

IMPROVING CAREGIVER BURDEN FOR PROFESSIONAL CAREGIVERS OF  
DEMENTIA RESIDENTS

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Improving Caregiver Burden for Professional Caregivers of Dementia  
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## **ABSTRACT**

This practice improvement project examines the burden on professional caregivers of persons with dementia (PWD), aiming to enhance their well-being. With dementia significantly impacting cognitive functions, caregivers face heightened levels of stress, depressive symptoms, and physical health issues, more so than those caring for individuals with other conditions. Utilizing Roy's Adaptation Model (RAM) and the Theory of Caregiver Stress, the dissertation proposes comprehensive strategies to understand and alleviate the challenges faced by caregivers.

The core of this practice improvement project aims to enhance the well-being of formal caregivers by implementing a comprehensive training session. This session was designed to equip caregivers with essential knowledge and skills for managing their roles effectively, including stress management techniques, behavior management, communication techniques, and an understanding of caregiver burdens. By addressing the significant challenges faced by caregivers the project highlights the importance of developing support systems and interventions tailored to the needs of both informal and professional caregivers.

Objectives of the project include conducting an educational presentation, enhancing caregiver knowledge on dementia care, reducing caregiver burden, and establishing a caregiver support group within the facility. This approach, grounded in theoretical frameworks and focused on practical interventions, sought to alleviate caregiver burden, thereby improving the quality of care for dementia residents and enhancing caregiver well-being. This practice improvement project contributes to the field of dementia care by addressing the critical need for effective interventions and education for professional caregivers, highlighting the project's significance in improving both resident care and caregiver mental health.

Data collected included a pre-and post-education knowledge questionnaire, and the PCTB scale scores pre-and one-month post-education. The results indicated there was a perceived positive change in knowledge post-education, and the PCTB scale indicated an improvement in burden over the one-month period. A total of 16 caregivers attended the educational sessions and 14 participated in the data collection surveys. Response rates varied for the knowledge surveys and burden scale post-education when compared to pre-education.

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## **DEDICATION**

I dedicate this dissertation to my family members who have supported me throughout this journey and providing practical advice to finish the dissertation strong. Specifically, thank you to Danelle Anderson for providing encouragement, emotional stability, financial support, and love. My promise to you is to be the best Nurse Practitioner I can possibly be.

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## LIST OF ABBREVIATIONS

AD.....	Alzheimer’s Disease
BADL.....	Basic Activities of Daily Living
BPSD.....	Behavioral and Psychological Symptoms of Dementia
NDSU.....	North Dakota State University
PCTB.....	Professional Care Team Burden Scale
PI.....	Practice Improvement
PWD.....	People with Dementia
QOL .....	Quality of Life
RAM .....	Roy’s Adaptation Model
RCT.....	Randomized Controlled Trial

## CHAPTER ONE: INTRODUCTION

Dementia is a progressive neurological disorder that has a significant impact on cognitive function, affecting memory, thinking, comprehension, language, and capacity. Individuals who provide care for persons with dementia (PWD) encounter distinct challenges and often experience a significant level of caregiver burden. This burden is characterized as the negative impact of the caregiving role on the caregiver's emotional and psychological well-being (Brini et al., 2020). Notably, caregivers of PWD tend to report higher levels of stress, depressive symptoms, and physical health issues compared to caregivers of individuals with other medical conditions (Cheng, 2017). Informal caregivers, typically family members or friends who offer unpaid assistance, constitute approximately 48% of the support provided to older adults with Alzheimer's and related dementias (Alzheimer's Association, 2023). In contrast, formal caregivers, who operate within structured settings such as skilled nursing facilities, play a crucial role in meeting the needs of PWD who require more intensive care than what can be provided at home.

As a result, implementing interventions that focus on improving the well-being of caregivers is essential. By adopting a structured approach through theoretical frameworks like Roy's Adaptation Model (RAM) and the Theory of Caregiver Stress, we can better understand and alleviate caregiver burden. RAM highlights the significance of adapting to the challenges and stresses that come with caregiving responsibilities (Nursing Theory, 2023). Meanwhile, the Theory of Caregiver Stress sheds light on the psychological and physical challenges caregivers encounter, emphasizing the importance of comprehensive strategies to manage these stresses effectively (Tsai, 2003).

This practice improvement project aimed to explore and enhance the well-being of formal caregivers for PWD through the implementation of a comprehensive training session. By equipping caregivers with the knowledge and skills necessary to manage their roles effectively, this project sought to alleviate the burdens associated with dementia care. The knowledge and skills included within the training session included stress management techniques, behavior management, communication techniques, and caregiver burden.

### **Background and Significance**

This practice improvement project addresses the significant burden faced by professional caregivers of dementia residents, a group that often confronts considerable challenges. The burden is especially acute in situations where the required extensive services for dementia residents are lacking or unavailable, a circumstance that aligns with the experiences of caregivers across various demographics (Connors et al., 2020). Additionally, factors such as gender, education, and economic status significantly intensify the burden, predominantly among informal caregivers (Chiao et al., 2015). While female caregivers, those with less education, and those under financial strain are particularly vulnerable in informal settings, similar patterns can be observed among professional caregivers. This overlap suggests that the challenges faced by informal caregivers - encompassing physical, emotional, and financial strains - are also relevant in a professional context. Recognizing these parallels is crucial in this practice improvement project, as it underscores the necessity of developing support systems and interventions that cater to the multifaceted needs of all caregivers, regardless of their formal or informal roles.

Psychological factors further compound the intensity of the burden. Caregivers with poor mental health, existing depressive symptoms, high levels of anxiety, and inadequate coping mechanisms are more likely to experience increased levels of burden (Chiao et al., 2015). Thus,

addressing and mitigating caregiver burden in this context is not only a matter of improving the quality of life for caregivers but also enhancing the overall care for PWD. Furthermore, the experiences of caregivers, particularly in specialized groups such as those caring for veterans with dementia, underscore the necessity of understanding and addressing caregiver needs. The adverse effects experienced by caregivers often include emotional and physical health strains, and a deterioration in overall well-being. These effects are exacerbated by the increasing demands of caregiving, particularly as the PWDs condition worsens and requires more intensive personal care (Bass et al., 2012). Therefore, building on the understanding of the multifaceted challenges faced by caregivers, this practice improvement project will highlight the urgent need for effective interventions and education to support professional caregivers experiencing caregiving burden.

### **Problem Statement**

Reducing the burden faced by professional caregivers working with dementia residents is critical, as their role significantly affects resident health outcomes. Insufficient training and support for these caregivers can heighten their burden, which may in turn negatively impact the quality of care provided.

### **Purpose**

The primary aim of this project was to implement an educational session to support professional caregivers working with PWD. The education material was designed to address the identified gaps in caregiver education and resources. By enhancing the skills and support available to these caregivers, the project sought to reduce their burden and, in turn, improve the quality of care they provide to PWD. Ultimately, this project aimed to positively influence

caregiver burden by ensuring the caregivers are better equipped, both professionally and emotionally, to manage the challenges associated with dementia care.

### **Objectives**

To ensure the effectiveness and success of this project focused on enhancing the capabilities of professional caregivers for PWD, establishing clear and well-defined objectives was essential. The measurable objectives are as follows:

1. Conduct an educational presentation for professional caregivers at the memory care unit of Eventide Senior Living in Fargo, ND.
2. Increase caregiver knowledge of dementia as a disease process, stress management, and challenges of caring for individuals with dementia.
3. Decrease caregiver burden for professional caregivers of individuals with dementia 1-month following the educational presentation.
4. Collaborate with Eventide Senior Living management to develop and implement a plan for establishing and facilitating a support group for caregivers of dementia patients within the facility by May 31<sup>st</sup>, 2024.

This comprehensive approach, emphasized by theoretical frameworks and focused on practical interventions, aimed to address the significant challenges faced by formal caregivers of PWD, enhancing their well-being and the quality of care they provide.



## **CHAPTER TWO: THEORETICAL FRAMEWORK AND LITERATURE REVIEW**

Roy's Adaptation Model and the Theory of Caregiver Stress will be utilized and applied to the overall project design and purpose. Furthermore, an in-depth review of literature on the topic of dementia, caregiver burden and needs, and strategies to improve caregiver burden will be described.

### **Theoretical Framework**

Roy's Adaptation Model (RAM) was first developed by Sister Callista Roy in 1976 and is relevant to individuals with dementia and their caregivers (Nursing Theory, 2023). This model views the individual holistically, while simultaneously considering their changing environment and ability to adapt to adversity. This adaptive model has guided nursing care by influencing the nursing process to view and implement strategic interventions based upon the individuals changing environment and health (Nursing Theory, 2023). This practice improvement project will be guided by RAM and the Theory of Caregiver Stress, which closely follows the principles of RAM, but is most applicable to this project (Tsai, 2003).

### **Assumptions**

There are four main assumptions of the caregiver stress theory: 1) caregivers can respond to environmental changes, 2) the caregiver's level of perception determines how they will respond to environmental stimulus, 3) caregiver's ability to adapt is based upon the environmental stimulus and level of adaptation, and 4) caregivers' physical ability, level of self-esteem, role enjoyment, and satisfaction with their loved one and marriage (Tsai, 2003). The theory utilizes the RAM structure but adds additional factors that are linked to the various components of RAM which add depth to the entire theory. Moreover, professional caregivers of PWD all can fit within the assumptions of this model. There are many factors that go into caring

for a person with dementia (PWD). The caregiver's ability to adapt to changing situations and their level of physical ability significantly impact their level of impact on the PWD.

### **Input**

The inputs are stimuli that regulate the environment of the caregiver and effect the level of caregiver burden. There are three main stimuli which are categorized as focal, contextual, and residual. The focal stimulus is the burden associated with caregiving. For example, the more hours needed to perform caregiving duties, the higher likelihood the caregiver experiences burden. While the contextual stimulus is related to stressful life events outside of caregiving, level of social support, and even roles within society. The residual stimulus is anything else that is a factor for burden, whether that's the caregivers' gender, age, race, or even relationship with the patient (Tsai, 2003). To relate this to professional caregivers of PWD, one major focal stimulus might be agitation associated with attempting to perform the caregiving duty. This is especially true if the PWD has a higher severity of disease.

