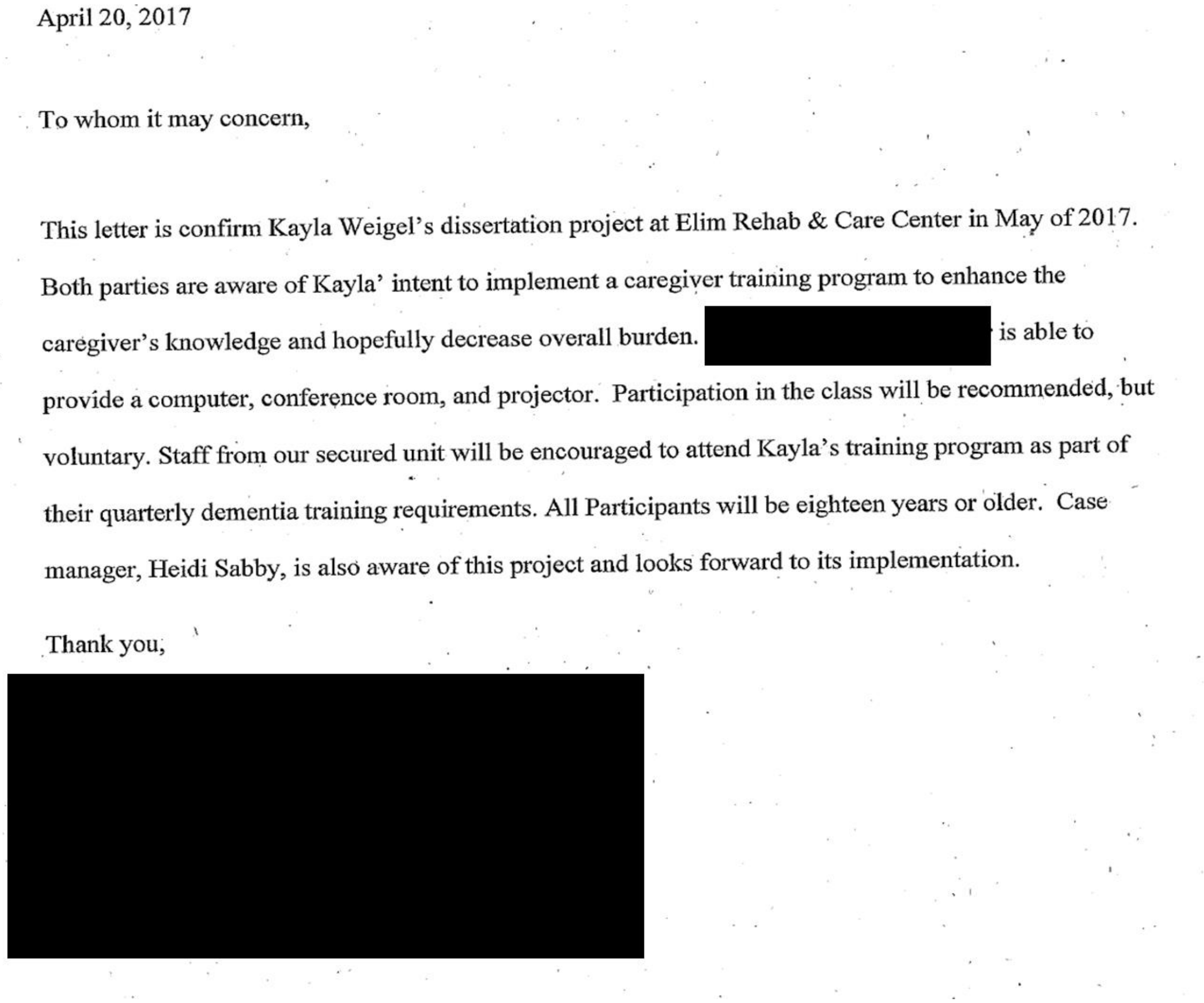
If you have any questions, please feel free to contact me at 319-384-9098 or kimberly-jordan@uiowa.edu. Thank you.

Sincerely,

Kimberly Jorda

Kimberly Jordan
Administrative Services Coordinator
Office of Nursing Research, Evidence-Based Practice and Quality
Department of Nursing Services and Patient Care

APPENDIX D. LOCAL LONG-TERM CARE AGENCY PARTNERSHIP LETTER



April 20, 2017

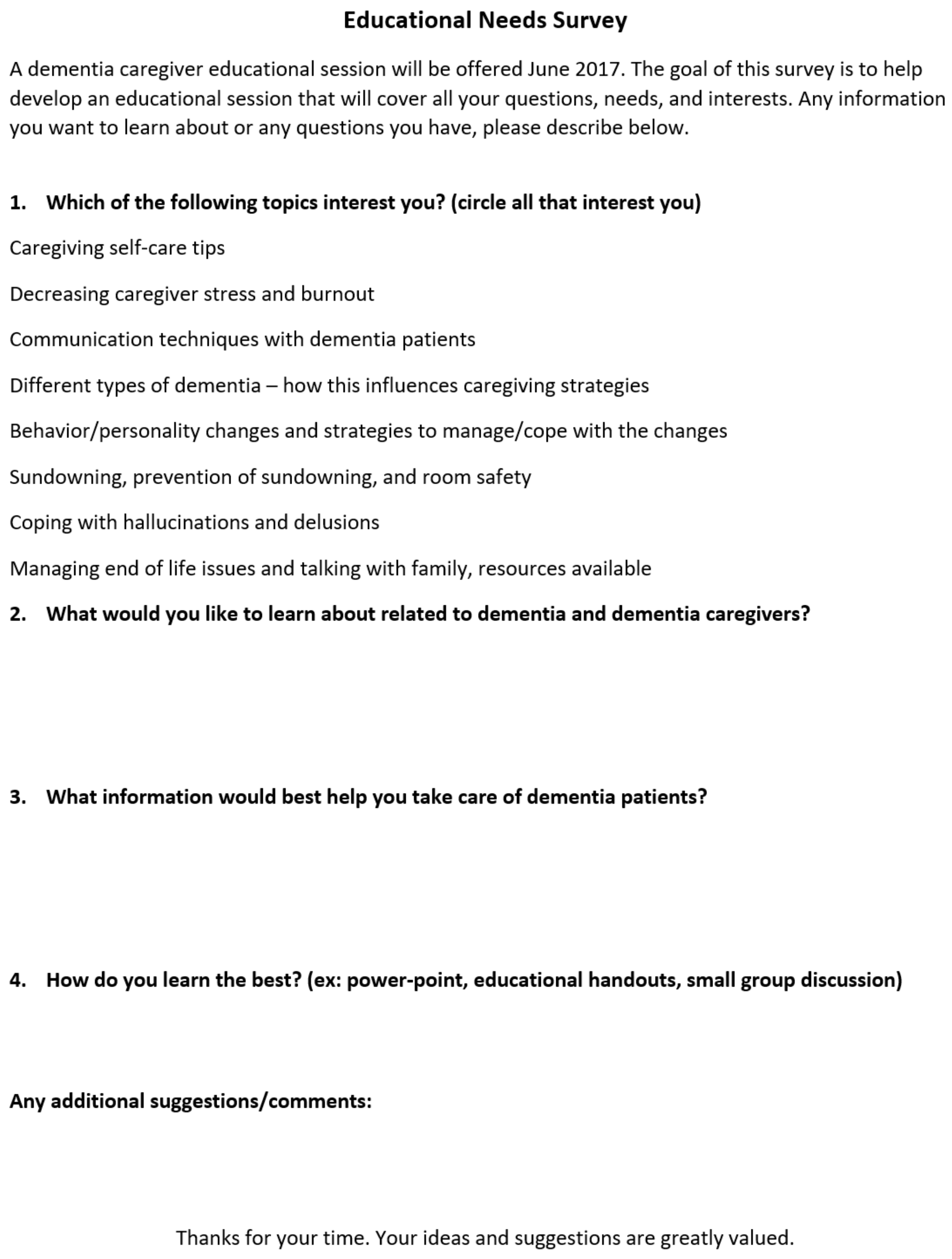
To whom it may concern,

This letter is confirm Kayla Weigel's dissertation project at Elim Rehab & Care Center in May of 2017. Both parties are aware of Kayla' intent to implement a caregiver training program to enhance the caregiver's knowledge and hopefully decrease overall burden. [redacted] is able to provide a computer, conference room, and projector. Participation in the class will be recommended, but voluntary. Staff from our secured unit will be encouraged to attend Kayla's training program as part of their quarterly dementia training requirements. All Participants will be eighteen years or older. Case manager, Heidi Sabby, is also aware of this project and looks forward to its implementation.

Thank you,

[redacted]

APPENDIX E. LOCAL LONG-TERM CARE AGENCY EDUCATION NEEDS SURVEY



Educational Needs Survey

A dementia caregiver educational session will be offered June 2017. The goal of this survey is to help develop an educational session that will cover all your questions, needs, and interests. Any information you want to learn about or any questions you have, please describe below.

1. Which of the following topics interest you? (circle all that interest you)

Caregiving self-care tips

Decreasing caregiver stress and burnout

Communication techniques with dementia patients

Different types of dementia – how this influences caregiving strategies

Behavior/personality changes and strategies to manage/cope with the changes

Sundowning, prevention of sundowning, and room safety

Coping with hallucinations and delusions

Managing end of life issues and talking with family, resources available

2. What would you like to learn about related to dementia and dementia caregivers?

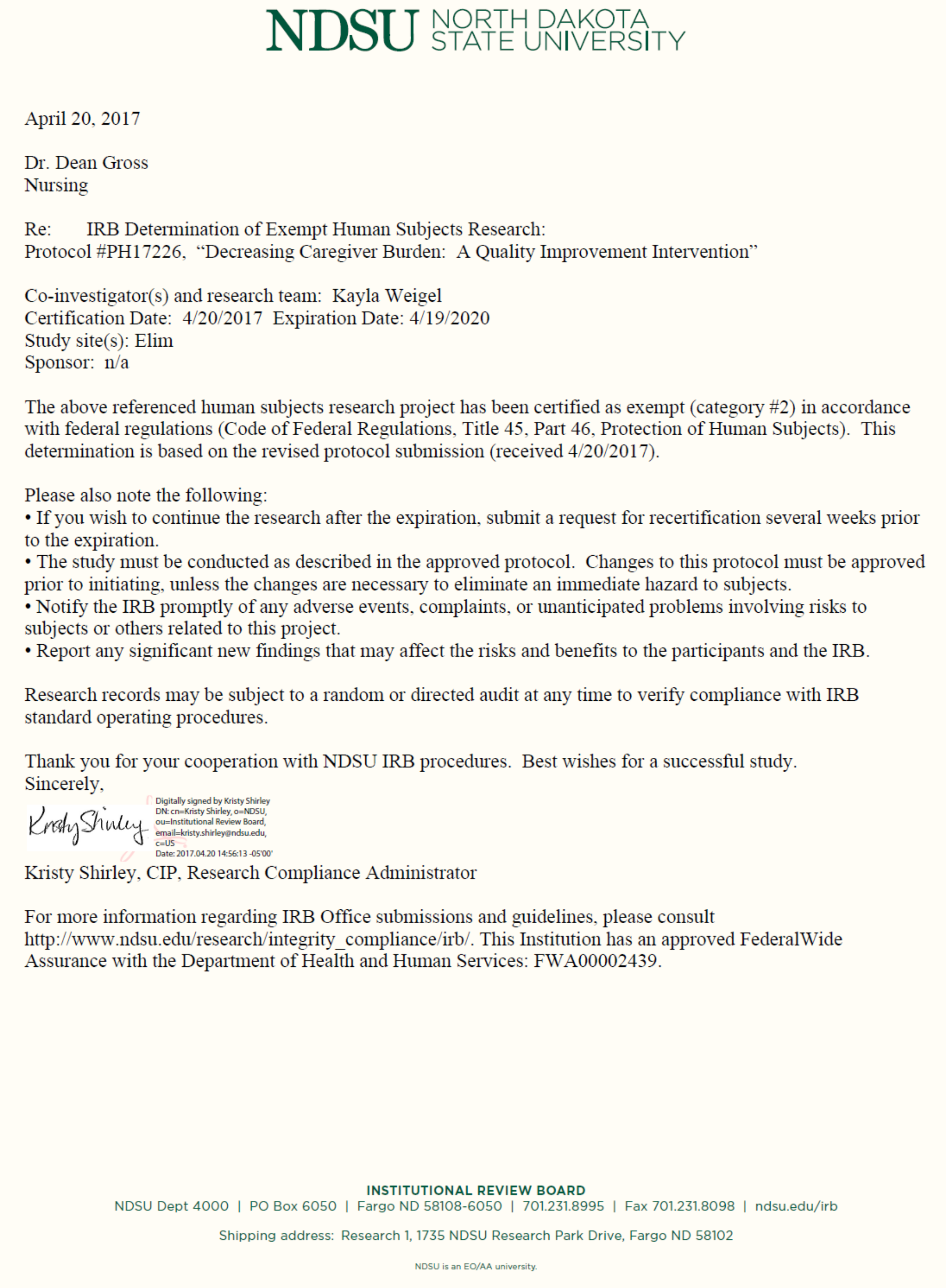
3. What information would best help you take care of dementia patients?

4. How do you learn the best? (ex: power-point, educational handouts, small group discussion)

Any additional suggestions/comments:

Thanks for your time. Your ideas and suggestions are greatly valued.