### **Control Process**

The control process refers to the coping mechanism the caregiver uses to adapt to the environmental stimuli of caregiving. The two subsystems of the coping process are called the cognator and regulator, which allow the caregiver to review their level of cognition when dealing with stress (Tsai, 2003). The cognator and regulator are observed in four adaptive modes which are physiological function, self-concept, role function, and interdependence. The hypothesis of the caregiver stress theory is that the focal stimulus of caregiving, life events, social roles, and level of social support creates an adaptation to their innate adaptive modes because of their perceived level of caregiver stress. In other words, each caregivers level of stimulus from caregiving effects their ability to function physiologically, view of their self-concept, and role.

Consequently, the amount of stress affects their perception of their coping mechanisms and their judgment of stress related to caregiving.

## **Output**

The response to the level of stress expresses itself in the four modes previously discussed. Their physiological function includes oxygenation, elimination, nutrition, fluid and electrolytes to name a few. The self-concept is made up of self-esteem and caregivers who experience high levels of stress tend to have lower self-esteem, which inevitably is associated with depression and burden. Low self-esteem is ineffective when responding to stress, meaning those with high levels of self-esteem are utilizing an adaptive response to stress. Role function is tied to their level of enjoyment with caregiving. In fact, high amounts of joy represent an adaptive function whereas low levels of enjoyment reflect an ineffective function. Thus, the role of the caregiver can lead to low levels of adaptive function assuming their expressive behavior is affected. Finally, interdependence is the level of function with their significant other and social system. The theory of caregiver stress uses marital satisfaction as a means to represent their level of interdependence. A person with low levels of marital satisfaction is an ineffective response, and high levels represent an adaptive response (Tsai, 2003). To summarize, high levels of caregiver burden lead to caregiver stress. Higher levels of caregiver stress results in ineffective responses to the four modes described.

## **Literature Review**

An in-depth literature review was completed utilizing PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Cochrane Database of Systematic Reviews (Cochrane). The keywords utilized, include: “Caregiver Burden” AND “Dementia” and “Professional Caregivers.” The Cochrane database search yielded zero relevant articles specific

to professional caregivers and caregiver burden for caregivers of PWD when utilizing the above keywords. However, when broadening the search to “Caregiver Burden” AND “Dementia,” 28 Cochrane reviews were identified, but only two were included in the Literature Review as they are most pertinent to the interventions to improve caregiver burden.

Furthermore, CINAHL and PubMed searches when using key terms “Caregiver Burden” AND “Dementia” yielded 2,320 and 2,444 articles, when reviewing for relevant articles within the last five years from 2018 to 2023, only 18 articles will be included in the Literature Review. It is important to note that when narrowing the search terms to include “Professional caregivers,” 259 articles were found; however, only two research articles were included in the literature review as they were pertinent to professional caregiver burden and dementia. The others were excluded due to non-applicability. Due to lack of current literature within the two to three years, six more relevant articles before 2016 are included in the Literature Review as they address the topic clearly and provide relevant detail regarding caregiver burden and dementia. Moreover, this literature review will introduce dementia as a clinical diagnosis, prevalence, discuss caregiver burden and needs, and suggest interventions to promote caregiver well-being.

### **Dementia**

The Alzheimer’s Association (2023) defines Alzheimer’s disease and related dementias (ADRD) as progressive neurological disorders that impair memory and essential cognitive functions, critical for a meaningful and productive life. Dementia serves as a broad term encompassing various symptoms, including challenges in memory, language, problem-solving, and other cognitive abilities. Among the different types of dementia, AD is the most prevalent, followed by others such as vascular dementia (VD), Lewy body dementia, frontotemporal dementia (FTD), and mixed dementia. In this study, these are collectively categorized under

dementia, with no significant differentiation in caregiver burden levels based on specific diagnoses. Instead, increased neuropsychiatric symptoms and disease progression correlate with a higher risk of caregiver burden (Connors et al., 2020).

As the population ages, the incidence of AD is projected to rise. The Alzheimer's Association (2023) reports that 5.3% of individuals aged 65, 13.8% of those aged 75, and 34.6% of those aged 85 and above are affected by AD. These figures are expected to escalate with the growing number of people living beyond 65 years. Consequently, the demand for both formal and informal caregivers is set to increase. Informal caregivers, comprising family members, friends, and others without professional caregiver training, are instrumental in caring for people with dementia (PWD). They represent about 48% of the caregiving support for older adults with Alzheimer's or other forms of dementia (Alzheimer's Association, 2023). While these informal caregivers are vital in enhancing the quality of life for PWD, the role of professional caregivers remains equally crucial, especially for families unable to meet the caregiving needs of their loved ones.

Managing dementia presents significant challenges due to its diverse array of signs and symptoms, particularly its cognitive manifestations that encompass various behavioral and psychological symptoms. These predominant symptoms, known as behavioral and psychological symptoms of dementia (BPSD), include memory loss, aggression, agitation, apathy, psychosis, delusions, depression, and wandering (Deardorff et al., 2019; Feast et al., 2016; Gottesman et al., 2019; Hugo, 2014; Kim et al., 2021; Kolanowski et al., 2017; Lyketsos et al., 2011). The severity of these symptoms is often indicative of the disease's progression in people with dementia (PWD). Those exhibiting severe symptoms typically require more comprehensive care to ensure their safety and their ability to perform daily activities.

The manifestation of these symptoms can vary among individuals. Apathy, characterized by diminished motivation, is the most common BPSD, affecting approximately 49% of PWD and often leading to reduced functional status. Depression is also prevalent, affecting about 42% of PWD. Caregivers frequently find symptoms such as aggression, agitation, delusions, and psychosis particularly distressing. The exacerbation of these symptoms is associated with increased rates of institutionalization and mortality (Deardorff et al., 2019). Therefore, the level of care and support required by PWD is largely contingent on the severity and advancement of their symptoms. It is crucial to recognize that as dementia progresses, the likelihood of PWD exhibiting challenging symptoms increases, subsequently heightening the burden on caregivers (Kim et al., 2021).

### **Caregiver Burden: Family vs. Professional and Needs**

In the scope of dementia care, there are two main types of caregivers: family and professional. Family caregivers, often close relatives without formal training, face intense emotional and physical strains due to their deep personal connections with the PWD. This group contends with the challenges of caregiving on a deeply personal level, leading to significant stress and health issues. On the other hand, professional caregivers, trained and working in healthcare settings, deal with the complexities of managing multiple PWDs. Their burden includes the clinical demands of care and the emotional labor of maintaining professionalism while providing compassionate support. This setup outlines the distinct challenges faced by each group, underscoring the need for tailored support strategies in dementia care.

### **Family Caregivers and Burden**

As the aging population increases and the demand for caregiving for older adults rises, the importance of caregivers equipped to handle the associated burdens becomes more apparent.

Over the past few decades, there has been growing research interest in the subjective well-being of caregivers. This research is critical as caregiving is necessary across various illnesses.

Numerous studies have examined the levels of burden associated with different diseases, with Alzheimer's and related dementia being the most frequently studied (Rodríguez-González & Rodríguez-Míguez, 2020). Their meta-analysis indicated that caregivers for mental illness and dementia/cognitive impairments experience the highest levels of burden, with Alzheimer's disease often resulting in greater burden depending on its severity.

Caring for a loved one while grappling with high levels of unresolved caregiver burden has multiple adverse effects. Zwingmann et al. (2018) highlight that caregiver burden can lead to the development of mood disorders, cognitive decline, hypertension, cardiovascular and kidney diseases, obesity, and depression. These negative impacts can influence caregivers' decisions regarding early institutionalization (e.g., nursing home placement) to improve both their own and the person with dementia's (PWD) quality of life (Deardorff, 2019). While placing a loved one in a nursing home can bring emotional relief and reduce psychological stress for informal caregivers as care responsibilities shift to formal caregivers like nurses, not all burdens are alleviated (Gaugler et al., 2010).

The decision for early institutionalization often depends on factors such as the caregiver's gender and their relationship with the PWD. For instance, female caregivers, particularly wives, may continue to experience emotional burden due to their attachment to the caregiving role. Conversely, male caregivers, like husbands, might struggle with emotional loss and feelings of guilt associated with relinquishing caregiving responsibilities (Gaugler et al., 2010). The intricate interplay of gender, relationship dynamics, and personal attachment to the caregiving role means that each caregiver's experience is unique and requires a sensitive and individualized approach to

support and counseling. Therefore, it's clear that institutionalization, while easing aspects of care, does not uniformly resolve the emotional and psychological challenges faced by the family caregiver.

In the realm of caregiving, certain risk factors are identified as contributing to an increased likelihood of caregiver burden. Contemporary research highlights various caregiver and patient characteristics that are associated with heightened levels of burden. Notably, symptoms such as agitation and depression in persons with dementia (PWD) are significant predictors of caregiver burden, indicating that caregivers of PWD with these symptoms are more susceptible to experiencing higher levels of burden (Connors et al., 2020). Additionally, sociodemographic factors, including gender, education level, income, and ethnicity, have been identified as influential in caregiver burden. Caregivers who belong to these demographic groups are predisposed to an elevated risk of burden.

Moreover, disease-related variables like the severity and duration of dementia also correlate with increased caregiver burden. Specific elements such as the PWD's behavioral problems, the extent of cognitive impairment, and the availability of adequate services are cited as primary reasons for escalated caregiver burden. These factors significantly impact the caregiver's well-being and mental health (Adelman et al., 2014; Chiao et al., 2015; Connors et al., 2020; Torrasi et al., 2017; Wiegelmann et al., 2021).

The duration (in hours) of caregiving for PWD is a key factor influencing caregiver burden. Specifically, providing more than 14 hours of daily care to PWD is associated with increased levels of burden. This correlation is attributed to the increased need for support and caregiving tasks required by caregivers of PWD (Xu et al., 2021). Additionally, aspects of positive social support, such as received support, satisfaction with support, and social network



size, are significant indicators of caregiver well-being. In this context, 'support' refers to assistance with caregiving tasks. 'Received support' encompasses any provided or available aid for caregiving tasks, 'satisfaction with support' relates to the quality of received support, and 'social network' denotes the network of assistance, including family and professional help. Caregivers who receive adequate support in these areas typically experience reduced levels of burden, as such support helps mitigate the relationship between the amount of caregiving hours and burden (Xu et al., 2021).

Lin et al. (2019) found that as the caregiving hours for PWD increase, particularly due to a decline in basic activities of daily living (BADL), caregiver burden also rises. This highlights the necessity for increased support to alleviate caregiver burden and enhance patient outcomes. Thus, the required caregiving hours and the level of support provided significantly affect the caregiver's burden.

Caregivers face significant challenges beyond the direct care of PWD. The Alzheimer's Association (2023) reports that dementia caregivers often neglect their health and are more likely to rate their quality of life as poor compared to non-caregivers. Chronic stress from caregiving is linked to higher rates of hypertension, reduced immune function, and coronary artery disease in caregivers. Moreover, Lloyd et al. (2019) identified that a lack of self-compassion is a key predictor of higher levels of caregiver burden. Caregivers with higher levels of self-compassion tend to use fewer dysfunctional coping strategies (such as denial, self-blame, substance use) and more emotion-focused strategies (like religion, acceptance, humor, active coping, planning). This underscores the need for assessing self-compassion in caregivers to identify current or future support needs, an area which currently lacks extensive research.

## **Professional Caregivers and Burden**

Conversely, professional caregivers face a different set of challenges, marked by the responsibility of caring for multiple residents with varying stages and symptoms of dementia. This not only involves a higher level of clinical and behavioral management skills but also the emotional labor of maintaining professional detachment while providing compassionate care. Therefore, the professional caregivers' burden is compounded by the institutional pressures of caregiving, including workload, emotional strain, and the need for specialized training to manage the behavioral changes in dementia effectively. Although they might share similar tasks to family caregivers, the context in which these tasks are performed—alongside the expectation to manage multiple caregiving relationships—distinguishes their experience and contributes to a unique form of professional burden.

While extensive research exists on informal caregivers of PWD and their burden levels, the dynamics between professional caregivers and PWD are less frequently explored. There is a notable gap in understanding the complex relationship between professional caregivers and PWD, especially considering the higher levels of behavioral changes encountered by professional caregivers (Appleton et al., 2019). Furthermore, professional caregivers have reported that their reactions and feelings towards behavioral changes in PWD tend to feel more 'permanent.' In contrast, informal caregivers often perceive their emotional responses to similar changes as more 'temporary.' This distinction underscores another dimension in the caregiver-PWD dynamic, highlighting the differing emotional impacts on professional versus informal caregivers.

Appleton et al. (2019) identified that the deterioration of the relationship between professional caregivers and residents with dementia is a significant concern. They also

discovered that professional caregivers who possess a comprehensive understanding of the progressive nature of dementia and the associated behavioral changes are more capable of maintaining positive relationships with residents suffering from dementia. To support this, it is recommended to provide in-depth training that focuses on the behavioral changes occurring during the disease's progression. Such training should emphasize the degenerative nature of dementia and recognize the variability in progression levels among individuals with the condition.

In their comparative study, Seidel and Thyrian (2019) examined the differences in perceived burden levels between family and professional caregivers. The results indicated that family caregivers generally experienced moderate levels of burden, while professional caregivers reported a burden ranging from low to moderate. A notable distinction was observed in the physical symptoms experienced by the two groups. Family caregivers frequently reported experiencing headaches, back pain, and sleep disturbances, more so than their professional counterparts. On the other hand, professional caregivers identified personal constraints (not explicitly defined in the study) and caregiving tasks as the primary contributors to their burden. Despite these differences, there were also similarities observed, particularly in relation to the gender of the PWD. Caregivers, both family and professional, reported higher levels of burden when caring for male PWD, attributed to more challenging cognitive impairments and aggressive or disoriented behaviors. Furthermore, the study found that caregiving tasks were perceived as equally burdensome by both family and professional caregivers.

### **Interventions Promoting Caregiver Well-Being**

To enhance the management of caregiver burden effectively, targeted interventions focusing on specific basic activities of daily living (BADL) are essential for PWD who exhibit

diminished BADL functions. Providing sufficient respite care hours for caregivers is crucial, as this can mediate and alleviate their caregiving responsibilities (Lin et al., 2019). Interventions that assist with bathing and feeding are particularly beneficial. Therefore, the literature suggests that reducing the hours spent on caregiving should be a focal point in supporting caregivers.

Various methods exist for delivering information and intervention to dementia caregivers. Gonzalez-Fraile et al. (2021) conducted a meta-analysis of 26 studies that used telephones, computers, or mobile devices to deliver interventions involving information, training, and support. This analysis indicated that, compared to information-only interventions, those offering training and support might reduce caregiver burden and depressive symptoms. However, these interventions showed minimal or no impact on quality of life (QOL), and higher dropout rates were observed among caregivers, suggesting that remotely delivered interventions might not be effective due to insufficient evidence in substantially reducing caregiver burden. This implies that in-person interventions could be more successful in mitigating caregiver burden, although research in this area is limited.

In another meta-analysis by Mohler et al. (2020), which reviewed 5 randomized control trials focusing on personally tailored interventions for PWD, one study demonstrated that an individualized activity plan, created after assessing the caregiver's personal interests and cognitive status, reduced challenging behavior and improved PWD's quality of life. However, these interventions did not significantly affect depressive symptoms, affect, apathy, or engagement. There was a minor improvement in caregiver distress, but little to no effect on caregiver burden, QOL, or depression. This suggests that while personalized activities for PWD may not reduce caregiver burden, they can improve other aspects, such as PWD's behavior.

In their systematic review, Frias et al. (2020) explored a range of psychoeducational interventions aimed at reducing caregiver burden. The interventions examined in the study varied in nature, encompassing educational concepts, problem-solving techniques, coping strategies, self-care tips, leisure activities, and even cognitive-behavioral therapy elements. Notably, these interventions were typically conducted in group settings, with variations in both the duration and frequency of the sessions. Interestingly, technology-based interventions also demonstrated some level of effectiveness. Frias et al. (2020), concluded that these psychoeducational interventions are not only practical but also serve as a protective mechanism for caregivers, helping to lessen their burden. Furthermore, these interventions have been found to enhance caregivers' self-efficacy, reduce anxiety, and have a notable effect on levels of depression. This comprehensive analysis underscores the significant potential of psychoeducational approaches in supporting caregivers of individuals with dementia.

## **CHAPTER THREE: METHODS**

### **Overall Project Design**

This practice improvement project aimed to alleviate the burden experienced by professional caregivers, which included registered nurses, licensed practical nurses, and certified nursing assistants, who worked with dementia residents in a specialized memory care unit at a local nursing home. The project evaluated the caregivers' burden before and one month after receiving dementia caregiver education. Additionally, their understanding and comfort in caring for individuals with dementia was assessed both before and after the educational intervention. The range of educational topics related to dementia caregiver burden offered to the caregivers covered areas such as cognitive impairment, self-care, communication strategies, and behavior management in dementia. The agency approved two sessions of education to cover the day-shift and night-shift caregivers.

### **Implementation Plan**

#### **Iowa Model Revised: Evidenced-Based Practice**

The Iowa Model Revised: Evidence-Based Practice model had guided the decision-making process for caregivers by way of enhancing healthcare practices that supported an improvement in healthcare outcomes (Melnik & Fineout-Overholt, 2019). Using the Iowa Model as a guide, the implementation of this project was facilitated through a structured process necessary for successful completion. According to Melnyk & Fineout-Overholt (2019), this model has many different phases and utilizes feedback loops to develop and strengthen changes to process and practice. Permission to use this evidence-based practice model was obtained from the University of Iowa Hospitals and Clinics (APPENDIX D).

## **Identifying Triggering Issues/Opportunities**

Research focused on improving subjective caregiver burden is necessary to promote the health and needs of caregivers of people with dementia. As the population ages, the incidence of dementia is rapidly increasing, with the number of patients doubling every five years. The number of individuals with dementia is expected to triple, reaching 14 million by the year 2060 (CDC, 2023). Given the growing number of individuals diagnosed with dementia, there's a natural increase in the need for caregivers. This situation suggests that caregivers might benefit significantly from additional support, particularly in terms of educational resources. Such support could improve their overall well-being and possibly lessen the often-intense demands of caregiving. Providing caregivers with better tools and knowledge about dementia care could not only make their role more manageable but also enhance the quality of care for those with dementia. Hence, enhancing the subjective well-being of caregivers for individuals with dementia through education programs has shown benefits. Such initiatives are positively correlated with diminishing symptoms of depression and anxiety, improving the physical health of caregivers, and reducing their overall burden (Wiegelmann et al., 2021).

## **Topic Selection**

The participating organization in focus operates as a skilled nursing facility, renowned for its comprehensive services in elder care. This includes memory care, hospice, transitional care, assisted living, and independent living. Their team comprises a wide array of healthcare professionals, including nurses, certified nursing assistants, and nurse practitioners, all dedicated to addressing the diverse needs of their residents. This facility is a key player in providing care to the elderly in Fargo, North Dakota, and surrounding regions within the state. They are committed to the ongoing education of their staff, consistently employing evidence-based methods to ensure

the highest standard of care for their residents. Given this commitment to continuous professional development, the proposed initiative to educate their caregiving staff was well-aligned with their ethos. This education aimed to ease the burdens associated with caregiving responsibilities, further enhancing the quality of care they provide.

### **Forming a Team**

The team consisted of the co-investigator, committee chair, an outside expert affiliated with the participating organizations and two additional committee members who provided guidance and helped facilitate the research project. The role of the co-investigator involved the screening of eligible participants, providing education, administering the burden scale and knowledge survey, and follow up burden scale one-month post intervention. The participating cohort was reminded and encouraged by the outside expert to complete the post intervention burden scale. Additionally, the co-investigator evaluated the burden scales and knowledge surveys.

### **Retrieval and Analysis of Relevant Research**

The completed literature review and subsequent summary underscore the necessity of addressing and enhancing the subjective caregiver burden experienced by caregivers of individuals with dementia. For a comprehensive exploration of the evidence supporting this need, refer to the detailed analysis presented in the above literature review section. The research compiled for the dementia caregiver project encompasses various key elements, such as the aging population, the increasing demand for caregivers, the extent of caregiver burden, turnover rates among caregivers, and various interventions designed to alleviate the burden experienced by dementia caregivers.



## **Implementation of Project**

The project was submitted to the NDSU Institutional Review Board (IRB) for which approval was given on December 12<sup>th</sup>, 2023 (APPENDIX A). Additionally, the participating facility agreed and approved the research plan and implementation of the project can begin at any time. The project was implemented in February 2024 and ended in March 2024.