APPENDIX F. NDSU INSTITUTIONAL REVIEW BOARD PROJECT APPROVAL



NDSU NORTH DAKOTA STATE UNIVERSITY

April 20, 2017

Dr. Dean Gross
Nursing

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #PH17226, "Decreasing Caregiver Burden: A Quality Improvement Intervention"

Co-investigator(s) and research team: Kayla Weigel
Certification Date: 4/20/2017 Expiration Date: 4/19/2020
Study site(s): Elim
Sponsor: n/a

The above referenced human subjects research project has been certified as exempt (category #2) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the revised protocol submission (received 4/20/2017).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.
Sincerely,

Kristy Shirley

Digitally signed by Kristy Shirley
DN: cn=Kristy Shirley, o=NDSU, ou=Institutional Review Board, email=kristy.shirley@ndsu.edu, c=US
Date: 2017.04.20 14:56:13 -05'00'

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult http://www.ndsu.edu/research/integrity_compliance/irb/. This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

INSTITUTIONAL REVIEW BOARD
NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | ndsu.edu/irb

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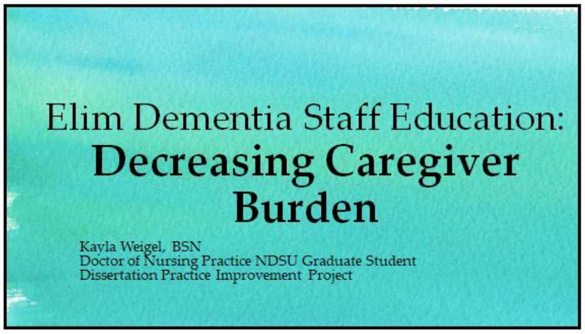
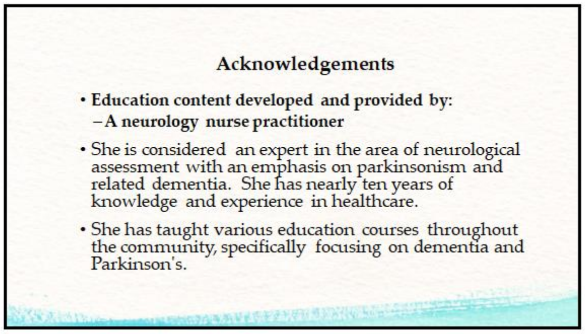
APPENDIX G. POWERPOINT PRESENTATION FOR TRAINING PROGRAM



Elim Dementia Staff Education:

Decreasing Caregiver Burden

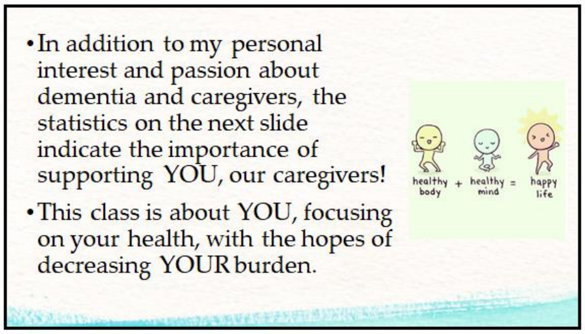
Kayla Weigel, BSN
Doctor of Nursing Practice NDSU Graduate Student
Dissertation Practice Improvement Project



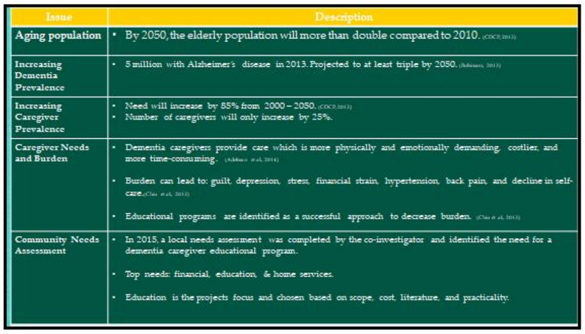
Acknowledgements

- **Education content developed and provided by:**
  - **A neurology nurse practitioner**
- She is considered an expert in the area of neurological assessment with an emphasis on parkinsonism and related dementia. She has nearly ten years of knowledge and experience in healthcare.
- She has taught various education courses throughout the community, specifically focusing on dementia and Parkinson's.

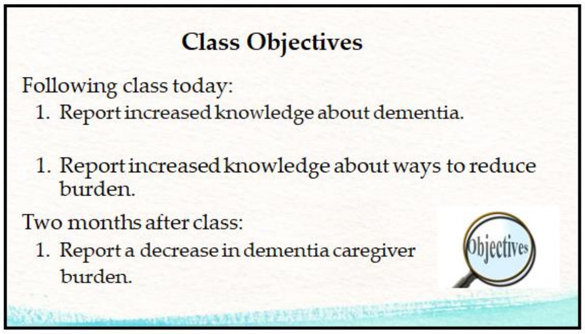
- RN - 6 years on a medical-surgical unit (charge and supervisor)
- DNP NDSU Graduate Student – Graduating May 2018
- Strong passion for taking care of the caregiver, The "invisible patient."
- Grandma had dementia – first hand witness to the strains/needs of caregiving
- Grew up in West Fargo and currently live in Fargo with my husband and our active 1.5yr boy



- In addition to my personal interest and passion about dementia and caregivers, the statistics on the next slide indicate the importance of supporting YOU, our caregivers!
- This class is about YOU, focusing on your health, with the hopes of decreasing YOUR burden.



Issue	Description
Aging population	• By 2050, the elderly population will more than double compared to 2010. (CDCP, 2013)
Increasing Dementia Prevalence	• 5 million with Alzheimer's disease in 2013. Projected to at least triple by 2050. ([illegible], 2013)
Increasing Caregiver Prevalence	• Need will increase by 85% from 2000 – 2050. (CDCP, 2013) • Number of caregivers will only increase by 25%.
Caregiver Needs and Burden	• Dementia caregivers provide care which is more physically and emotionally demanding, costlier, and more time-consuming. (Adelman et al., 2014) • Burden can lead to: guilt, depression, stress, financial strain, hypertension, back pain, and decline in self-care. (Chiu et al., 2013) • Educational programs are identified as a successful approach to decrease burden. (Chiu et al., 2013)
Community Needs Assessment	• In 2015, a local needs assessment was completed by the co-investigator and identified the need for a dementia caregiver educational program. • Top needs: financial, education, & home services. • Education is the projects focus and chosen based on scope, cost, literature, and practicality.



Class Objectives

Following class today:

1. Report increased knowledge about dementia.

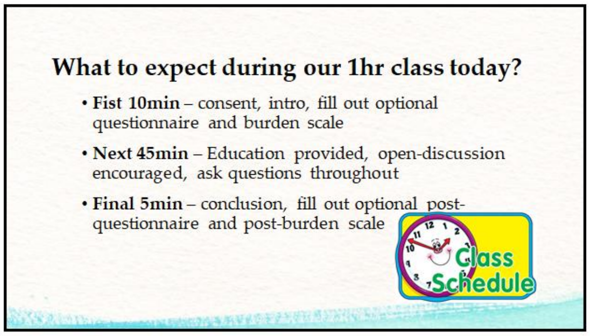
1. Report increased knowledge about ways to reduce burden.

Two months after class:

1. Report a decrease in dementia caregiver burden.

What will be discussed today?

- Communication techniques
- Dealing with agitation/behavior/personality changes
- Sundowning, hallucinations, delusions, and paranoia
- Importance of dementia caregivers and burden
- Managing personal stress
- Tips for self care – to reduce caregiver burden



What to expect during our 1hr class today?

- **Fist 10min** – consent, intro, fill out optional questionnaire and burden scale
- **Next 45min** – Education provided, open-discussion encouraged, ask questions throughout
- **Final 5min** – conclusion, fill out optional post-questionnaire and post-burden scale

Caregiving in the Cognitively Impaired (CI)

Caregiving in CI

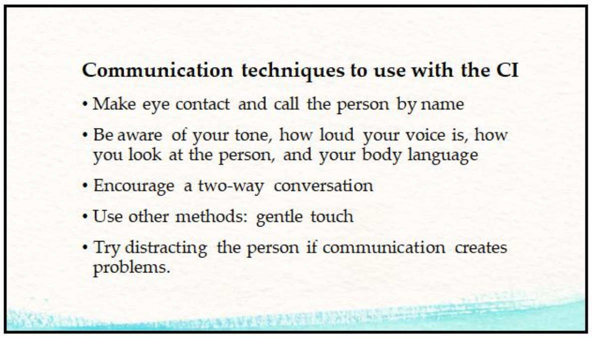
- Caregiving in general has it's own challenges -- add to that a person who is unable to rationally think or problem solve consistently and we are playing a different ball game

Cognitive Impairment

- Factors in caregiving for the person with CI will depend on the type of CI.
- Alzheimer's disease, frontotemporal dementia, Lewy Body Dementia, Parkinson's disease related dementia and Huntington's disease related dementia all have different characteristics and will respond differently to treatment and interactions with others

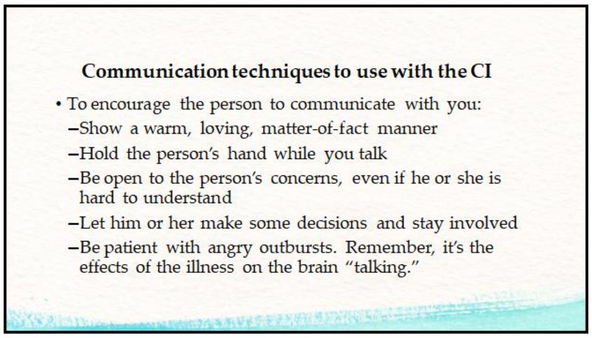
Potential early signs of CI

- Finding the right word or losing his or her train of thought
- Understanding what words mean
- Paying attention during long conversations
- Delayed processing speed
- Frustration
- Troubles blocking out background noises (radio, TV)
- Being very sensitive to touch and to the tone and loudness of voices



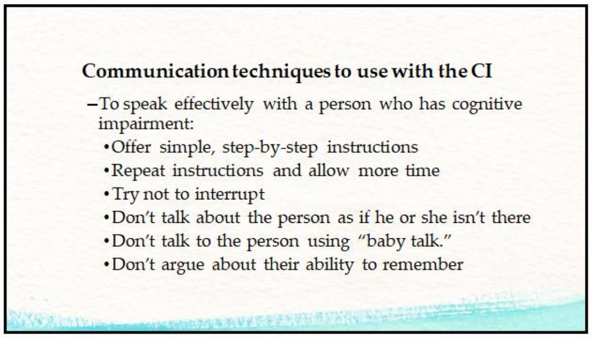
Communication techniques to use with the CI

- Make eye contact and call the person by name
- Be aware of your tone, how loud your voice is, how you look at the person, and your body language
- Encourage a two-way conversation
- Use other methods: gentle touch
- Try distracting the person if communication creates problems.



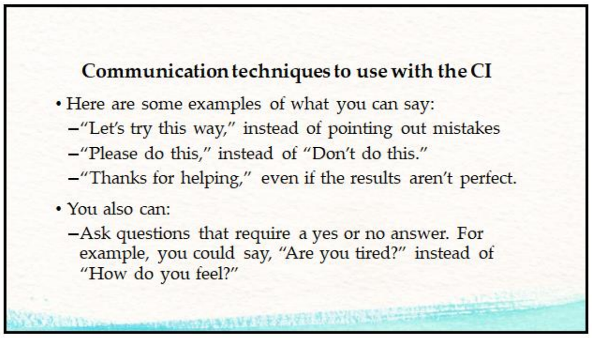
Communication techniques to use with the CI

- To encourage the person to communicate with you:
  - Show a warm, loving, matter-of-fact manner
  - Hold the person's hand while you talk
  - Be open to the person's concerns, even if he or she is hard to understand
  - Let him or her make some decisions and stay involved
  - Be patient with angry outbursts. Remember, it's the effects of the illness on the brain "talking."



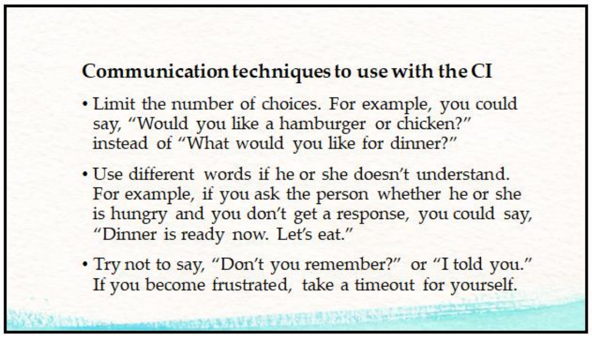
Communication techniques to use with the CI

- To speak effectively with a person who has cognitive impairment:
  - Offer simple, step-by-step instructions
  - Repeat instructions and allow more time
  - Try not to interrupt
  - Don't talk about the person as if he or she isn't there
  - Don't talk to the person using "baby talk."
  - Don't argue about their ability to remember



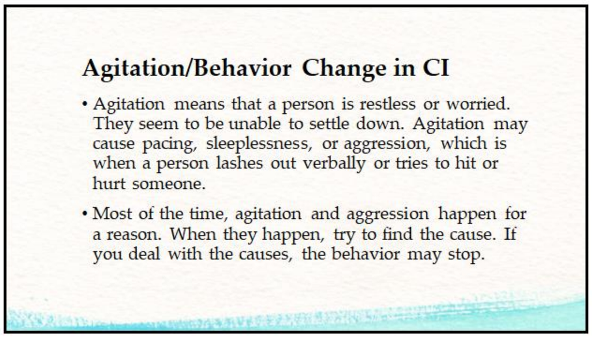
Communication techniques to use with the CI

- Here are some examples of what you can say:
  - "Let's try this way," instead of pointing out mistakes
  - "Please do this," instead of "Don't do this."
  - "Thanks for helping," even if the results aren't perfect.
- You also can:
  - Ask questions that require a yes or no answer. For example, you could say, "Are you tired?" instead of "How do you feel?"



Communication techniques to use with the CI

- Limit the number of choices. For example, you could say, "Would you like a hamburger or chicken?" instead of "What would you like for dinner?"
- Use different words if he or she doesn't understand. For example, if you ask the person whether he or she is hungry and you don't get a response, you could say, "Dinner is ready now. Let's eat."
- Try not to say, "Don't you remember?" or "I told you." If you become frustrated, take a timeout for yourself.



Agitation/Behavior Change in CI

- Agitation means that a person is restless or worried. They seem to be unable to settle down. Agitation may cause pacing, sleeplessness, or aggression, which is when a person lashes out verbally or tries to hit or hurt someone.
- Most of the time, agitation and aggression happen for a reason. When they happen, try to find the cause. If you deal with the causes, the behavior may stop.