## **Integrate and Sustain Practice Change**

Following the examination of burden scores and survey results, the participating organization received an executive summary and debriefing encompassing the descriptive statistics and key findings. Additionally, the educational material developed was supplied to the facility for ongoing utilization in staff training sessions. The aspiration and objective are for this educational content to serve as a resource for future staff members, enhancing their knowledge and highlighting strategies to mitigate the challenges associated with caregiving.

## **Setting**

The practice improvement project launched at Eventide Sheyenne Crossings, a skilled nursing facility. This facility is characterized by its multidisciplinary approach, involving a diverse team of professionals including nurses, certified nursing assistants, nurse practitioners, social workers, dietitians, and several others. Eventide Sheyenne Crossings is situated in West Fargo, North Dakota, a city with an approximate population of 39,985 as of July 1, 2022, with a nearly equal gender distribution of 49.9% female and 50.1% male (United States Census Bureau, n.d.). In the broader context of North Dakota, there are about 21,620 nursing professionals, encompassing both licensed practical nurses and registered nurses. Among these, 91.2% are female, while 8.8% are male (NDBON, 2024). Given these demographics, it is anticipated that most caregivers participating in the educational sessions will be female.

## **Sample/Sample Size/Recruitment**

In this practice improvement project, it has adopted a nonrandomized convenience sampling method, focusing on enlisting participants from the dedicated memory care unit of the skilled nursing facility. The participant pool primarily included registered nurses, licensed practical nurses, and certified nursing assistants employed within this memory care unit. To facilitate participant recruitment, an internal expert employed at the facility will aid by sending emails to the staff of the memory care unit, informing them about the educational opportunity. While participation is not mandatory, it is strongly encouraged by the unit's management. To accommodate both day and night shifts, two sessions are scheduled: one at 1 PM and another at 9 PM, ensuring equal participation opportunities for all staff. The sessions will be one hour long. Coffee and snacks will be provided. The goal is to enlist at least 20 professional caregivers between the two sessions for the study. Eligible participants are those directly involved in resident care, of any gender and race/ethnicity, aged 18 or above, and fluent in English. The study excludes minors and individuals who do not speak English.

## **Intervention**

The educational sessions, lasting one hour each, are structured into three parts: introduction, educational content, and conclusion. In the initial ten minutes, participants received oral consent (APPENDIX H), completed the burden scale assessment (APPENDIX F), and filled out the pre-education knowledge questionnaire (APPENDIX G). This was followed by a 45-minute review of a PowerPoint presentation, which covered topics like caregiver burden, cognitive impairment, self-care, communication techniques, and managing behaviors associated with dementia. The session concluded with participants filling out the post-education knowledge questionnaire in the final five minutes (APPENDIX G).

One month after the educational session, the outside expert emailed the participating caregivers to complete the final burden scale assessment. While this assessment is not mandatory, participation is highly encouraged as its results are crucial for evaluating the intervention's impact. The questionnaires, available in an online format via Qualtrics, utilize a five-point Likert scale. The burden scale, also online, can both be accessed through a link and QR code. The questionnaire gathered data on caregiver demographics, including age, gender, job title, years of experience with PWD, and tenure at the agency. It also probed into their comfort level in caring for PWD, knowledge about dementia and related behaviors, perceived burden, and the significance of self-care. The employed burden scale is the Professional Care Team Burden Scale (PCTB) (Auer et al., 2015), used with permission from its original creators (APPENDIX I). It comprises 10 questions focusing on aspects of caregiver burden.

### **Evaluation/Outcomes/Data Analysis**

The evaluation of this project was based on the changes seen in the Professional Care Team Burden Scale pre-education and post-education. Assuming there is a positive change in caregiver burden following the educational session, one can glean that the educational session is proven to help reduce burden levels among professional caregivers. The data will be stored on a password-protected computer and password-protected flash drive. The aggregate data will only be shared with the committee chair and its members, the NDSU school of nursing, and the participating organization.

### **Evaluation of Objective One**

The first objective was to conduct an educational presentation for professional caregivers at the memory care unit of Eventide Senior Living in Fargo, ND. This presentation, which was executed by the co-investigator, aimed to reduce caregiver burden and enhance their knowledge

base. The effectiveness of this educational initiative is assessed through a descriptive analysis of both pre-and-post session questionnaires and the burden scale. To facilitate a straightforward evaluation of the session's impact, the knowledge questionnaire incorporated a Likert-scale to rate each question for measurement.

### **Evaluation of Objective Two**

Objective two was to increase caregiver knowledge of dementia as a disease process, stress management, and challenges of caring for individuals with dementia. The educational session provided education to caregivers, primarily focusing on dementia and behavior management techniques. The assessment of knowledge enhancement was based on the analysis of pre- and post-education knowledge questionnaires. Participants completed the pre-education questionnaire at the beginning of the training session and the post-education questionnaire at its conclusion. Participation in these questionnaires was voluntary. By analyzing responses from both before and after the training, we were able to measure the change in caregivers' knowledge levels, offering a deeper insight into the effectiveness of the training. The questionnaires employed a five-point Likert scale to gauge caregivers' understanding of the covered topics.

### **Evaluation of Objective Three**

Objective three was to decrease caregiver burden for professional caregivers of individuals with dementia one-month following the educational presentation. The educational session aimed to educate caregivers on strategies to decrease their burden. To evaluate this objective, the knowledge questionnaires previously mentioned and the PCTB scale were utilized. This tool is clinically validated for measuring caregiver burden among formal caregivers (Auer et al., 2015). Utilizing the established PCTB scale enabled data to be quantified, which enhanced the validity and reliability of the measurements. By comparing the burden scores of dementia

caregivers both at baseline and one month after the program, we can effectively evaluate the success of this objective.

### **Evaluation of Objective Four**

Objective four was to develop and implement a plan for establishing and facilitating a support group for caregivers of dementia patients within the facility by May 31st, 2024. This objective involves having a meeting with the nursing manager to plan sessions, promote participation, and provide ongoing support. The aim was to create a safe support group that offers emotional support and guidance for caregivers, contributing to their holistic well-being within the facility.

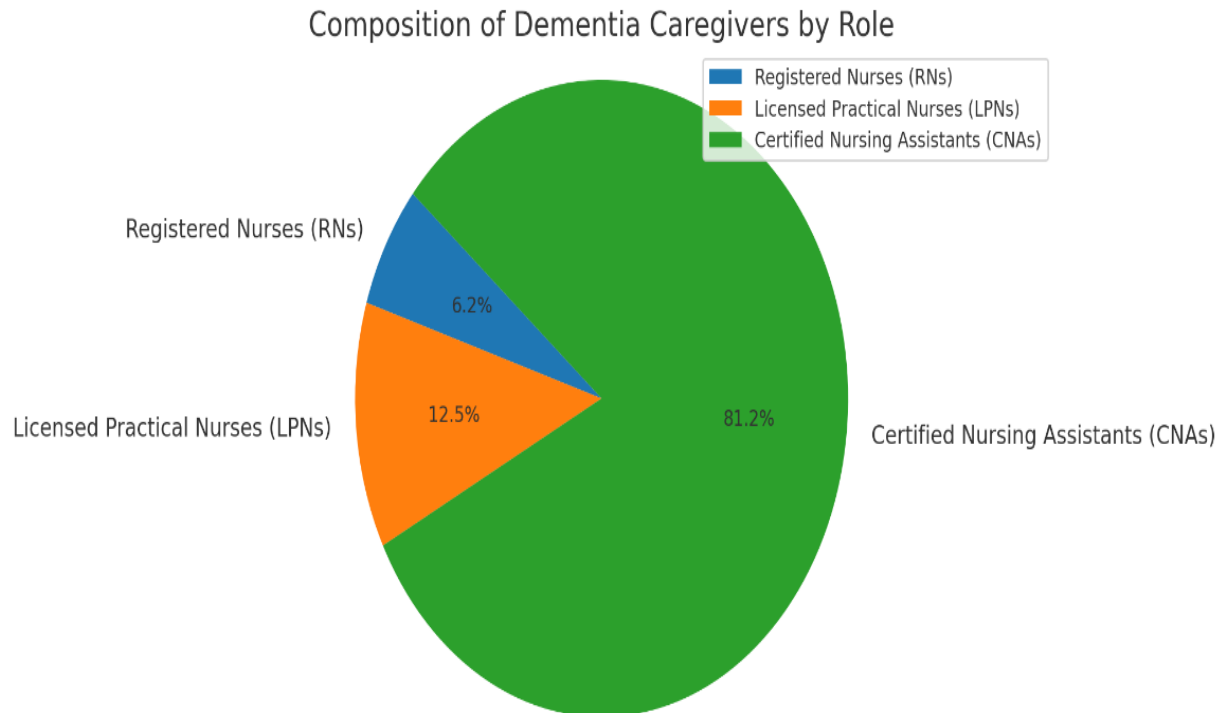
### **Conclusion**

This project was effectively carried out using the structure of the IOWA model. Central to the project are methods such as conducting educational sessions, measuring burden levels, enhancing knowledge of dementia caregiving, and ultimately improving the burden experienced by caregivers. The objectives of the project include assessing the degree of improvement in caregiver burden and analyzing changes in caregivers' knowledge before and after the educational session. The skilled nursing facility stands to benefit from insights into their staff's perceived levels of burden, potentially leading to ongoing educational initiatives on caregiver burden and dementia caregiving. The primary goal of this project was to alleviate the burden of professional caregivers caring for PWD. It was hoped that this intervention would foster a sustained emphasis on education in this area.

## CHAPTER FOUR: RESULTS

### Demographics

The study population included only female caregivers for PWD, all employed by the specified agency. The participant group consisted of various roles: one Registered Nurse (RN), two Licensed Practical Nurses (LPNs), and thirteen Certified Nursing Assistants (CNAs), who were all providing care to dementia residents. Their work experience varied significantly, from less than a year to up to 30 years. The average age of the caregivers was 38 years, with a median age of 36.5 years. Regarding work experience, the group's average was 11 years, with a median of 8 years, indicating a broad range of professional backgrounds. Every participant was proficient in English, met the minimum age requirement of 18 years, and had provided verbal consent to take part in the practice improvement project.