Causes for Agitation/Behavior Change in CI

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Soiled underwear or brief
- Sudden change in a well-known place, routine, or person
- A feeling of loss—for example, the person may miss the freedom to drive

Causes for Agitation/Behavior Change in CI

- Too much noise, confusion or too many people in the room
- Being pushed by others to do something—for example, to bathe or to remember events or people
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Dealing with Agitation & Behavior Change in CI

- Reassure the person
- Speak calmly
- Listen to their concerns and frustrations
- Try to show that you understand if the person is angry or fearful
- Allow the person to keep as much control in his or her life as possible
- Coping with changes is hard for someone with cognitive impairment.
- Try to keep a routine, such as bathing, dressing, and eating at the same time each day.

Dealing with Agitation & Behavior Change in CI

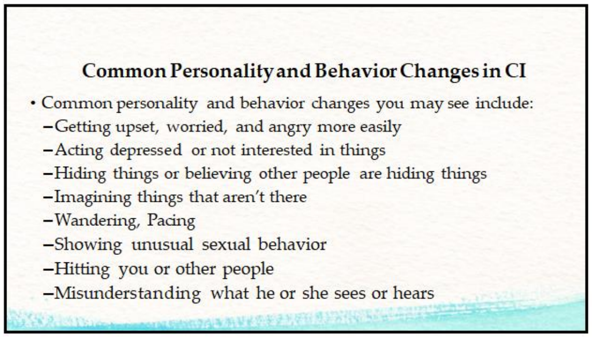
- Build quiet times into the day, along with activities
- Keep well-loved objects and photographs around the house to help the person feel more secure
- Try gentle touching, soothing music, reading, or walks
- Reduce noise, clutter, or the number of people in the room
- Try to distract the person with a favorite snack, object, or activity

Dealing with Agitation & Behavior change in CI

- Limit the amount of caffeine, sugar, and "junk food" the person drinks and eats.
- Here are some things you can do
  - Slow down and try to relax if you think your own worries may be affecting the person with cognitive impairment
  - Try to find a way to take a break from caregiving.

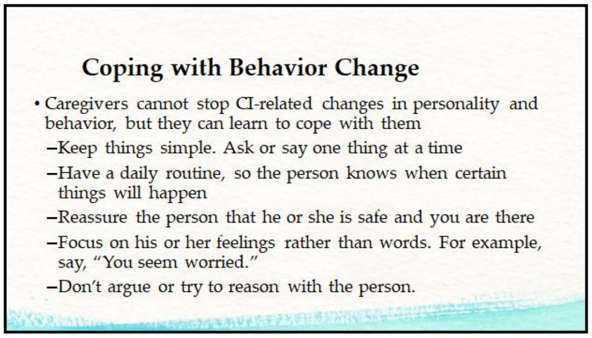
Dealing with Behavior Change in CI

- While some behaviors related to cognitive change can be managed medically, many, such as wandering and agitation, cannot.
- It is more effective to change the person's surroundings—for example, to remove dangerous items—than to try to change behaviors.



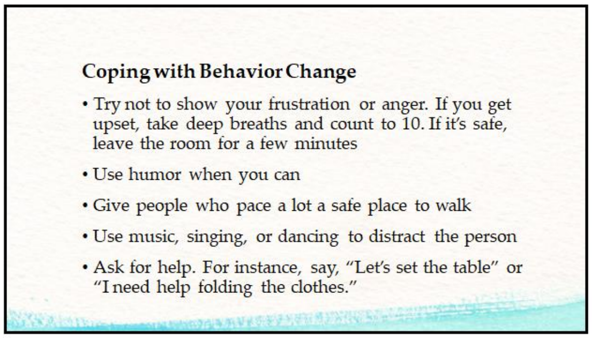
Common Personality and Behavior Changes in CI

- Common personality and behavior changes you may see include:
  - –Getting upset, worried, and angry more easily
  - –Acting depressed or not interested in things
  - –Hiding things or believing other people are hiding things
  - –Imagining things that aren't there
  - –Wandering, Pacing
  - –Showing unusual sexual behavior
  - –Hitting you or other people
  - –Misunderstanding what he or she sees or hears



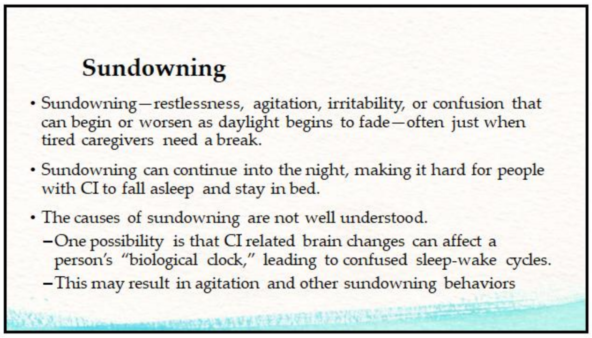
Coping with Behavior Change

- Caregivers cannot stop CI-related changes in personality and behavior, but they can learn to cope with them
  - –Keep things simple. Ask or say one thing at a time
  - –Have a daily routine, so the person knows when certain things will happen
  - –Reassure the person that he or she is safe and you are there
  - –Focus on his or her feelings rather than words. For example, say, "You seem worried."
  - –Don't argue or try to reason with the person.



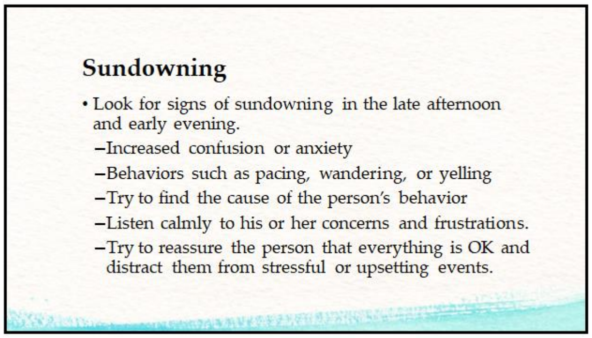
Coping with Behavior Change

- Try not to show your frustration or anger. If you get upset, take deep breaths and count to 10. If it's safe, leave the room for a few minutes
- Use humor when you can
- Give people who pace a lot a safe place to walk
- Use music, singing, or dancing to distract the person
- Ask for help. For instance, say, "Let's set the table" or "I need help folding the clothes."



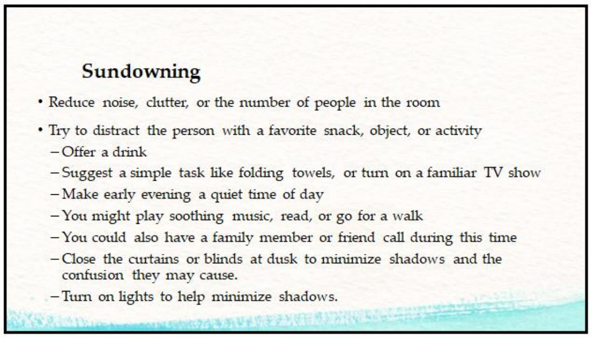
Sundowning

- Sundowning—restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade—often just when tired caregivers need a break.
- Sundowning can continue into the night, making it hard for people with CI to fall asleep and stay in bed.
- The causes of sundowning are not well understood.
  - –One possibility is that CI related brain changes can affect a person's "biological clock," leading to confused sleep-wake cycles.
  - –This may result in agitation and other sundowning behaviors



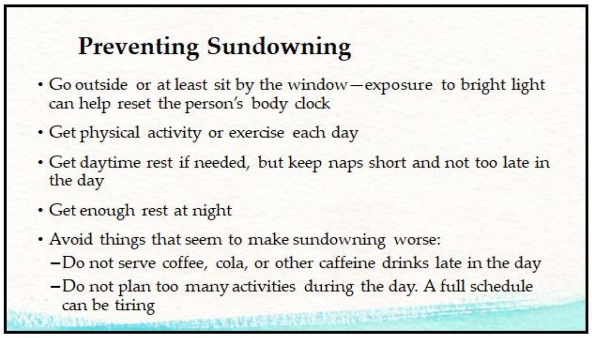
Sundowning

- Look for signs of sundowning in the late afternoon and early evening.
  - –Increased confusion or anxiety
  - –Behaviors such as pacing, wandering, or yelling
  - –Try to find the cause of the person's behavior
  - –Listen calmly to his or her concerns and frustrations.
  - –Try to reassure the person that everything is OK and distract them from stressful or upsetting events.



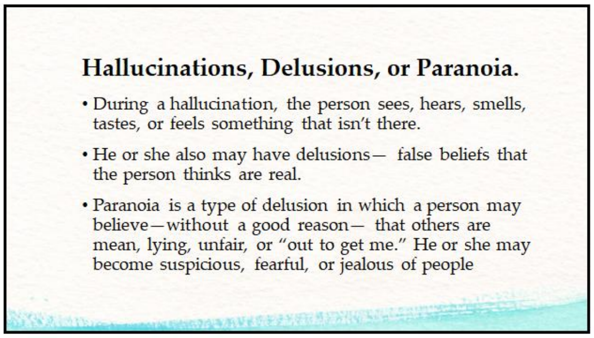
Sundowning

- Reduce noise, clutter, or the number of people in the room
- Try to distract the person with a favorite snack, object, or activity
  - –Offer a drink
  - –Suggest a simple task like folding towels, or turn on a familiar TV show
  - –Make early evening a quiet time of day
  - –You might play soothing music, read, or go for a walk
  - –You could also have a family member or friend call during this time
  - –Close the curtains or blinds at dusk to minimize shadows and the confusion they may cause.
  - –Turn on lights to help minimize shadows.



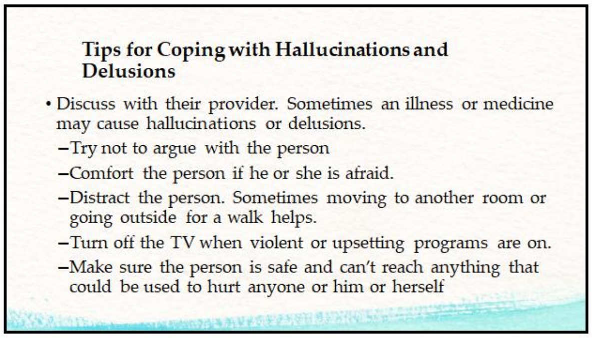
Preventing Sundowning

- Go outside or at least sit by the window—exposure to bright light can help reset the person's body clock
- Get physical activity or exercise each day
- Get daytime rest if needed, but keep naps short and not too late in the day
- Get enough rest at night
- Avoid things that seem to make sundowning worse:
  - Do not serve coffee, cola, or other caffeine drinks late in the day
  - Do not plan too many activities during the day. A full schedule can be tiring



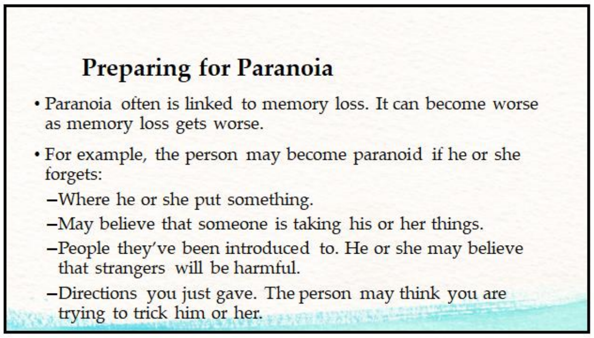
Hallucinations, Delusions, or Paranoia.

- During a hallucination, the person sees, hears, smells, tastes, or feels something that isn't there.
- He or she also may have delusions— false beliefs that the person thinks are real.
- Paranoia is a type of delusion in which a person may believe—without a good reason— that others are mean, lying, unfair, or "out to get me." He or she may become suspicious, fearful, or jealous of people



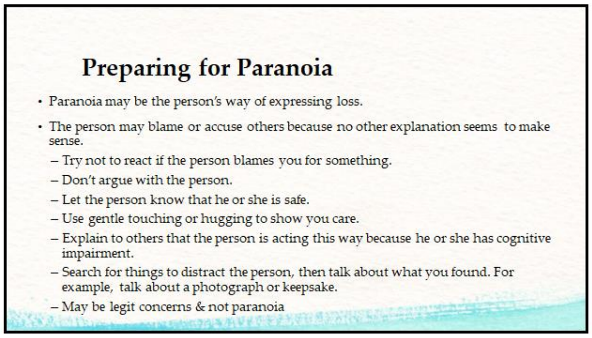
Tips for Coping with Hallucinations and Delusions

- Discuss with their provider. Sometimes an illness or medicine may cause hallucinations or delusions.
  - Try not to argue with the person
  - Comfort the person if he or she is afraid.
  - Distract the person. Sometimes moving to another room or going outside for a walk helps.
  - Turn off the TV when violent or upsetting programs are on.
  - Make sure the person is safe and can't reach anything that could be used to hurt anyone or him or herself



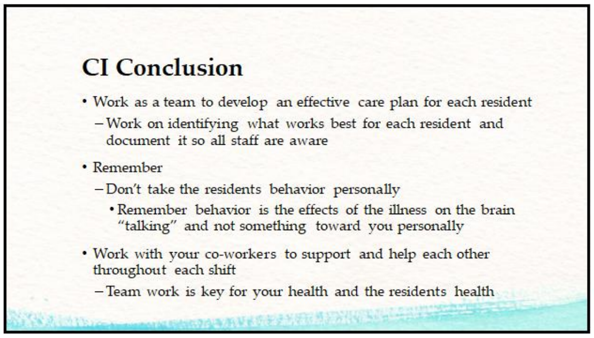
Preparing for Paranoia

- Paranoia often is linked to memory loss. It can become worse as memory loss gets worse.
- For example, the person may become paranoid if he or she forgets:
  - Where he or she put something.
  - May believe that someone is taking his or her things.
  - People they've been introduced to. He or she may believe that strangers will be harmful.
  - Directions you just gave. The person may think you are trying to trick him or her.



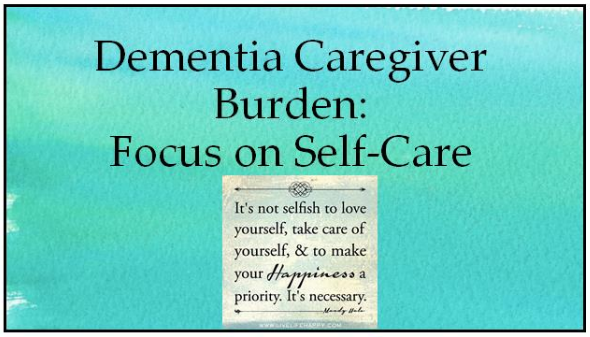
Preparing for Paranoia

- Paranoia may be the person's way of expressing loss.
- The person may blame or accuse others because no other explanation seems to make sense.
  - Try not to react if the person blames you for something.
  - Don't argue with the person.
  - Let the person know that he or she is safe.
  - Use gentle touching or hugging to show you care.
  - Explain to others that the person is acting this way because he or she has cognitive impairment.
  - Search for things to distract the person, then talk about what you found. For example, talk about a photograph or keepsake.
  - May be legit concerns & not paranoia



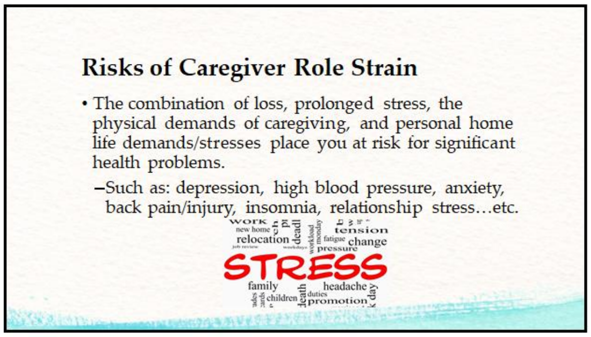
CI Conclusion

- Work as a team to develop an effective care plan for each resident
  - Work on identifying what works best for each resident and document it so all staff are aware
- Remember
  - Don't take the residents behavior personally
    - Remember behavior is the effects of the illness on the brain "talking" and not something toward you personally
- Work with your co-workers to support and help each other throughout each shift
  - Team work is key for your health and the residents health



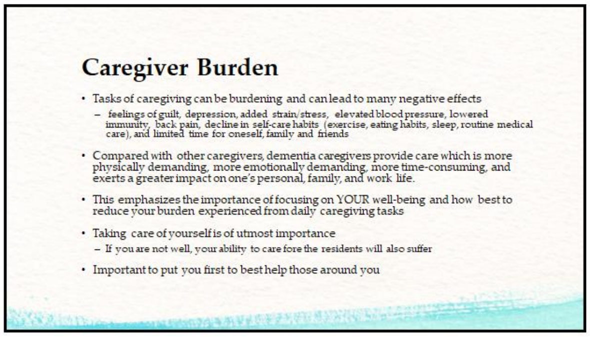
Dementia Caregiver Burden: Focus on Self-Care

It's not selfish to love yourself, take care of yourself, & to make your *Happiness* a priority. It's necessary.



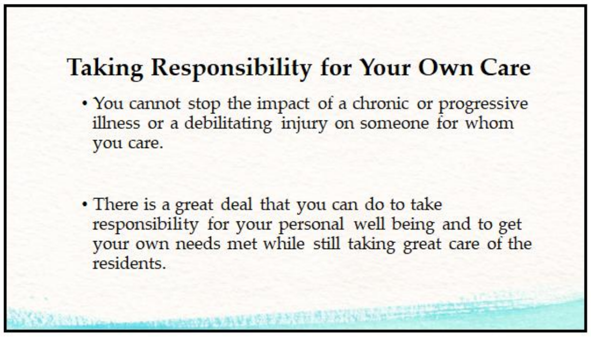
Risks of Caregiver Role Strain

- The combination of loss, prolonged stress, the physical demands of caregiving, and personal home life demands/stresses place you at risk for significant health problems.
  - Such as: depression, high blood pressure, anxiety, back pain/injury, insomnia, relationship stress…etc.



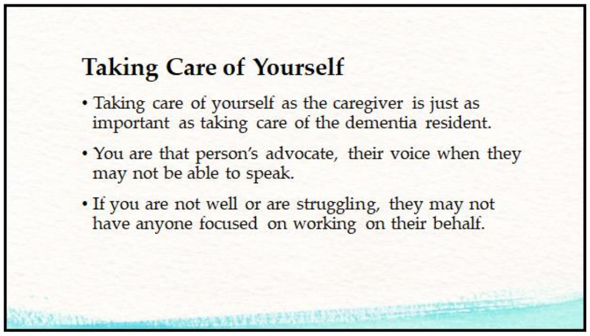
Caregiver Burden

- Tasks of caregiving can be burdening and can lead to many negative effects
  - feelings of guilt, depression, added strain/stress, elevated blood pressure, lowered immunity, back pain, decline in self-care habits (exercise, eating habits, sleep, routine medical care), and limited time for oneself, family and friends
- Compared with other caregivers, dementia caregivers provide care which is more physically demanding, more emotionally demanding, more time-consuming, and exerts a greater impact on one's personal, family, and work life.
- This emphasizes the importance of focusing on YOUR well-being and how best to reduce your burden experienced from daily caregiving tasks
- Taking care of yourself is of utmost importance
  - If you are not well, your ability to care fore the residents will also suffer
- Important to put you first to best help those around you



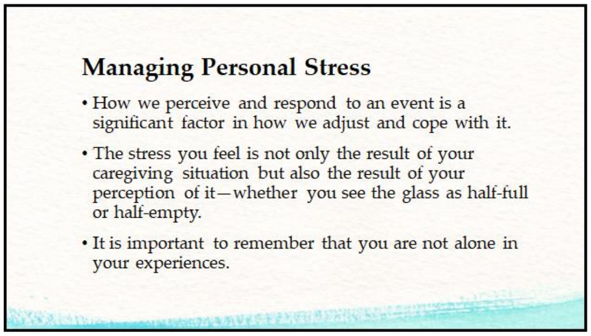
Taking Responsibility for Your Own Care

- You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care.
- There is a great deal that you can do to take responsibility for your personal well being and to get your own needs met while still taking great care of the residents.



Taking Care of Yourself

- Taking care of yourself as the caregiver is just as important as taking care of the dementia resident.
- You are that person's advocate, their voice when they may not be able to speak.
- If you are not well or are struggling, they may not have anyone focused on working on their behalf.



Managing Personal Stress

- How we perceive and respond to an event is a significant factor in how we adjust and cope with it.
- The stress you feel is not only the result of your caregiving situation but also the result of your perception of it—whether you see the glass as half-full or half-empty.
- It is important to remember that you are not alone in your experiences.

Managing Stress

- Recognize warning signs early.
- Identify sources of stress. Ask yourself, "What is causing stress for me?"
- Identify what you can and cannot change.
  - *"God grant me the serenity to accept the things I cannot change,*
    Courage to change the things I can, and (the) wisdom to know the difference."
- Take action.

Setting Goals

- Take meal breaks and little "time outs" for yourself as needed.
- Talk with other co-workers
- Ask for help as you need. Don't have the mindset that you can do it ALL.
- Engage in activities that will make you feel healthy.
- Goals are generally too big to work on all at once.
  - Break it down into smaller action steps.
  - Make an action plan by deciding which step you will take first, and when.
  - Get started!

Asking for and Accepting Help

- Help can come from community resources, family, friends and professionals.
- Ask them - - you are NOT a burden.
- Don't wait until you are overwhelmed and exhausted or your health fails.
- Reaching out for help when you need it is a sign of personal strength.

Seeing a Healthcare Provider Regularly

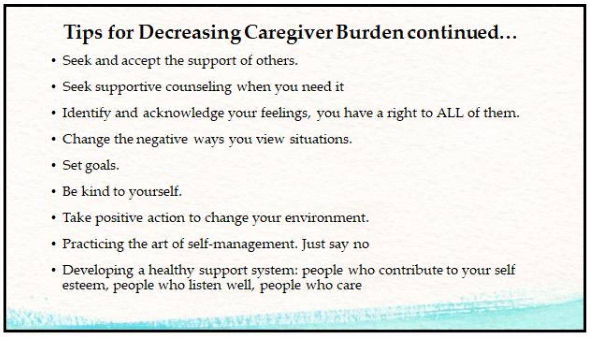
- How many of you complete yearly physicals?
- Statistics show caregivers are at least 40% less likely to see a provider regularly resulting in decreased health outcomes
- Yearly exams/physicals are recommended
- Encouraged to schedule a yearly physical to assess for any health issues and for you to discuss any concerns you have
- Important to help develop a trusting relationship with your provider

Exercise is Key

- Research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking
- Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity.
- Walking, one of the best and easiest exercises, is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension.
- Walking 20 minutes a day, three times a week

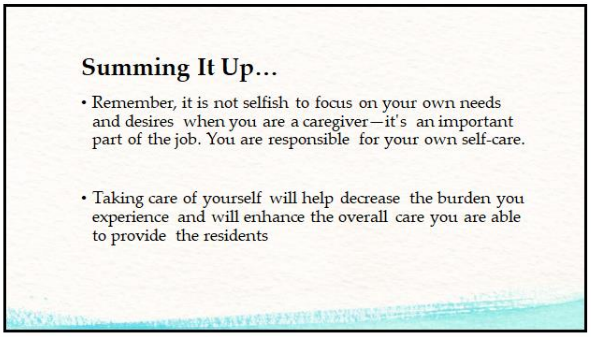
Tips for Decreasing Caregiver Burden

- Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition. Eating healthy, drinking plenty of water.
- Exercise regularly, if only for 10 minutes at a time.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, taking a warm bath.



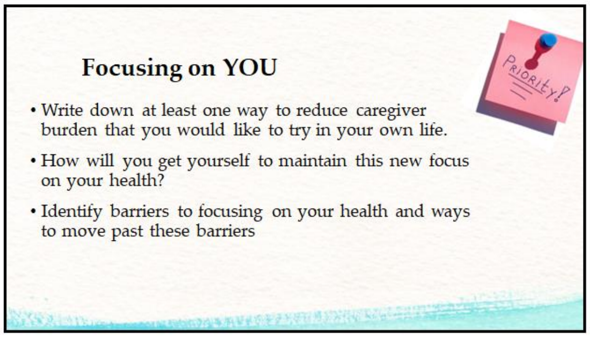
Tips for Decreasing Caregiver Burden continued…

- Seek and accept the support of others.
- Seek supportive counseling when you need it
- Identify and acknowledge your feelings, you have a right to ALL of them.
- Change the negative ways you view situations.
- Set goals.
- Be kind to yourself.
- Take positive action to change your environment.
- Practicing the art of self-management. Just say no
- Developing a healthy support system: people who contribute to your self esteem, people who listen well, people who care



Summing It Up…

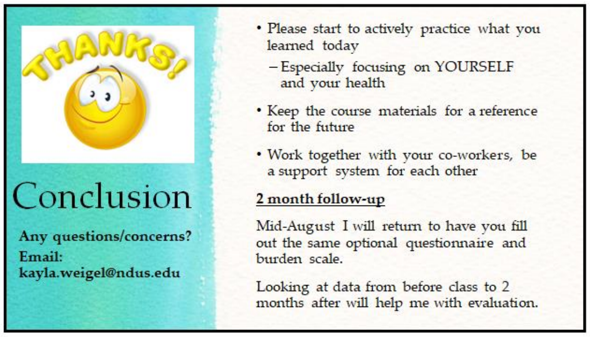
- Remember, it is not selfish to focus on your own needs and desires when you are a caregiver—it's an important part of the job. You are responsible for your own self-care.
- Taking care of yourself will help decrease the burden you experience and will enhance the overall care you are able to provide the residents



Focusing on YOU

- Write down at least one way to reduce caregiver burden that you would like to try in your own life.
- How will you get yourself to maintain this new focus on your health?
- Identify barriers to focusing on your health and ways to move past these barriers

Questions or Comments???



Conclusion

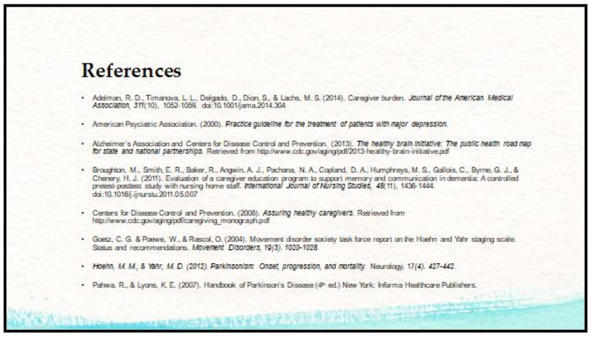
Any questions/concerns?
Email: kayla.weigel@ndus.edu

- Please start to actively practice what you learned today
  - Especially focusing on YOURSELF and your health
- Keep the course materials for a reference for the future
- Work together with your co-workers, be a support system for each other

2 month follow-up

Mid-August I will return to have you fill out the same optional questionnaire and burden scale.

Looking at data from before class to 2 months after will help me with evaluation.



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APPENDIX H. LOCAL LONG-TERM CARE AGENCY PROGRAM POSTER

RECOMMENDED EDUCATION: DEMENTIA CAREGIVER BURDEN

Date/Time: 06/13/2017, 12pm and 06/14/2017, 4pm
Instructor: Kayla Weigel, BSN, DNP-S

My name is Kayla Weigel. I am a graduate student in the Doctor of Nursing Practice program at NDSU. I am implementing a quality improvement intervention focused on decreasing dementia caregiver burden. I will be implementing a dementia educational session in hopes of increasing caregiver knowledge and providing caregivers with strategies to decrease burden.

Two separate one-hour classes will be offered. You must be at least 18 years of age and work on the memory care unit. The classes will have between 10-20 participants.