*Figure 1. Caregiver Roles*

## Data Results

The PCTB scale, a 10-item questionnaire utilizing a Likert scale, offered responses ranging from *Strongly Disagree* to *Strongly Agree*. Participants' responses to the ten questions on the burden scale were scored on a numerical scale, where '*strongly disagree*' was assigned four points and '*strongly agree*' received zero points. However, for negatively phrased items—specifically questions five and seven—the scoring was inverted: '*strongly disagree*' earns zero points, and '*strongly agree*' scores four points. Each participant's scores across all ten questions were summed to derive a quantitative burden score. Consequently, these burden scores reflected the level of burden experienced by the participants, with higher scores indicating greater levels of burden. The maximum achievable score on the burden scale was 40/40, indicating significant levels of burden, whereas the minimum score was 0/40, signifying negligible levels of burden. This scale was distributed electronically both before the educational intervention and one month afterwards.

In conjunction with this, a knowledge survey comprising four Likert-scaled questions was conducted to evaluate pre-knowledge and post-knowledge, this featured response options from *Not at all* to *Extremely knowledgeable*. Additionally, one question gauging the perceived importance of taking care of the caregivers' self, with choices extending from *Very Important* to *Not Important* were used. The gathered data was exclusively quantitative and was analyzed using the Qualtrics platform. The proceeding bar graphs depict the collated data from the pre-education phase and one month thereafter for the burden scale, as well as from both before and after the education for the knowledge survey.

### **Objective One**

Objective one was to conduct an educational presentation for professional caregivers at the memory care unit at Eventide Senior Living in Fargo, ND. This objective was successfully met. The practice improvement project outlined earlier commenced on February 15th, 2024, and concluded on March 22nd, 2024. Aimed at professional caregivers of PWD in a Senior Living Memory Care unit, the project engaged a total of 16 participants in specialized dementia care education. The educational component was organized into two sessions, scheduled for February 15th, 2024, at 1 PM and 9 PM, to accommodate caregivers working different shifts. Eleven caregivers attended the first session, while the second session was attended by five additional caregivers. Both sessions delivered the same educational content, ensuring uniformity in training across shifts. Data collection included a pre-education knowledge survey, a pre-education burden scale, and a post-education knowledge survey conducted on the day of the training. Additionally, from March 15th to March 22nd, caregivers were asked to complete a one-month post-education burden scale to evaluate the training's lasting impact.

### **Objective Two**

Objective two was to increase caregiver knowledge of dementia as a disease process, stress management, and challenges of caring for individuals with dementia. To measure an improvement in caregiver knowledge, a knowledge survey was administered before and after the educational session. Initially, 13 caregivers completed the pre-education survey, six completed the post-education survey. Although not all caregivers who participated in the session completed the post-education survey, the available data indicates an improvement in knowledge. However, the clarity of this improvement is somewhat obscured by the limited number of survey responses. This objective was partially met. The survey responses are detailed below.



### Pre-Education Knowledge Survey

Question	Not at all	Slightly	Moderately	Very Important	Extremely Important	Total
How comfortable do you feel with providing care for dementia patients?	0%	0%	14.29%	20.69%	40%	13
How knowledgeable do you feel about caring for individuals with dementia?	0%	0%	0%	31.03%	26.67%	13
How knowledgeable do you feel about managing difficult behaviors for those with dementia?	0%	0%	28.57%	24.14%	26.67%	13
How knowledgeable do you feel about ways to decrease feelings of burden?	0%	0%	57.14%	24.14%	6.67%	13
Question	Very Important	Important	Moderately Important	Slightly Important	Not Important	Total
How important would you consider taking care of yourself?	53.85%	30.77%	7.69%	7.69%	0%	13

Figure 2. Pre-Education Knowledge Survey

### Post-Education Knowledge Survey

Question	Not at all	Slightly	Moderately	Very Important	Extremely Important	Total
How comfortable do you feel with providing care for dementia patients?	0%	0%	0%	40%	60%	5
How knowledgeable do you feel about caring for individuals with dementia?	0%	0%	0%	60%	20%	5
How knowledgeable do you feel about managing difficult behaviors for those with dementia?	0%	0%	20%	60%	20%	5
How knowledgeable do you feel about ways to decrease feelings of burden?	0%	0%	20%	60%	20%	5
Question	Very Important	Important	Moderately Important	Slightly Important	Not Important	Total
How important would you consider taking care of yourself?	80%	20%	0%	0%	0%	5

Figure 3. Post-Education Knowledge Survey

## Question One

*How comfortable do you feel with providing care for dementia patients?* The intention behind this question was to gauge each caregiver's self-assessment of their comfort level in caring for individuals with dementia. The initial survey responses, collected before the educational intervention, revealed a range of comfort levels among caregivers when it comes to providing care for individuals with dementia. Notably, one caregiver's response indicated a moderate level of comfort. This suggests a baseline familiarity with dementia care, potentially pointing to some experience or prior knowledge in this area. However, this also implies an awareness of the complexities and challenges associated with dementia care, which might have moderated their confidence.

Six caregivers reported feeling very comfortable and another six feeling extremely comfortable, indicating a strong self-confidence in their ability to provide care. Those who felt very comfortable likely possess a solid foundation in dementia care practices, possibly supplemented by personal or professional experiences. Their confidence suggests they feel well-equipped to handle the responsibilities and challenges of dementia care but may acknowledge room for growth or learning. The caregivers who felt extremely comfortable likely see themselves as highly skilled and knowledgeable, with extensive experience or specialized training in dementia care. Their responses suggest a level of self-assurance and preparedness that likely contributes positively to their caregiving approach.

Following the educational intervention, the distribution of comfort levels shifted, with fewer caregivers identifying as very or extremely comfortable. This is in part due to the limited number of responses; however, this shift to two caregivers feeling very comfortable and three recognizing themselves as extremely comfortable could be interpreted in several ways. One

perspective might be that the caregivers gained awareness of the complexities involved in dementia care post-education, leading some caregivers to reassess and slightly moderate their self-assessed comfort levels. This adjustment suggests a more nuanced understanding of dementia care, recognizing that while they are competent, there is always more to learn and ways to improve. Alternatively, the shift could also indicate a consolidation of confidence among the caregivers, where those who initially felt very or extremely comfortable have now gained an even deeper understanding and appreciation of the skills and knowledge required for effective dementia care.

In analyzing these responses, it's crucial to consider the broader implications for dementia care training and support. The initial confidence levels indicate a strong foundation among the caregiver group, yet the subtle shifts post-intervention highlight the value of continuous education and the dynamic nature of self-assessment in caregiving. These insights can inform future strategies for caregiver training, emphasizing the importance of ongoing development and reflection to enhance care quality for individuals with dementia.

## **Question Two**

*How knowledgeable do you feel about caring for individuals with dementia?* This inquiry aimed to capture each caregiver's self-perception of their knowledge about providing care to dementia residents. The pre-education responses indicated a high level of self-perceived knowledge among most respondents, with nine caregivers considering themselves very knowledgeable and four viewing themselves as extremely knowledgeable. This distribution suggests a confident group of caregivers, comfortable in their understanding of dementia care principles and practices.

The post-education responses, however, presented a modest shift in this perception, with three caregivers rating themselves as very knowledgeable and two as extremely knowledgeable. The reduced number of respondents in the post-education survey (six compared to the initial thirteen) is a significant factor to consider in interpreting these changes. This reduced sample size could imply that the observed shift might not solely reflect a change in self-perceived knowledge but may also be influenced by the characteristics of the caregivers who chose to participate in both rounds of the survey. However, it is possible that the sessions introduced complexities and nuances of dementia care that were previously unconsidered or underappreciated by the caregivers, leading them to adjust their self-perceptions to reflect a more nuanced understanding of what it means to be knowledgeable in this area.

Moreover, the dynamics of the smaller post-education survey group suggest that those who felt most impacted by the education were perhaps more inclined to reevaluate and report their knowledge levels. This selection bias might indicate that the education sessions were particularly effective for a subset of caregivers, leading to more profound reflections on their knowledge and competencies.

### **Question Three**

*How knowledgeable do you feel about managing difficult behaviors for those with dementia?* This inquiry was designed to gauge caregivers' confidence in their ability to manage the often challenging and unpredictable behaviors presented by individuals with dementia. Managing such behaviors effectively is crucial for the well-being of both the resident and the caregiver, making this a key area of competency in dementia care.

The pre-education survey responses revealed a distribution that suggests most of the caregivers felt confident in their knowledge, with seven rating themselves as very knowledgeable

and four as extremely knowledgeable. This indicates a strong baseline confidence among most respondents in their ability to handle difficult behaviors, a confidence that is crucial in the demanding context of dementia care. However, the presence of two caregivers feeling only moderately knowledgeable highlights a recognition of the complexity of behavior management in dementia, acknowledging that there are areas of challenge and potential growth.

The post-education responses exhibited a shift, with fewer caregivers rating themselves at the highest levels of self-assessed knowledge—three feeling very knowledgeable and just one feeling extremely knowledgeable. This change, especially in the context of a reduced response rate, might initially suggest a decrease in confidence among the caregivers. However, the educational intervention likely provided insights into the complexities and nuances of managing difficult behaviors, offering strategies that caregivers had not previously considered or fully appreciated. This exposure might have led some caregivers to reassess their own levels of expertise, adjusting their self-perception to reflect a more informed and possibly more humble understanding of what it means to be knowledgeable in this area. Furthermore, the continued presence of a caregiver who feels moderately knowledgeable, even post-education, emphasizes the ongoing challenges and learning opportunities in dementia care. It highlights the need for continuous education and support for caregivers to enhance their skills and confidence in managing difficult behaviors.

#### **Question Four**

*How knowledgeable do you feel about ways to decrease feelings of burden?* This question aimed to probe caregivers' awareness and understanding of strategies to mitigate feelings of burden. Given the demanding nature of providing care to individuals with dementia, understanding and applying strategies to mitigate feelings of burden is crucial for sustaining

caregiver well-being and preventing burnout. The initial survey results indicate a wide spread of self-assessed knowledge levels, with most respondents feeling very knowledgeable, suggesting confidence among many caregivers in their ability to manage personal feelings of burden. However, the presence of one caregiver feeling only slightly knowledgeable and four feeling moderately knowledgeable highlights a significant variance in self-awareness and access to coping mechanisms among the group. This variance underscores the potential for educational interventions to make a meaningful difference in equipping caregivers with the necessary strategies to support their mental health.

Post-education, the distribution of responses shifted, showing a general reduction in the self-rated levels of knowledge with no respondents identifying as slightly knowledgeable, one as moderately knowledgeable, three as very knowledgeable, and one as extremely knowledgeable. Similar to observations made with previous questions, this shift could be attributed to several factors. The education provided likely offered new perspectives and strategies not previously considered by the caregivers, leading to a recalibration of their self-assessments. This recalibration could reflect a deeper understanding of the complexity involved in managing personal feelings of burden and a recognition of areas for growth and development in their self-care practices. Moreover, the shift could also suggest that the educational content prompted a more reflective and critical evaluation of the caregivers' own coping strategies. By highlighting the importance of self-care and presenting various methods to manage feelings of burden, education might have made some caregivers more aware of the gaps in their knowledge and the need for more effective coping mechanisms.

This analysis points to the valuable role that education plays not only in enhancing practical caregiving skills but also in fostering caregiver resilience. By encouraging caregivers to

reflect on their own well-being and providing them with tools to manage stress and burden, educational interventions can contribute significantly to the sustainability of caregiving.

### **Question Five**

*How important would you consider taking care of yourself?* This question sought to understand how caregivers perceive the importance of self-care. The initial responses to this query reflect a consensus on the importance of self-care, with a majority considering it very important. This indicates a recognition among caregivers of the need to maintain their own health and wellness as a prerequisite for providing effective care. However, the varied levels of importance attributed to self-care, including one caregiver who deemed it only slightly important, highlight a diversity in attitudes toward self-care practices among the caregiver population. This diversity suggests the potential for educational interventions to play a significant role in reshaping and reinforcing the value of self-care among caregivers.

After the educational sessions, the responses indicated a consolidation in the perception of self-care's importance, with a notable absence of the lower levels of importance seen pre-education. This shift towards viewing self-care as very or important, albeit among a smaller number of respondents, suggests a possible increase in the recognition of self-care's critical role in sustaining caregiving activities. By highlighting the practical benefits of self-care and offering strategies for integrating self-care into daily routines, the educational sessions may have provided caregivers with the tools and motivation needed to prioritize their well-being more effectively. This, in turn, can enhance their resilience, reduce burnout risk, and improve their overall capacity to care for individuals with dementia.



### **Objective Three**

Objective three was to decrease caregiver burden for professional caregivers of individuals with dementia 1-month following the educational presentation. This objective was partially met. To accurately assess the data, it was necessary to first determine the burden level for each participant. This process involves calculating the average burden score. For the 13 caregivers who completed the pre-education burden scale, the average burden score was found to be 12.54 out of a possible 40. In contrast, the average burden score among the 6 caregivers who completed the scale one month after the educational session was 11.67 out of 40. The decrease in the average burden score suggests a potential improvement. However, the small number of participants who completed the one-month post-education burden scale and not pairing the first survey with the second makes it challenging to conclusively determine the effectiveness of the educational session in reducing caregiver burden.

### Pre-Education Burden Scale

Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Total
My work performance is respected by my colleagues.	15.38%	0%	0%	46.15%	38.46%	13
I can discuss work related issues with my colleagues.	15.38%	7.69%	0%	46.15%	30.77%	13
I feel that the contact with my superiors is good.	15.38%	0%	7.69%	53.85%	23.08%	13
I can participate in organizing the daily routine in my organization.	15.38%	0%	0%	46.15%	38.46%	13
The loss of ability to communicate in persons with dementia bothers me.	0%	46.15%	23.08%	15.38%	15.38%	13
I can manage behaviors resulting from disorientation in persons with dementia.	0%	0%	0%	69.23%	30.77%	13
Difficult behaviors (Aggression, Wandering) of persons with dementia are difficult to bear.	0%	7.69%	23.08%	46.15%	23.08%	13
I can handle constructive criticism.	7.69%	0%	7.69%	61.54%	23.08%	13
I can keep my personal problems out of my daily work routine.	0%	0%	0%	46.15%	53.85%	13
My personal life/family environment is supportive and able to unburden me.	7.69%	1%	0%	38.46%	53.85%	13

*Figure 4. Professional Care Team Burden Scale – Pre-Education*

### One-Month Post-Education Burden Scale

Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Total
My work performance is respected by my colleagues.	0%	0%	0%	66.67%	33.33%	6
I can discuss work related issues with my colleagues.	0%	0%	0%	83.33%	16.67%	6
I feel that the contact with my superiors is good.	0%	0%	100%	0%	0%	6
I can participate in organizing the daily routine in my organization.	0%	0%	16.67%	83.33%	0%	6
The loss of ability to communicate in persons with dementia bothers me.	0%	0%	100%	0%	0%	6
I can manage behaviors resulting from disorientation in persons with dementia.	0%	0%	83.33%	16.67%	0%	6
Difficult behaviors (Aggression, Wandering) of persons with dementia are difficult to bear.	0%	0%	83.33%	16.67%	0%	6
I can handle constructive criticism.	0%	0%	66.67%	33.33%	0%	6
I can keep my personal problems out of my daily work routine.	0%	0%	100%	0%	0%	6
My personal life/family environment is supportive and able to unburden me.	0%	0%	33.33%	66.67%	0%	6

*Figure 5. Professional Care Team Burden Scale – One-Month Post-Education*

**Statement One**

*My work performance is respected by my colleagues.* In the pre-education burden assessment from 13 responses: two caregivers strongly disagreed, six agreed, and five strongly agreed. One-month post-education, out of six responses: four agreed and two strongly agreed.

**Statement Two**

*I can discuss work-related issues with my colleagues.* Initially, the pre-education burden scale showed: two strongly disagreed, one disagreed, six agreed, and four strongly agreed. One month later, out of six responses: five agreed and one strongly agreed.

**Statement Three**

*I feel that the contact with my superiors is good.* In the initial burden scale: two strongly disagreed, one was neutral, seven agreed, and three strongly agreed. One month later, all six responses were agree.

**Statement Four**

*I can participate in organizing the daily routine in my organization.* In the initial burden scale: two strongly disagreed, six agreed, and five strongly agreed. One month later, of the six responses: one agreed and five strongly agreed.

**Statement Five**

*The loss of ability to communicate in persons with dementia bothers me.* In the initial burden scale: six disagreed, three were neutral, two agreed, and two strongly agreed. One month later, all six responses were agree.

### **Statement Six**

*I can manage behaviors resulting from disorientation in persons with dementia.* In the initial burden scale: nine agreed, and four strongly agreed. One month later: five agreed and one strongly agreed.

### **Statement Seven**

*Difficult behaviors (aggression, Wandering) of persons with dementia are difficult to bear.* In the initial burden scale: one disagreed, three were neutral, six agreed, and three strongly agreed. One-month later: five agree, and one strongly agree.

### **Statement Eight**

*I can handle constructive criticism.* Initially: one strongly disagreed, one was neutral, eight agreed, and three strongly agreed. One month later: four agreed and two strongly agreed.

### **Statement Nine**

*I can keep my personal problems out of my daily work routine.* Initially: six agreed and seven strongly agreed. One month later, all six responses were agreed.

### **Statement Ten**

*My personal life/family environment is supportive and able to unburden me.* Initially: one strongly disagreed, five agreed, and seven strongly agreed. One month later: two agreed and four strongly agreed.

## **Objective Four**

Objective four was to develop and implement a plan for establishing and facilitating a support group for caregivers of dementia patients within the facility by May 31st, 2024. This initiative was designed to foster a community of support and understanding among caregivers, providing them with a space to share experiences, offer mutual support, and strengthen their

resilience in the face of the challenges posed by dementia caregiving. This first support group date has been scheduled for April 25<sup>th</sup>, 2024. Therefore, this objective has been partially met. The planned gatherings offer caregivers an opportunity to connect on a personal level—engaging in casual socialization, enjoying refreshments together, and participating in activities designed to foster friendship and solidarity. These activities, planned by the Eventide management team, aim to build a strong, supportive community among caregivers, enhancing their ability to support one another through the unique challenges of dementia caregiving.

In addition to these social and community-building activities, the support group would feature specialized resiliency training led by an assistant professor from North Dakota State University (NDSU) certified as a resiliency trainer. The training would equip caregivers with the anticipated skills and strategies necessary to enhance their resilience, with the goal of reducing the emotional and psychological burdens they face. By improving resilience, caregivers are better prepared to navigate the complexities of their roles, potentially leading to improved caregiving outcomes and personal well-being. The initial resiliency training is offered at no cost to participants and has been discussed with Eventides’ management team, who agreed to work with NDSU.

## **CHAPTER FIVE: DISCUSSION AND RECOMMENDATIONS**

### **Summary**

The purpose of this practice improvement project was to implement an educational session to support professional caregivers working with dementia residents. The project was structured around four key objectives: (a) delivering an educational seminar for professional caregivers in a memory care unit, (b) enhancing caregiver understanding of dementia, including its disease process, stress management techniques, and the complexities of providing care, (c) decreasing the burden felt by caregivers of individuals with dementia, and (d) fostering collaboration through the establishment of a support group for dementia caregivers within the agency. The intervention consisted of an educational seminar that specifically addressed dementia and caregiver burden. Its impact was evaluated using both the PCTB scale and a knowledge questionnaire.

### **Objective One**

An educational session was provided for professional caregivers at a local memory care facility. This comprehensive session consisted of a 10-minute period allocated for a pre-education knowledge assessment and burden measurement, followed by a 45-minute PowerPoint presentation, and concluded with 5-minute segment for a post-education knowledge evaluation. Caregivers were highly engaged throughout the educational session, actively participating, raising pertinent questions, and providing positive feedback on the educational material presented. Although no direct quantitative data was collected for this objective, the enthusiastic verbal feedback suggested that the educational session was a valuable resource for the caregivers.

The educational session was available to all professional caregivers at the facility within the memory care unit, this includes one Registered Nurse, seven Licensed Practical Nurses, and forty-two Certified Nursing Assistants. However, not all caregivers could attend due to scheduling conflicts, vacations, or other obligations. After the session, there was a push for attendees to disseminate their new insights and experiences to colleagues who were unable to participate. The session saw attendance from 16 dementia caregivers, with 13 completing the pre-education assessment and burden evaluation, and only 6 partaking in the post-education feedback. Despite strong encouragement for comprehensive participation, the diminished response rate to the post-session questionnaire limited the assessment of outcomes.

### **Objective Two**

Objective two was to increase caregiver knowledge of dementia as a disease process, stress management, and challenges of caring for individuals with dementia. The effectiveness of this objective in increasing knowledge was difficult to quantify, given the limited response of only five participants in the post-education assessment. Despite this, the results from these respondents supported an improvement in knowledge on average.