The educational session is a recommended option to help fulfill your mandated quarterly dementia training. You will not be penalized for missing the educational session. However, you will need to fulfill your quarterly dementia training requirements by completing one-hour of continuing education modules or watch the video recording of the dementia caregiver burden education at time which works for you.

The class will involve presentation and discussion. You will be asked to fill out two questionnaires before class, at the end of class, and two months after class; all of which are voluntary. All class discussion will be kept confidential. Only the co-investigator will see the information you provide. Your identity will not be linked to your survey responses.

FOR MORE INFORMATION CONTACT: KAYLA.WEIGEL@NDSU.EDU

APPENDIX I. LOCAL LONG-TERM CARE AGENCY PROGRAM STAFF EMAIL

Memory Care Unit Staff:

A NDSU DNP student, Kayla Weigel, will be providing an educational session on dementia caregiver burden. The class will be one hour in length and will be power-point presentaion and discussion based. The education will be held in the conference room.

Two separate one-hour sessions will be offered. Classes will be June 13th at 12pm and June 14th at 4pm. You must be at least 18 years of age and work on the secured memory unit. The classes will have between 10-20 participants, depending on attendance.

The educational session is a recommended option to help fulfill your mandated quarterly dementia training. The session will count towards your mandatory quarterly dementia training requirements. You will not be penalized for missing the educational session. However, you will still need to fulfill your quarterly dementia training requirements by completing one-hour of continuing education modules or watch the video recording of the dementia caregiver burden education at time which works for you.

We are excited to partner with Kayla to provide you with this education. She will be touring the unit within the next couple of weeks to meet all of you and find out what you want to learn about.

Class date/time options: <u>June 13th, 12pm and June 14th, 4pm</u>

We are excited to welcome Kayla and hope you enjoy this great learning opportunity.

Please contact Kayla with any questions about the project: kayla.weigel@ndsu.edu

Please contact your nursing manager with any attendance questions.

APPENDIX J. CAREGIVER TRAINING PROGRAM ORAL CONSENT

NDSU – North Dakota State University
School of Nursing
NDSU Dept 2670 - PO Box 6050
Fargo, ND 58108-6050

NDSU Quality Improvement Project

Decreasing Caregiver Burden: A Quality Improvement Intervention

Dear Memory Care Unit Staff:

My name is Kayla Weigel. I am a graduate student in the Doctor of Nursing Practice program at North Dakota State University. I am implementing a quality improvement intervention focused on decreasing dementia caregiver burden. I will be implementing a dementia educational session in hopes of increasing caregiver knowledge, increasing caregiver confidence, and providing caregivers with strategies to decrease burden. The ultimate goal is to decrease overall caregiver burden.

The class will take place in the conference room. Two separate one-hour sessions will be offered. Classes will be offered June 13th and June 14th at 12:30PM. You must be at least 18 years of age and work on the memory care unit.

The educational session is a recommended option to help fulfill your mandated quarterly dementia training. The session will count towards your mandatory quarterly dementia training requirements. You will not be penalized for missing the educational session.

What will I be asked to do?

Knowledge Questionnaire

You will be asked to complete a questionnaire at the beginning of class, end of class, and two months after class. The questionnaire will ask questions about class content, dementia, caregiving, strategies to decrease burden, and suggestions for class improvement. The questionnaire will help with future class development and analysis of content effectiveness. All questionnaires are voluntary.

Caregiver Burden Scale

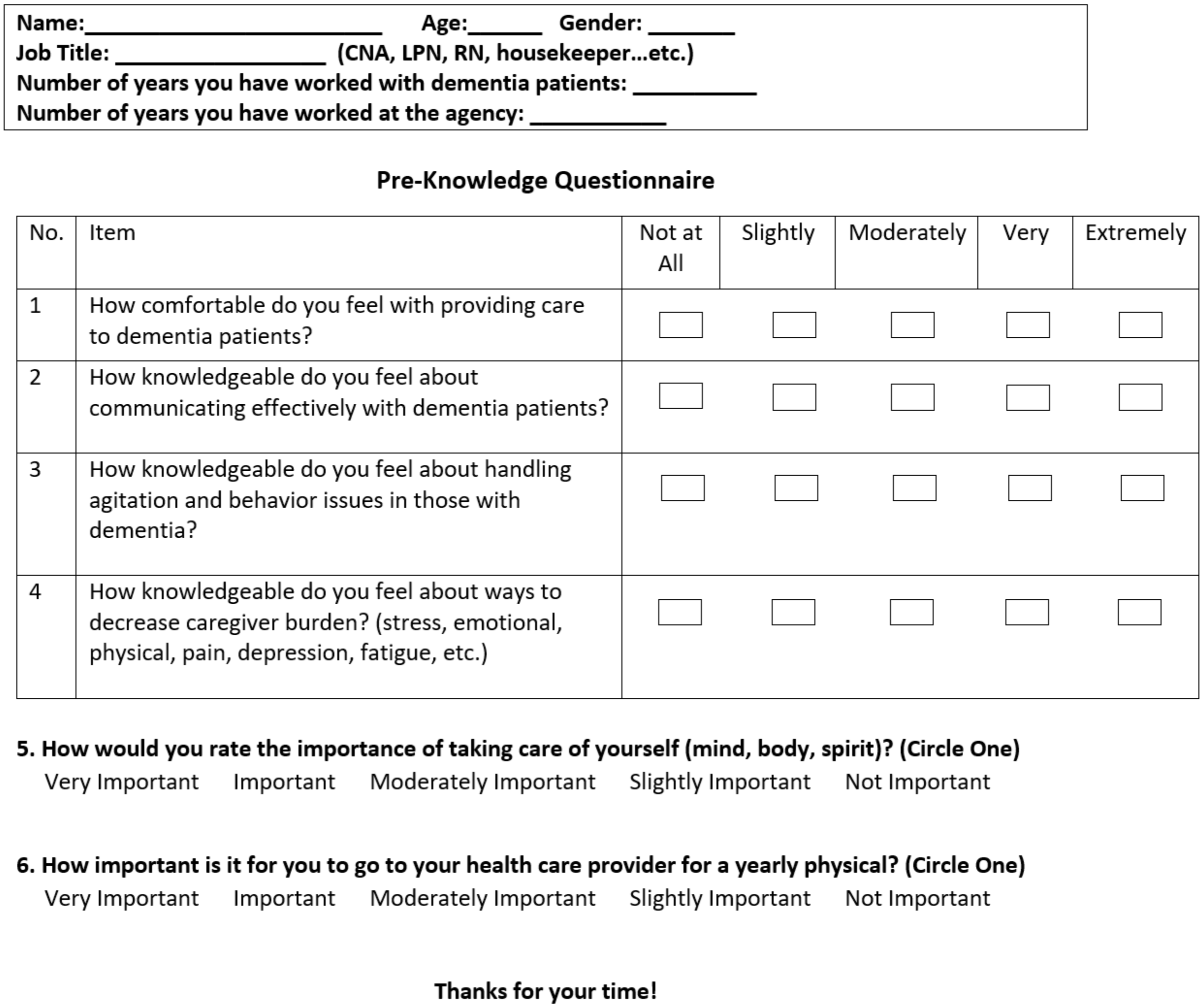
You will be asked to complete a burden scale at the beginning of class, end of class, and two months after class. The purpose of the survey is to provide a scale to indicate burden level. The burden scale will help determine if the course helped to decrease caregiver burden. Completion is voluntary.

All class discussion will be kept confidential. Only the co-investigator will see the information you provide. Your identity will not be linked to your survey responses. Your information will be combined with information from other people taking part in the project, we will write about the combined information that we have gathered. You will not be identified in these written materials.

If you have any questions about this project, please contact me at 701-866-2946, kayla.weigel@ndsu.edu or contact my principal investigator, Dean Gross, at 701-231-8355, dean.gross@ndsu.edu. If you have questions about the rights of human participants in research, or to report a problem, you may contact the NDSU Human Research Protection Program, at 701-231-8995, toll-free at 1-855-800-6717 or via email at ndsu.irb@ndsu.edu.

Thank you for your participation in this project. If you wish to receive a copy of the project results, please email me at: kayla.weigel@ndsu.edu.

APPENDIX K. PRE-EDUCATION KNOWLEDGE QUESTIONNAIRE



Name:_________________________ Age:______ Gender: _______

Job Title: __________________ (CNA, LPN, RN, housekeeper…etc.)

Number of years you have worked with dementia patients: __________

Number of years you have worked at the agency: ___________

Pre-Knowledge Questionnaire

No.	Item	Not at All	Slightly	Moderately	Very	Extremely
1	How comfortable do you feel with providing care to dementia patients?	☐	☐	☐	☐	☐
2	How knowledgeable do you feel about communicating effectively with dementia patients?	☐	☐	☐	☐	☐
3	How knowledgeable do you feel about handling agitation and behavior issues in those with dementia?	☐	☐	☐	☐	☐
4	How knowledgeable do you feel about ways to decrease caregiver burden? (stress, emotional, physical, pain, depression, fatigue, etc.)	☐	☐	☐	☐	☐

5. How would you rate the importance of taking care of yourself (mind, body, spirit)? (Circle One)

Very Important Important Moderately Important Slightly Important Not Important

6. How important is it for you to go to your health care provider for a yearly physical? (Circle One)

Very Important Important Moderately Important Slightly Important Not Important

Thanks for your time!

APPENDIX L. PRE-EDUCATION BURDEN SCALE

Name:__________________________ **Age:**______ **Gender:** ________
Job Title: ___________________ **(CNA, LPN, RN, housekeeper…etc.)**
Number of years you have worked with dementia patients: ____________
Number of years you have worked at the agency: __________

Professional Care Team Burden (PCTB) Scale – 10 item version
Pre-Burden Scale

No.	Item	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	My work performance is respected by my colleagues.	☐	☐	☐	☐	☐
2	I can discuss work related issues with my colleagues.	☐	☐	☐	☐	☐
3	I feel that the contact with my superiors is good.	☐	☐	☐	☐	☐
4	I can participate in organizing the daily routine in my organization.	☐	☐	☐	☐	☐
5	The loss of ability to communicate in persons with dementia bothers me.	☐	☐	☐	☐	☐
6	I can manage behaviours resulting from disorientation in persons with dementia.	☐	☐	☐	☐	☐
7	Difficult behaviours (Aggression, Wandering) of persons with dementia are difficult to bear.	☐	☐	☐	☐	☐
8	I can handle constructive criticism.	☐	☐	☐	☐	☐
9	I can keep personal problems out of my daily work routine.	☐	☐	☐	☐	☐
10	My personal life/family environment is supportive and is able to unburden me.	☐	☐	☐	☐	☐

(Auer et al., 2015)

APPENDIX M. POST-EDUCATION KNOWLEDGE QUESTIONNAIRE

Name:_________________________ Age:______ Gender: _______
Job Title: __________________ (CNA, LPN, RN, housekeeper…etc.)
Number of years you have worked with dementia patients: __________
Number of years you have worked at the agency: ___________

Post-Knowledge Questionnaire

No.	Item	Not at All	Slightly	Moderately	Very	Extremely
1	How comfortable do you feel with providing care to dementia patients?	☐	☐	☐	☐	☐
2	How knowledgeable do you feel about communicating effectively with dementia patients?	☐	☐	☐	☐	☐
3	How knowledgeable do you feel about handling agitation and behavior issues in those with dementia?	☐	☐	☐	☐	☐
4	How knowledgeable do you feel about ways to decrease caregiver burden? (stress, emotional, physical, pain, depression, fatigue, etc.)	☐	☐	☐	☐	☐

5. How would you rate the importance of taking care of yourself (mind, body, spirit)? (Circle One)

Very Important Important Moderately Important Slightly Important Not Important

6. How important is it for you to go to your health care provider for a yearly physical? (Circle One)

Very Important Important Moderately Important Slightly Important Not Important

What was most helpful? Any suggestions to improve the training?

Thanks for your time!

APPENDIX N. POST-EDUCATION BURDEN SCALE

Name:______________________________ Age:_______ Gender: ________
Job Title: _____________________ (CNA, LPN, RN, housekeeper…etc.)
Number of years you have worked with dementia patients: _____________
Number of years you have worked at the agency: __________

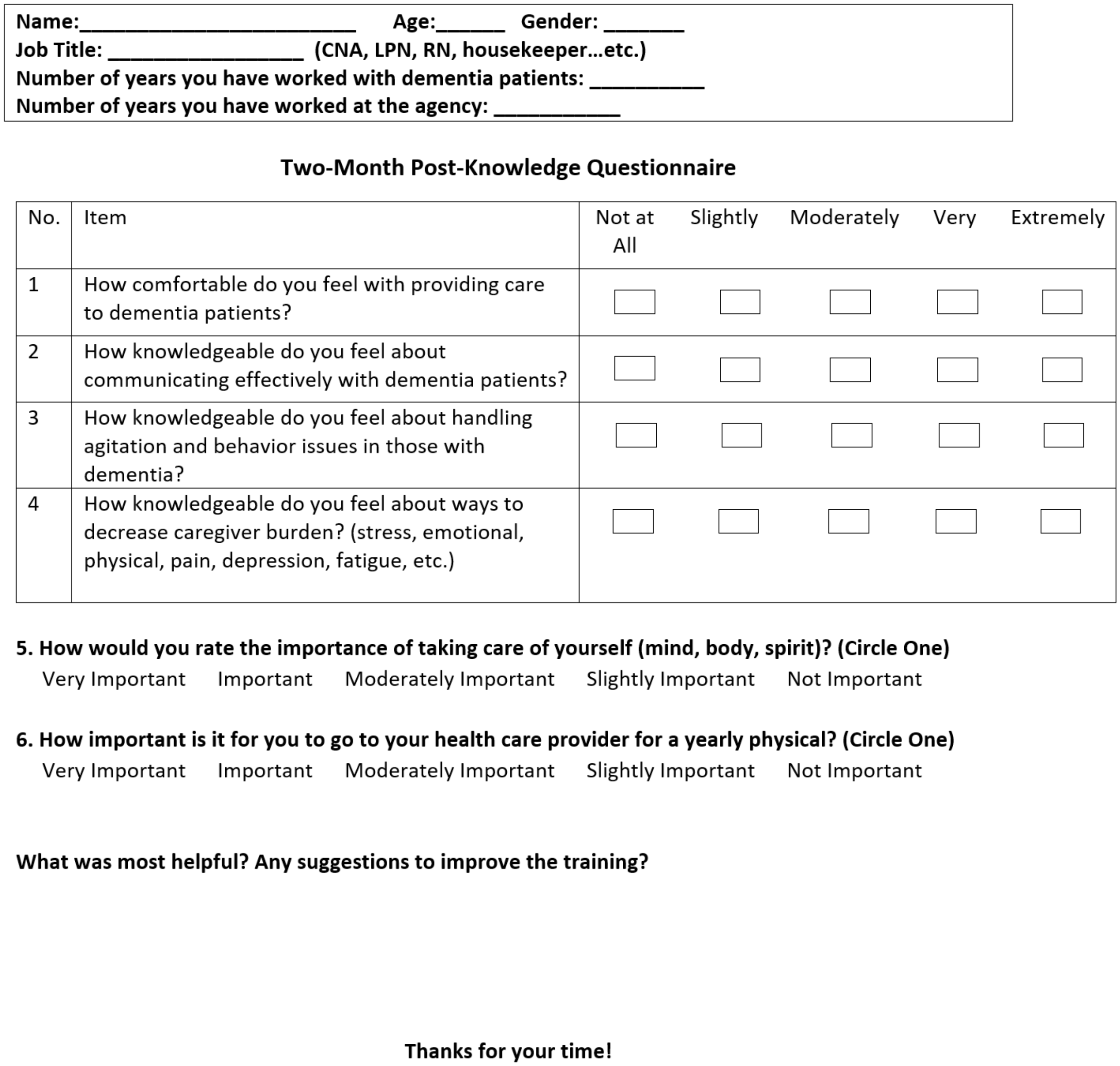
Professional Care Team Burden (PCTB) Scale – 10 item version

Post-Burden Scale

No.	Item	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	My work performance is respected by my colleagues.	☐	☐	☐	☐	☐
2	I can discuss work related issues with my colleagues.	☐	☐	☐	☐	☐
3	I feel that the contact with my superiors is good.	☐	☐	☐	☐	☐
4	I can participate in organizing the daily routine in my organization.	☐	☐	☐	☐	☐
5	The loss of ability to communicate in persons with dementia bothers me.	☐	☐	☐	☐	☐
6	I can manage behaviours resulting from disorientation in persons with dementia.	☐	☐	☐	☐	☐
7	Difficult behaviours (Aggression, Wandering) of persons with dementia are difficult to bear.	☐	☐	☐	☐	☐
8	I can handle constructive criticism.	☐	☐	☐	☐	☐
9	I can keep personal problems out of my daily work routine.	☐	☐	☐	☐	☐
10	My personal life/family environment is supportive and is able to unburden me.	☐	☐	☐	☐	☐

(Auer et al., 2015)

APPENDIX O. TWO-MONTH POST-EDUCATION KNOWLEDGE QUESTIONNAIRE



Name:________________________ Age:______ Gender: _______
Job Title: _________________ (CNA, LPN, RN, housekeeper…etc.)
Number of years you have worked with dementia patients: __________
Number of years you have worked at the agency: ___________

Two-Month Post-Knowledge Questionnaire

No.	Item	Not at All	Slightly	Moderately	Very	Extremely
1	How comfortable do you feel with providing care to dementia patients?	☐	☐	☐	☐	☐
2	How knowledgeable do you feel about communicating effectively with dementia patients?	☐	☐	☐	☐	☐
3	How knowledgeable do you feel about handling agitation and behavior issues in those with dementia?	☐	☐	☐	☐	☐
4	How knowledgeable do you feel about ways to decrease caregiver burden? (stress, emotional, physical, pain, depression, fatigue, etc.)	☐	☐	☐	☐	☐

5. How would you rate the importance of taking care of yourself (mind, body, spirit)? (Circle One)
Very Important Important Moderately Important Slightly Important Not Important

6. How important is it for you to go to your health care provider for a yearly physical? (Circle One)
Very Important Important Moderately Important Slightly Important Not Important

What was most helpful? Any suggestions to improve the training?

Thanks for your time!

APPENDIX P. TWO-MONTH POST-EDUCATION BURDEN SCALE

Name:__________________________ Age:______ Gender: ________
Job Title: __________________ (CNA, LPN, RN, housekeeper…etc.)
Number of years you have worked with dementia patients: ____________
Number of years you have worked at the agency: __________

Professional Care Team Burden (PCTB) Scale – 10 item version
Two-Month Post-Burden Scale

No.	Item	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	My work performance is respected by my colleagues.	☐	☐	☐	☐	☐
2	I can discuss work related issues with my colleagues.	☐	☐	☐	☐	☐
3	I feel that the contact with my superiors is good.	☐	☐	☐	☐	☐
4	I can participate in organizing the daily routine in my organization.	☐	☐	☐	☐	☐
5	The loss of ability to communicate in persons with dementia bothers me.	☐	☐	☐	☐	☐
6	I can manage behaviours resulting from disorientation in persons with dementia.	☐	☐	☐	☐	☐
7	Difficult behaviours (Aggression, Wandering) of persons with dementia are difficult to bear.	☐	☐	☐	☐	☐
8	I can handle constructive criticism.	☐	☐	☐	☐	☐
9	I can keep personal problems out of my daily work routine.	☐	☐	☐	☐	☐
10	My personal life/family environment is supportive and is able to unburden me.	☐	☐	☐	☐	☐

(Auer et al., 2015)

APPENDIX Q. PERMISSION FOR UTILIZATION OF BURDEN SCALE

Donau-Universität Krems
Universität für Weiterbildung

Department für Klinische
Neurowissenschaften und
Präventionsmedizin

Dr.-Karl-Dorrek-Straße 30
3500 Krems, Austria

T +43 (0)2732 893-2814
F +43 (0)2732 893-4810
kmpm.sekretariat@donau-uni.ac.at

Leitung
Univ.-Prof. Dr. Dr. h.c. **Michael Brainin**

www.donau-uni.ac.at/kmpm

To
Kayla Weigel

April 9, 2017

Betreff: RE: Permission to Use and/or Reproduce the Professional Care Team Burden (PCTB) Scale

Dear Ms. Weigel,

As requested via email, you have permission to use the Professional Care Team Burden (PCTB) Scale in your DNP project development, implementation, and final publication of your project. Permission is limited to your DNP project.

It is our understanding that you are developing a dementia caregiver training program for the Fargo, ND community. The program will be focused on enhancing confident, increasing caregiver knowledge, and decreasing overall caregiver burden. You will be utilizing the burden assessment scale to address burden of formal dementia caregivers. You will be providing paper copies of the scale to each formal dementia caregiver participating in your DNP project. The formal caregivers will be completing the scale right before class, right after class, and two months after class to help assist with evaluation of project objectives.

Please be sure to include a reference of our published study within your final paper. Please inform us about your study results and your experience with the PCTB.

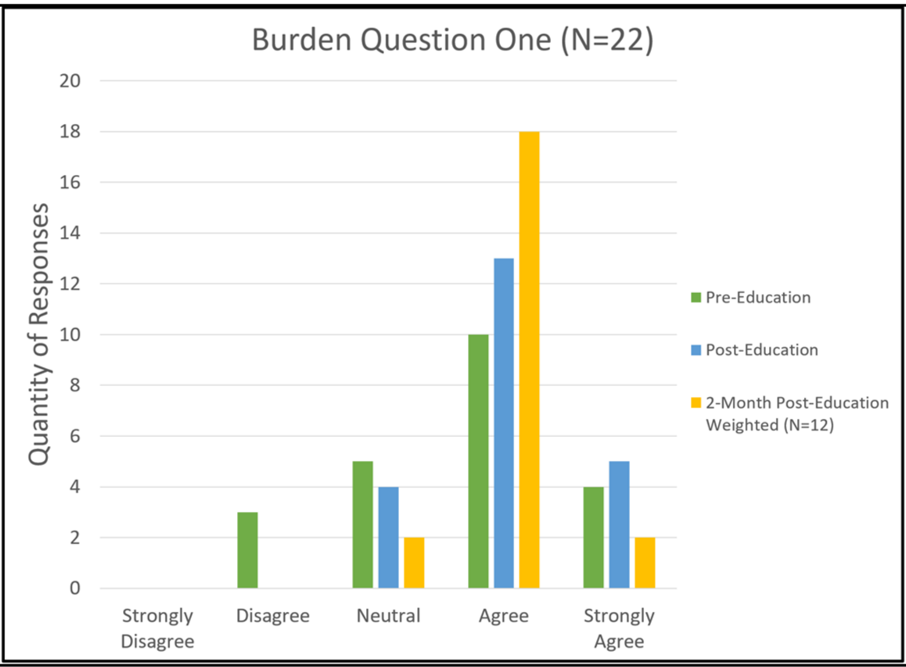
If you have any questions, please feel free to contact me at Stefanie.Auer@mas.or.at or Stefanie.Auer@donau-uni.ac.at.

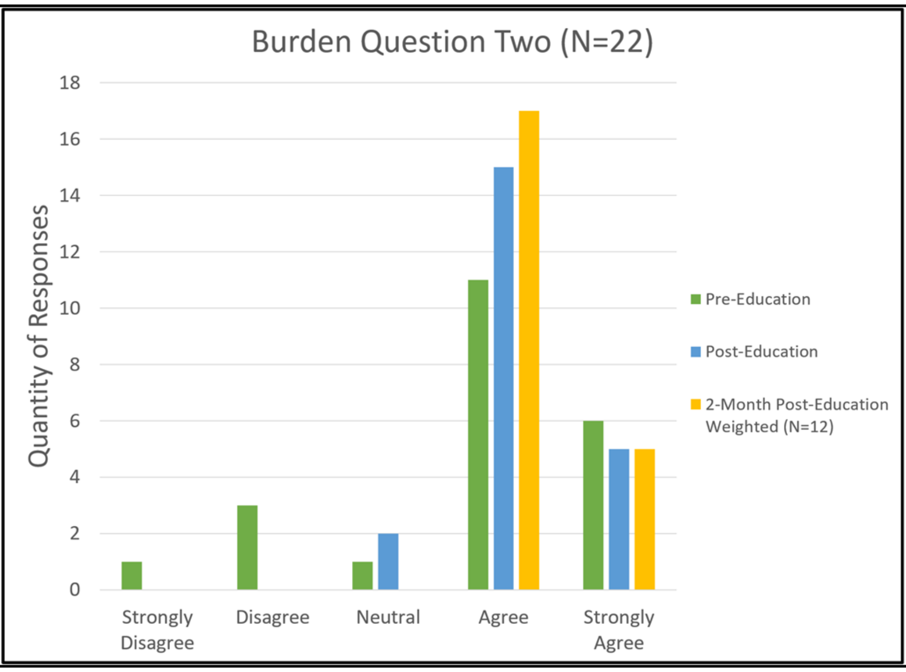
Sincerely,

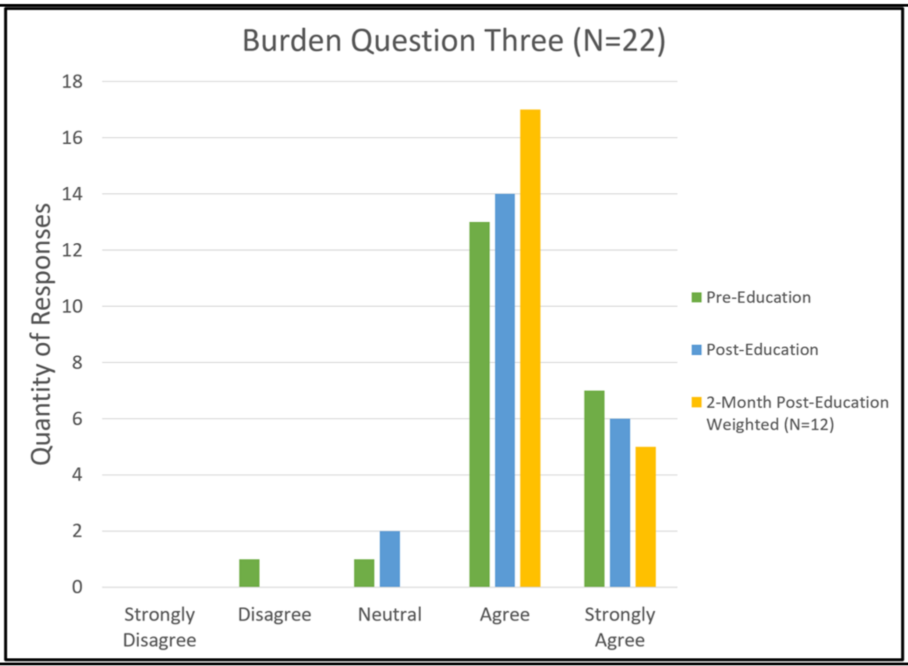
Dr. Stefanie Auer
Corresponding Author PCTB Scale
Professor of Dementia Studies
Danube University Krems/Austria