Building off the details above for each question, the caregivers exhibited varied levels of comfort in providing care, with a significant number feeling very to extremely comfortable. This suggests they had a foundation of experience or knowledge. After the educational program, there was a slight shift, indicating a deeper insight into the complexities of dementia care. This change could reflect a growing awareness of the challenges involved and a strengthening of confidence among caregivers. Despite high initial confidence, the education prompted caregivers to reconsider and perhaps adopt a more modest view of their abilities.



Before the educational intervention, caregivers generally felt they had a strong grasp on dementia care, with the majority rating their knowledge as very high or even expert-level. Following the educational sessions, a shift emerged, with a smaller group self-identifying as experts. This shift might suggest that the training illuminated the deeper intricacies of dementia care, encouraging a reassessment of their own knowledge levels.

In handling challenging behaviors, caregivers' initial confidence in their expertise saw a decline after the intervention. The educational content likely unveiled new approaches and considerations for behavior management, prompting caregivers to reevaluate their level of expertise. Additionally, psychoeducational interventions, which include providing information about the illness and advice on responding to specific situations, are practical and can protect caregivers by improving self-efficacy, reduce anxiety, and depression levels (Frias, et al., 2020).

The discussion on strategies to alleviate caregiver burden also resulted in a shift from a broad range of self-assessed knowledge to a more modest appraisal post-education. This change indicates that the training introduced new concepts and methods, potentially helping caregivers to identify previously unrecognized challenges and complexities in managing their own stress and burden.

As for the emphasis on self-care, there was already a strong acknowledgment of its importance among caregivers before the intervention. This acknowledgment only grew stronger afterward, suggesting the educational sessions effectively underscored the essential nature of self-care for sustainable caregiving.

Overall, the educational program seemed to offer a broad spectrum of effects, potentially deepening caregivers' insights into dementia care, behavior management, stress reduction, and self-care. Initial reports indicated high confidence and knowledge. However, given the

complexity and variability of caregiving experiences, it's difficult to ascertain the full extent of the program's effectiveness on caregiver perspectives, practices, or well-being from the data available. The relationship between continued education and its benefits to care quality and caregiver health remains an area for further exploration, highlighting the need for cautious interpretation of the program's outcomes.

### **Objective Three**

Objective three was to decrease caregiver burden amongst the professional caregivers of PWD. This objective was partially met, as shown by the decrease in the average burden score from 12.54 out of 40 (pre-education) to 11.67 out of 40 (post-education) among the participants. While this reduction in the average burden score indicates a potential improvement in caregiver burden, the limited sample size of participants completing the one-month post-education burden scale introduces caution in the overall interpretation of the educational session's effectiveness.

The responses to specific statements reveal meaningful shifts in perceptions and experiences of the caregivers. For example, there was an observable increase in positive responses concerning respect from colleagues, the ability to discuss work-related issues, and quality of contact with superiors post-education (L.Letness, personal communication, April 5<sup>th</sup>, 2024). The unanimous agreement on the quality of contact with superiors post-education indicates a satisfactory communication dynamic, likely contributing to a more supportive work atmosphere.

Additionally, post-education responses suggest an increased confidence among caregivers in organizing daily routines and accepting constructive criticism, with more caregivers strongly affirming these abilities. This change may reflect an increased sense of empowerment and self-efficacy following the educational intervention. Concerning specific challenges of

dementia care, such as managing disorientation behaviors and dealing with the loss of communication abilities in individuals with dementia, responses post-education uniformly acknowledged these as significant sources of stress. This points to the enduring emotional and practical difficulties caregivers face, indicating that while the educational intervention may have provided strategies for addressing these challenges, the complex nature of dementia care continues to impose a substantial burden (Wiegelmann et al., 2021).

Responses related to personal coping mechanisms, like maintaining a separation between personal issues and work and feeling supported by personal or family life (Xu et al., 2021), exhibited a positive trend. This suggests that the educational session might have not only addressed professional caregiver challenges but also enhanced caregivers' personal resilience and support networks.

In conclusion, the educational presentation has positively influenced professional caregivers' perceptions of their work environment and personal coping strategies, despite the limitations posed by a small follow-up sample. These findings highlight areas for further research and development, particularly in improving communication and support within caregiving environments and addressing the enduring challenges of caring for individuals with dementia (Xu et al., 2021). Future efforts should focus on expanding educational content to confront the emotional impact of dementia-specific challenges more directly and developing comprehensive support systems to bolster caregivers' professional and personal resilience. Furthermore, integrating survey feedback by linking pre-education surveys to post-education surveys will be essential in assessing the effectiveness of these educational sessions.

## **Objective Four**

Objective four was to develop and implement a plan for establishing and facilitating a support group for caregivers of dementia patients within the facility by May 31st, 2024. This initiative has been planned for successful launch with the intent of building a community of support and understanding among dementia caregivers, who often face considerable challenges in their caregiving roles. Scheduled to commence on April 25th, 2024, this support group represents a significant step towards providing caregivers with a platform for sharing experiences, offering mutual support, and fostering resilience.

A critical component of this support group is the inclusion of specialized resiliency training session, led by nursing faculty who are certified resiliency trainers at North Dakota State University. This session is specifically designed to arm caregivers with effective skills and strategies to bolster their resilience. Given the emotional and psychological demands of dementia caregiving, enhancing resilience is crucial for caregivers to effectively manage the complexities of their roles. Improved resilience, in turn, is anticipated to lead to better caregiving outcomes and a higher level of personal well-being for the caregivers (C. Nelson, personal communication, April 5<sup>th</sup>, 2023). Importantly, this valuable resiliency training is offered at no cost to the participants, ensuring accessible support for all caregivers involved.

In summary, the establishment of the support group within Eventide's Senior Living management framework marks a pivotal advancement in supporting dementia caregivers. By combining opportunities for personal connection with structured resiliency training (Maneewat et al., 2020; Xu et al., 2021), the initiative is poised to reduce the emotional and psychological burdens faced by caregivers. This multifaceted approach aims not only to enhance the immediate

support network for caregivers but also to equip them with long-term skills and strategies for resilience, ultimately benefiting both caregivers and those they support.

### **Recent Literature**

Online interventions, such as virtual support groups and psychoeducation, hold considerable value for professional caregivers by offering a convenient and accessible platform for support and professional development (Goto et al., 2024). These digital avenues enable caregivers to connect with peers and experts from across the globe, breaking down geographical barriers and fitting seamlessly into their often-irregular work schedules. Additionally, the vast array of online resources, including educational webinars, interactive workshops, and evidence-based caregiving strategies, can significantly enhance their clinical skills and emotional resilience. For professional caregivers navigating the complexities of dementia care, online interventions offer a community, continuous education, and help personal well-being, however, evidence does not correlate directly to impacting the quality-of-care caregivers provide (Sitges-Macia et al., 2021).

The inclusion of resiliency training in the support group program at Eventide reflects a growing recognition of the need for psychological resilience among caregivers. Recent literature emphasizes the role of resilience as a buffer against the stress of caregiving, with training programs shown to significantly reduce symptoms related to role overload and sleep disturbance (Irani et al., 2023). These programs are designed to equip caregivers with strategies and tools to enhance their ability to withstand and adapt to the stressors inherent in their roles. By emphasizing resilience as a buffer, such training aims to not only reduce immediate symptoms of stress and fatigue but also to foster long-term well-being and effectiveness in caregiving. The positive outcomes associated with resilience training underscore its value as a critical component

of caregiver support programs, highlighting its potential to transform the caregiving experience by promoting health, well-being, and sustainability in the face of ongoing challenges.

### **Recommendations**

Based on the findings from the establishment and facilitation of a support group for caregivers of PWD within Eventide's Senior Living facility, several recommendations can be made for practice, education, policy, and future projects. These recommendations are designed to enhance the support framework for caregivers, improve educational programs on dementia care, inform policy-making, and guide the development of future initiatives.

#### **For Practice**

To enhance support for professional caregivers, promoting the formation and growth of caregiver support groups in various facilities should be a priority, while customizing them to cater to the diverse needs of caregivers in different environments. This approach aims to extend support more widely. Incorporating regular feedback systems within these groups, to constantly refine and enhance the assistance offered is a must. Furthermore, the caregivers' experiences and input should shape the improvement of activities. Additionally, integrating thorough resiliency training programs into the support frameworks for caregivers is crucial. These programs should concentrate on practical techniques that caregivers can use daily to better manage stress and emotional challenges, ensuring they receive the most effective support possible.

#### **For Education**

The development of specialized training modules, such as online recorded education, by Eventide Senior Living Management after the successful implementation of resiliency training by NDSU could enhance and continue to provide value for new caregivers employed at this facility. These modules should be made available as part of ongoing professional development at

Eventide Senior Living facilities (Mlambo et al., 2021). Additionally, to enhance dementia caregiving education, real-life case studies and experiences should be shared in the support group sessions. This approach can provide valuable insights and practical knowledge for both current and future caregivers.

### **For Policy**

Encourage the participating agency to recognize support groups as an important way to support caregivers within their professional settings. Policies could encourage funding, resources and institutional support for the establishment of these groups in senior living facilities.

Additionally, working toward institutional policy changes that incentivize the caregiver to attend resiliency training would acknowledge its critical role in improving caregiving outcomes and caregiver well-being.

### **For Future Projects**

The initiation of a longitudinal study to assess the long-term impact of support groups and resiliency training on caregiver well-being and patient care quality should be considered for future projects. Such research could provide valuable data to guide future projects and policy-making. Additionally, expanding collaboration by seeking cooperative opportunities with educational institutions, healthcare providers, and community organizations to enhance the reach and effectiveness of caregiver support initiatives. These partnerships could facilitate the sharing of resources, expertise, and best practices.

The integration of yoga as an intervention for caregivers of individuals with dementia emerges as a promising strategy to alleviate caregiver burden (Parkman & Olausson, 2023). Studies suggest that engaging in yoga can significantly reduce anxiety, stress, depression, and cortisol levels, while concurrently enhancing quality of life, self-compassion, self-efficacy,

mindfulness, and sleep quality among caregivers. Additionally, yoga aids caregivers in establishing a deeper connection with their bodies, which is instrumental in stress reduction and can foster improved relationships. The appeal of yoga lies not only in its effectiveness but also in its practicality; it is a cost-effective, easily implemented intervention that carries minimal risks (Parkman & Olausson, 2023). Given these benefits, there is a compelling case for further research to explore yoga's full potential as a supportive tool for caregivers, emphasizing its role in promoting physical and emotional well-being in a demographic known for its vulnerability to high stress and emotional fatigue. This evidence positions yoga as an accessible, practical intervention capable of offering significant relief and improved well-being for caregivers, meriting its inclusion in comprehensive support strategies for this population.