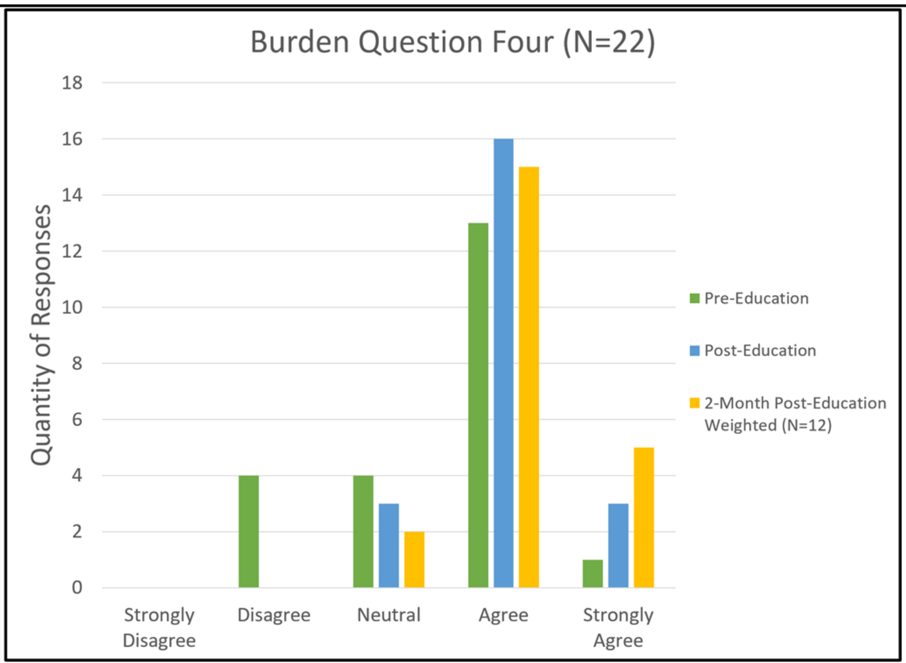
i.A. Iwona Kaminski
Sekretariat
Department für Klinische Neurowissenschaften und Präventionsmedizin
Leiter: Univ.-Prof. Dr. Dr. h.c. Michael Brainin
Donau-Universität Krems
Dr. Karl-Dorrek-Strasse 30
3500 Krems

APPENDIX R. GRAPHS OF BURDEN QUESTIONS






Burden Question Three (N=22)
Quantity of Responses
0
2
4
6
8
10
12
14
16
18
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Four (N=22)
Quantity of Responses
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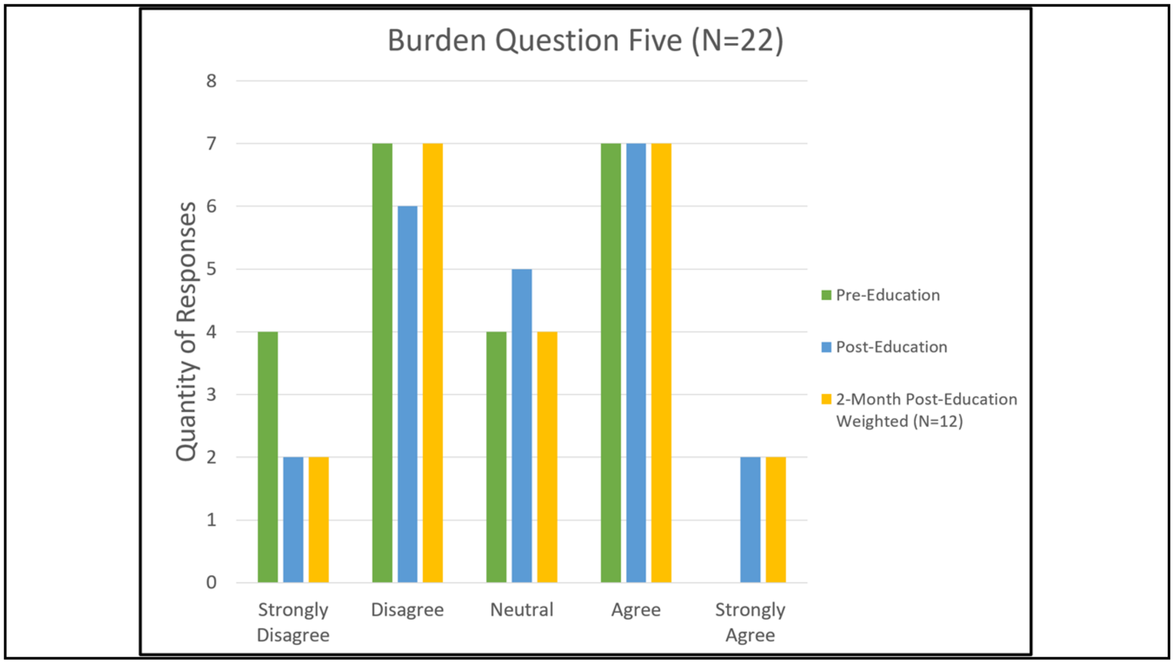
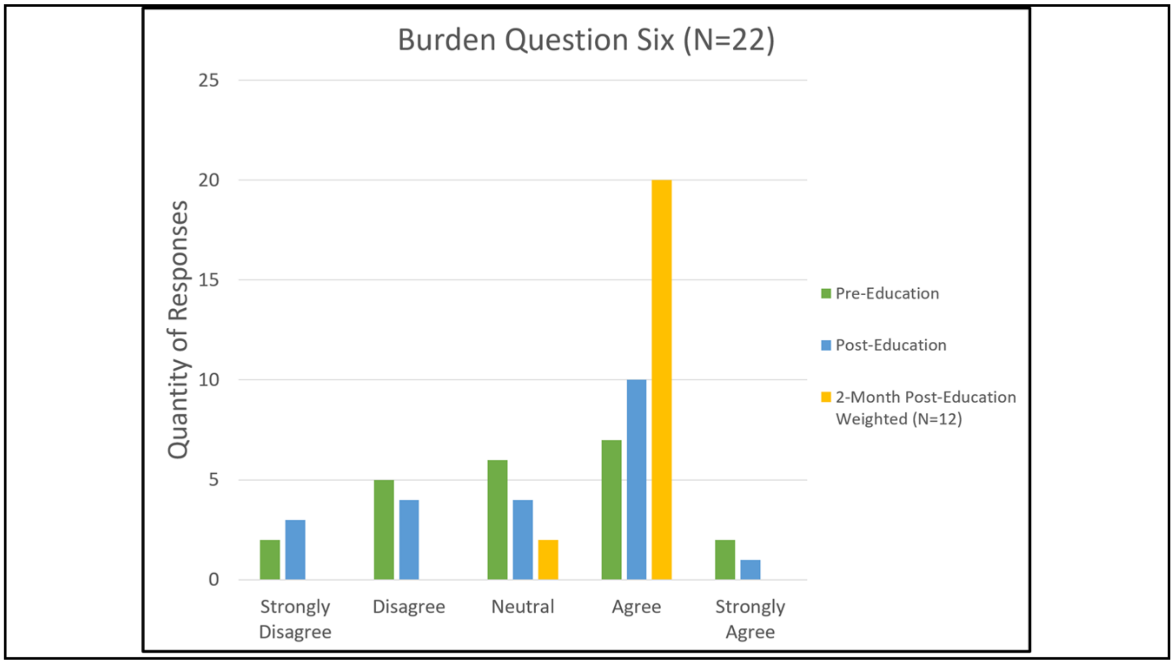
2
4
6
8
10
12
14
16
18
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Five (N=22)
Quantity of Responses
0
1
2
3
4
5
6
7
8
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Six (N=22)
Quantity of Responses
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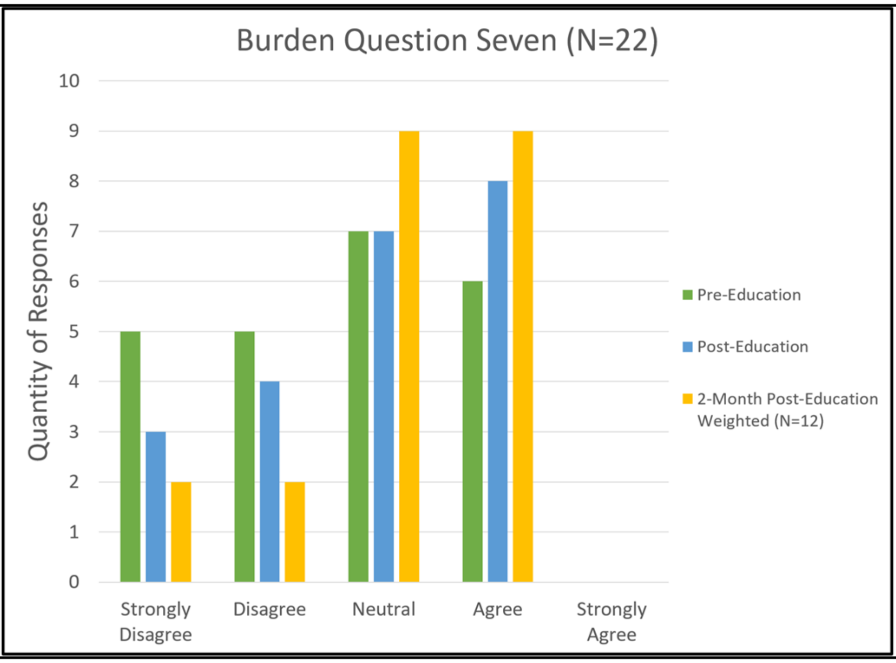
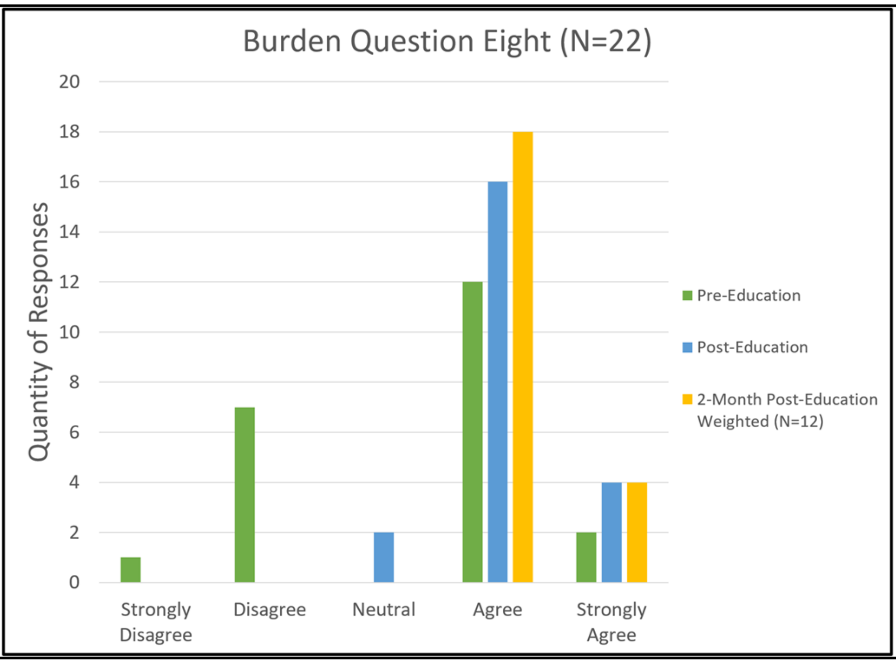
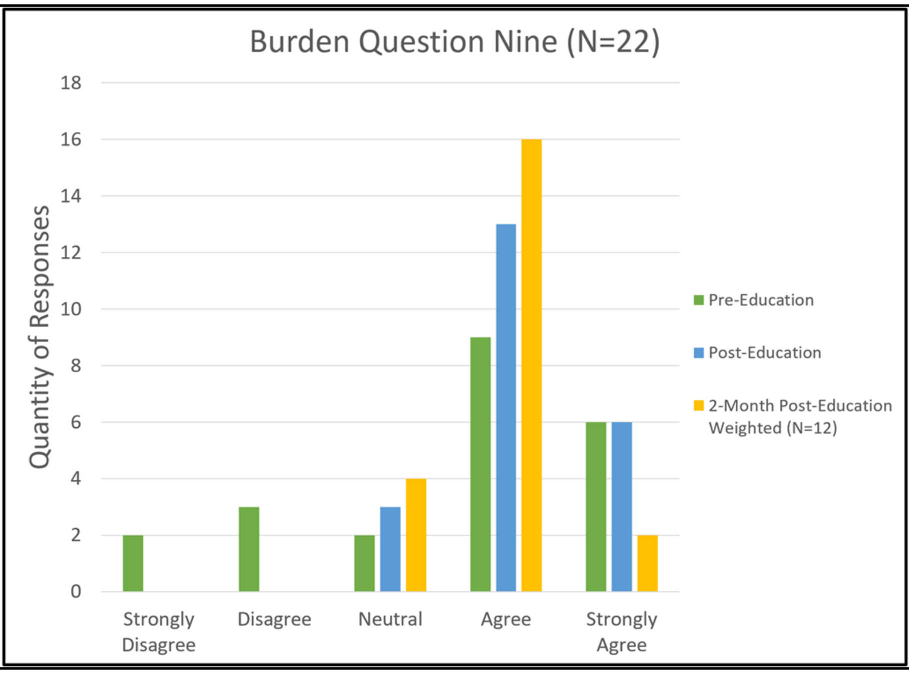
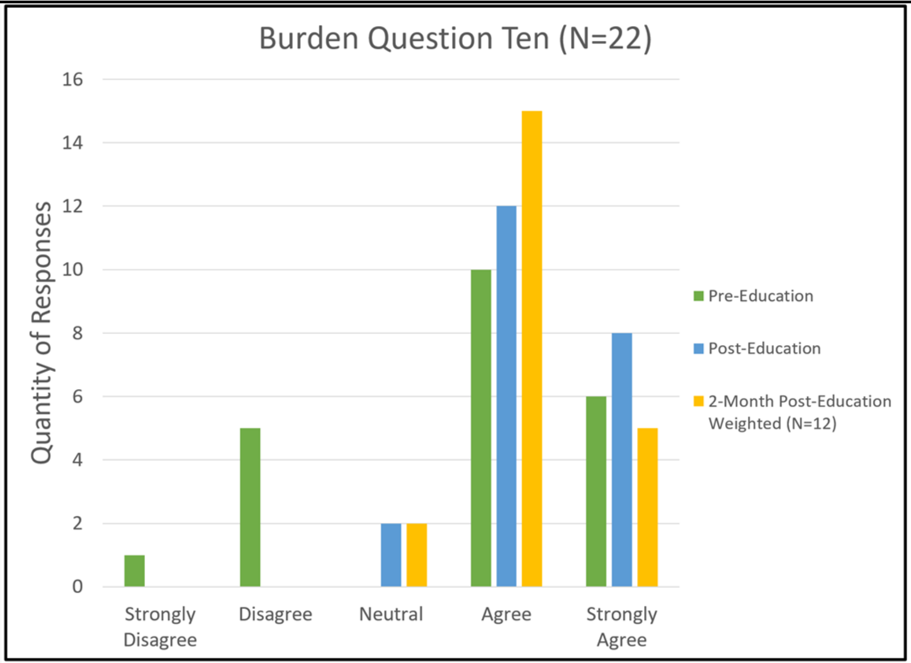
10
15
20
25
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)

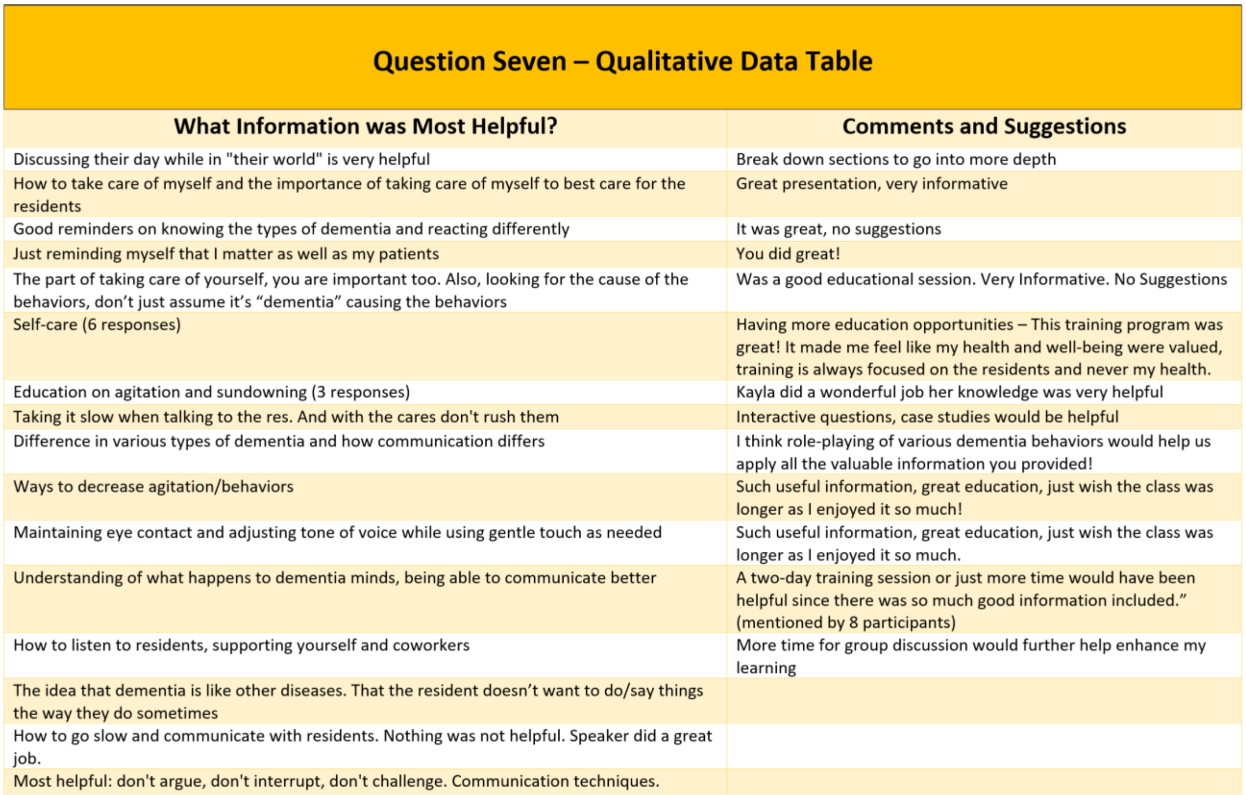

Burden Question Seven (N=22)
Quantity of Responses
10
9
8
7
6
5
4
3
2
1
0
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Eight (N=22)
Quantity of Responses
20
18
16
14
12
10
8
6
4
2
0
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Nine (N=22)
Quantity of Responses
18
16
14
12
10
8
6
4
2
0
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)


Burden Question Ten (N=22)
Quantity of Responses
16
14
12
10
8
6
4
2
0
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree
Pre-Education
Post-Education
2-Month Post-Education Weighted (N=12)

APPENDIX S. QUESTION SEVEN QUALITATIVE DATA TABLE



Question Seven – Qualitative Data Table

What Information was Most Helpful?	Comments and Suggestions
Discussing their day while in "their world" is very helpful	Break down sections to go into more depth
How to take care of myself and the importance of taking care of myself to best care for the residents	Great presentation, very informative
Good reminders on knowing the types of dementia and reacting differently	It was great, no suggestions
Just reminding myself that I matter as well as my patients	You did great!
The part of taking care of yourself, you are important too. Also, looking for the cause of the behaviors, don’t just assume it’s “dementia” causing the behaviors	Was a good educational session. Very Informative. No Suggestions
Self-care (6 responses)	Having more education opportunities – This training program was great! It made me feel like my health and well-being were valued, training is always focused on the residents and never my health.
Education on agitation and sundowning (3 responses)	Kayla did a wonderful job her knowledge was very helpful
Taking it slow when talking to the res. And with the cares don't rush them	Interactive questions, case studies would be helpful
Difference in various types of dementia and how communication differs	I think role-playing of various dementia behaviors would help us apply all the valuable information you provided!
Ways to decrease agitation/behaviors	Such useful information, great education, just wish the class was longer as I enjoyed it so much!
Maintaining eye contact and adjusting tone of voice while using gentle touch as needed	Such useful information, great education, just wish the class was longer as I enjoyed it so much.
Understanding of what happens to dementia minds, being able to communicate better	A two-day training session or just more time would have been helpful since there was so much good information included.” (mentioned by 8 participants)
How to listen to residents, supporting yourself and coworkers	More time for group discussion would further help enhance my learning
The idea that dementia is like other diseases. That the resident doesn’t want to do/say things the way they do sometimes	
How to go slow and communicate with residents. Nothing was not helpful. Speaker did a great job.	
Most helpful: don't argue, don't interrupt, don't challenge. Communication techniques.	

APPENDIX T. POSTER PRESENTATION ABSTRACT

ABSTRACT FOR PROPOSED POSTER PRESENTATION
NDNPA 9th Annual Pharmacology Conference

Implementation of a Dementia Caregiver Educational Program

Millions of Americans provide care to individuals who can no longer care for themselves. The role of caregivers is often overlooked, but their contributions are foundation to our nation's long-term healthcare. It is estimated that dementia caregiver demand will increase by 85% from 2000 to 2050. However, over the same time span, the number of caregivers is expected to only increase by 25%. To meet the needs of dementia patients, support to caregivers will be necessary to help meet increasing demands. Dementia caregivers provide care which is more physically and emotionally demanding, costlier, and more time-consuming. Numerous studies report caregiving tasks can be burdening and can lead to negative effects such as guilt, depression, added strain, hypertension, back pain, and decline in self-care. Educational programs have been identified through research as a successful approach to decreasing caregiver burden. The purpose of this project is to develop, implement, and evaluate a dementia caregiver educational program. Focus of the educational program will be on decreasing caregiver burden and increasing caregiver confidence, knowledge, and support. Implementation of one-hour educational sessions at a local long-term care agency were completed in July 2017. All participants worked on the agency's secured dementia unit. Educational sessions were power-point and discussion based. Data will be analyzed from two surveys completed by participants. The surveys will be completed before and after class along with three months after class. One of the surveys was identified through literature, with a focus on rating dementia caregiver burden levels. The other survey was individually developed to help identify strengths and weaknesses of the program. Data analysis and dissemination will be completed by May 2018. Developing and implementing a dementia caregiver educational program will hopefully enhance health of caregivers within the community, decrease caregiver burden, and increase community awareness of dementia caregiver needs.

APPENDIX U. EXECUTIVE SUMMARY

Introduction

A caregiver is defined as someone who offers care to another individual who is not capable of carrying out activities essential for daily living (NCC, 2016). Formal caregiving includes those who are trained and paid for their care. Informal caregivers are unpaid and usually untrained. The role of caregivers is often overlooked, but their contributions are foundational to the nation's long-term healthcare organization (AARP, 2015). Numerous reasons exist for the projected increase in caregiver demand and burden, including: the nation's aging population, increased dementia prevalence, increased caregiver demand, and increased long-term care turnover rates (Adelman et al., 2014). A current and projected shortage of caregivers will profoundly impact the long-term care workforce (HHS, 2016).

Job turnover and burden rates are reported highest among dementia caregivers related to increased physical, mental, and emotional demands (AANAC, 2014). Support provided to dementia caregivers is essential to decrease burden and enhance outcomes. Research emphasizes the importance of enhancing dementia caregiver education levels to decrease turnover, reduce burden, and enhance caregiver outcomes. Research suggests the highest need for formal and informal caregivers is increased training to best reduce burden (Adelman et al., 2014; Chiu et al., 2013; HHS, 2016). Based on practicality, scope of practice, a detailed literature review, and a community needs assessment, a dementia caregiver training program was chosen as the priority dementia caregiver need.

Project Description

The practice improvement project design was focused on increasing dementia caregiver knowledge and decreasing levels of burden through implementation of a dementia caregiver training program at a local long-term care agency. To address dementia caregivers needs, an interactive PowerPoint based training program was developed for formal dementia caregivers. Training program participants included agency dementia caregivers who worked on the memory care unit. Two training sessions were provided. During the training program, the co-investigator provided training to caregivers through an interactive PowerPoint presentation and group discussion. The training session included an introduction followed by participant completion of a pre-education knowledge questionnaire and a pre-education burden scale. Training content included burden, self-care tips, communication, and managing dementia associated behaviors. Evaluation included group discussion and completion of the post-education knowledge questionnaire and the post-education burden scale. Two-months following program completion, a two-month post-education knowledge questionnaire and two-month post-education burden scale were completed by participants.

Results

The training program was attended by a total of 26 formal agency dementia caregivers. Twenty-two (84.6%) participants fully completed the pre-post knowledge questionnaire and burden scale. Twelve (46.2%) participants fully completed the two-month post-education knowledge questionnaire and burden scale. Examination of the pre-post burden scale data indicated a 12.25% burden reduction for participants. Examination of the pre-post and two-month post-education knowledge questionnaire data indicated increased knowledge levels and comfort levels. A 19.25% increase in participant comfort level was noted. A 12.5% increased knowledge level of communication techniques was noted. A 20.5% increased knowledge level about managing dementia behaviors and agitation was noted. An 11.25% increased knowledge level about ways to decrease caregiver burden was noted. Finally, a 10.25% increased importance rating for participant self-care was noted. Implementation of the dementia caregiver training program resulted in increased knowledge, increased comfort, and decreased caregiver burden.

Recommendations

The training program is supported as a recommendation to formal dementia caregivers based on positive project outcomes and current literature support of dementia caregiver education. Project results are consistent with literature reports of decreased dementia caregiver burden and increased knowledge levels following educational training programs (Adelman et al., 2014; Cheng, 2017; Sprangers et al., 2015). Continued implementation of the developed dementia training program is suggested based on positive outcomes. The co-investigator anticipates continuing the dementia caregiver training program as a part of continued professional development, continuing education, and community service.

Adding training sessions to match all shifts will help increase participant numbers. To further enhance survey completion rates, the following could be utilized: shortening surveys, monetary incentives, and scheduling a formal meeting with caregivers (Brown et al., 2016). To enhance education, longer training program session times would be recommended. Also, to assist with time constraints, removal of the post-surveys could have been considered.

Expanding dementia caregiver training to informal caregivers would further enhance community caregiver knowledge levels. Informal caregivers often need more support and education since they are often untrained and unpaid (Cheng, 2017). Expanding dementia caregiver training to informal caregivers (spouse, children, relatives) would be of great benefit to enhance caregiver and care recipient outcomes, since education is also a top need identified for informal dementia caregivers (AARP, 2015; Adelman et al., 2014; Bouldin et al., 2017).

Implications for Practice

The results of the practice improvement project support the need for increased burden management and education among formal dementia caregivers. Healthcare professionals who have contact with dementia caregivers need to ensure they provide caregivers with education and support. Caregivers are 40% less likely to go to routine health maintenance visits with a primary care provider (Zhu et al., 2015). Therefore, when a caregiver does come to an appointment, the healthcare professional must focus on education and assess for burden. Healthcare professionals can also enhance caregiver support by assisting with dementia caregiver training within the community.

Caregivers often put their health last. Burden rates are reported highest among dementia caregivers related to increased physical, mental, and emotional demands required to meet caregiving demands (AANAC, 2014). Dementia caregivers are at risk for chronic health issues especially depression, anxiety, hypertension, and back injuries (AANAC, 2014). Additionally, North Dakota reported the highest Alzheimer’s death rate in America (ND Health, 2016). Therefore, healthcare professionals need to advocate for increased dementia caregiver support to enhance both dementia caregiver outcomes and care recipient outcomes. Additionally, awareness and knowledge of dementia caregiver needs can lead to enhanced health outcomes for the caregiver. Literature suggests primary care providers lack necessary education about dementia, caregiver burden, and caregiver needs (Kerns, 2018). When healthcare providers are more aware and knowledgeable about dementia caregiver needs and burden, they can better educate caregivers about ways to reduce burden and enhance outcomes.

Nurse practitioners (NPs), practicing in family medicine and a variety of other healthcare settings, will likely provide care to dementia caregivers on a regular basis. Family medicine NPs will often be the initial contact dementia caregivers have with the healthcare system. Therefore, NPs can identify dementia caregivers, assess for health issues associated with caregiving, and talk to the caregiver about how caregiving is influencing daily life. NPs have a unique emphasis on health promotion and health education and are widely recognized as great listeners and educators (American Association of Nurse Practitioners, 2017). NPs can provide dementia caregivers with education about health maintenance, ways to reduce burden, and to connect caregivers to support resources throughout the community. As healthcare providers, educators, mentors, researchers, and advocates, NP’s can enhance health outcomes for dementia caregivers and reduce overall burden.