By considering these recommendations, the organization could build upon the success of the initial training and support group initiative, potentially enhancing the support for caregivers of dementia residents. Implementing these suggestions is at the discretion of the facility and could lead to improved outcomes for both caregivers and residents, contributing to a more resilient and supportive caregiving community.

### **Dissemination**

Upon the project's completion, this dissertation will be published and accessible through ProQuest Dissertations & Theses Global, making it available in the public domain for unrestricted access. Once available on ProQuest, this dissertation will be shared with Eventide Senior Living's management team and corporate members. Efforts will be made to further disseminate the findings through reputable academic journals in the field of nursing and healthcare, such as *Nurse Practitioner*. Plans to submit this dissertation to the annual poster presentations through North Dakota Nurse Practitioner Association (NDNPA) Pharmacology



Conference will be pursued, broadening its exposure to a professional audience. Furthermore, the team responsible for developing the PCTB scale, a central element of this project, will receive a copy, fostering collaboration and feedback from a foundational perspective.

### **Strengths and Limitations**

#### **Strengths**

The practice improvement project has several strengths. First, it received strong support from Eventide's RN manager and Director of Clinical Services. These individuals played a crucial role in facilitating the project and connecting the co-investigator with professional caregivers. Second, the project was designed to be repeatable, and the PowerPoint slides are available for future use by Eventide.

Additionally, the Eventide's RN manager, who closely observes the day-to-day operations within the memory care unit, has provided invaluable insights into the behavioral changes among the caregivers following the educational sessions. Noting that, following the training, the caregivers are showing positive changes in behavior, communication, and openness about caregiving burden. These positive changes suggest that the program not only enhanced theoretical knowledge and possibly alleviated perceived caregiver burden but also translated into practical improvements in caregiving practices (L. Letness, personal communication, April 5<sup>th</sup>, 2024). This qualitative evidence underscores the efficacy of the educational intervention, pointing to its role in fostering more effective, compassionate, and informed caregiving approaches for individuals with dementia.

#### **Limitations**

This practice improvement project encountered several limitations. A significant challenge was the decreased participation in the post-education knowledge questionnaire and

burden scale by the caregivers involved. Only five caregivers fully completed the knowledge questionnaire, and just six individuals submitted the one-month post-education burden scale. This made it challenging to accurately evaluate the effectiveness of the educational intervention in reducing caregiver burden.

A notable limitation of this study stems from the decision not to link pre-surveys with post-surveys for each participant. This choice was made to streamline the survey process. However, this inadvertently impacts the depth of analysis possible. Without direct linkage, it becomes challenging to track individual changes over time, thereby limiting the ability to make definitive statements about the evolution of respondents' attitudes, knowledge, or behaviors in response to the study's interventions. Even though this method doesn't affect the overall quality of the data gathered, it does limit how precisely the data can connect changes. This made it harder to understand exactly how the training influenced the results.

Another limitation concerned the timing between the educational intervention and the subsequent evaluation of caregiver burden. The gap was set at one month, but extending this period to three months could have provided a more comprehensive understanding of the intervention's impact over time. Unfortunately, project approval logistics necessitated a shorter timeframe, limiting ability to observe longer-term effects.

Furthermore, participation in this project was not mandatory for all caregivers at the facility, which restricted the number of participants available for assessment. As a result, the project was conducted in a single facility, limiting the generalizability of the findings to other memory care units. Variations in operational practices and caregiver preparedness across facilities mean that our results might not accurately reflect the situation in newly established or differently managed institutions.

## **Conclusion**

This project aimed to show that caregivers attending an educational session on managing dementia-related caregiver burden may experience a reduction in their burden one month after the session. Even though Frias et al. (2020) recommends 3 months post-intervention as an ideal time for gauging effectiveness of the intervention, due to time constraints this was not feasible. There was an improvement in burden levels after the education. However, the small number of caregivers who completed the burden scale makes it difficult to apply these findings broadly. The project suggests that ongoing education for dementia caregivers may help reduce caregiver burden. Additionally, forming a support group for caregivers could be a valuable step forward in improving how they manage burden and enhance resilience.

## **Application to DNP/APRN Role**

The findings from this project, which focused on the delivery of an educational session, highlighted the distinctive role nurse practitioners can play in education. This role extends beyond dementia caregivers to include anyone seeking better health understanding or knowledge. In fact, Nurse Practitioners are crucial in healthcare, providing diagnoses, treatment, and holistic care. Beyond patient care, NPs with a Doctor of Nursing Practice (DNP) degree are pivotal in education of patients, professionals, and themselves. Their educational role improves practice, builds systems and communities, impacts policy, and emphasizes the importance of continuous learning (American Association of Nurse Practitioners, 2024). Given their capability to deliver top-tier healthcare education, it's essential for nurse practitioners to prioritize the use of their educational skills. Without adequate education and training, individuals may find it challenging to manage their mental health effectively. Therefore, it's imperative for nurse practitioners to

establish and maintain educational standards for patients, families, caregivers, and others, ensuring comprehensive support and guidance.

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## APPENDIX A: IRB APPROVAL



12/12/2023

Dr. Adam G Hohman  
Nursing

Re: IRB Determination of Exempt Human Subjects Research:  
Protocol #IRB0004986, "Improving Caregiver Burden for Professional Caregivers of Dementia Patients"

NDSU Co-investigator(s) and research team:

- Adam G Hohman
- Austin Andrew Anderson

Approval Date: 12/12/2023

Expiration Date: 12/11/2024

Study site(s): Eventide Senior Living - Fargo, ND (Specifically, Sheyenne Crossing in West Fargo, ND)

Funding Source:

The above referenced human subjects research project has been determined exempt (category 1,2) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, *Protection of Human Subjects*).

Please also note the following:

- 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.
- Promptly report adverse events, unanticipated problems involving risks to subjects or others, or protocol deviations related to this project.

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

*NDSU has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.*

### RESEARCH INTEGRITY AND COMPLIANCE

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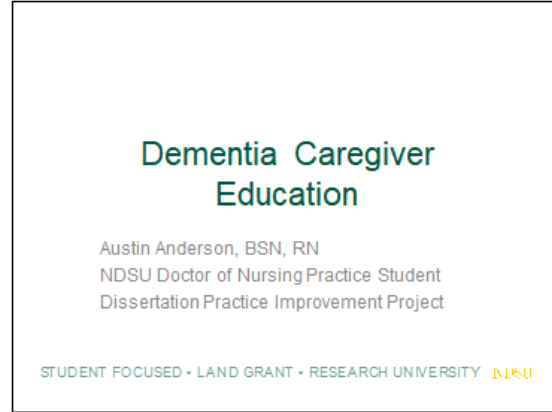
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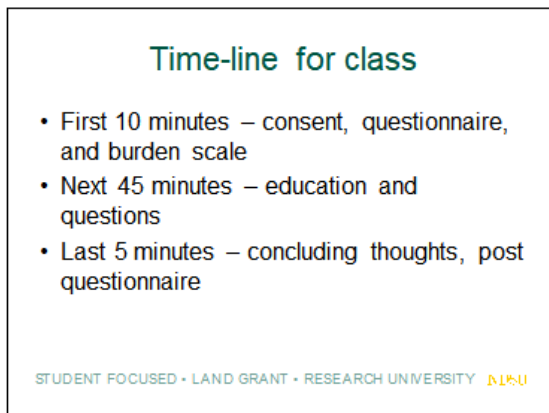
## APPENDIX B: POWERPOINT PRESENTATION FOR CAREGIVERS



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## Acknowledgements

- Education and content developed by a current neurology nurse practitioner
  - An expert in her field of neurology specializing in parkinsonism and related dementia with over 15 years of experience.
  - This education has been provided elsewhere within the community but proves to be invaluable in educating on dementia and caregiver burden.

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## About me

- RN – 7 years @ Sanford Health
  - ICU 2.5 years
  - Dermatology 1.5 years
  - Neurosurgery – 3 years
- Current NDSU DNP Student – Graduate May 2024
- Grew up in central Minnesota but been in Fargo now for 10 years.
- Grandfather struggled with lewy-body dementia-witnessed the immense caregiving struggle.

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## Statistics

- Aging population
  - By 2050, the elderly population will more than doubled compared to 2010
- Increasing dementia prevalence
  - 5 million with Alzheimer's disease in 2013. Projected to triple by 2050.
- Increasing caregiver prevalence
  - Need for caregivers will increase by 85% by 2050
  - Number of caregivers will increase by 25%
- Caregiver Needs and Burden
  - Dementia caregivers provide care which is more physically and emotionally demanding, costlier, and more time-consuming
  - Burden can lead to guilt, depression, stress, hypertension, back pain, and a decline in self-care

(CDC, 2013; Adelman et al., 2014)

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## Objectives

- Following class
  - Report increased knowledge about dementia
  - Report increased knowledge about ways to reduce burden
- One month after class:
  - Report a decrease in caregiver burden

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## Today's Discussion

- Communication techniques
- Dealing with agitation/behavior/personality changes
- Sundowning, hallucinations, delusions, and paranoia
- Importance of understanding caregiver burden
- Stress management tips to reduce burden

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## Caregiving for the cognitively impaired (CI)

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## Caregiving in CI

- Caregiving in general has its 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

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## 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

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## 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

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## Communication techniques to use with 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

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## Communication techniques to use with CI

- To encourage the person to communicate:
  - 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."

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## Communication techniques to use with 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

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### Communication techniques to use with CI

- Here are some examples of what you 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?”

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### Communication techniques to use with 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.

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### Agitation/Behavior Changes 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.

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### 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

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### Causes for Agitation/Behavior Change in CI


- To 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

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### Dealing with Agitation & Behavior Changes 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.

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### Dealing with agitation & behavior changes 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

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### 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 break from caregiving.

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## 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

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## 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

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## 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 the his or her feelings rather than words. For example, say "You seem worried."
  - Don't argue or try to reason with the person

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## 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."

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## Sundowning

- Sundowning—restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade—often 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 damage can affect a person's "biological clock," leading to confused sleep-wake cycles.
  - This may result in agitation and other sundowning behaviors

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## 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.

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## 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.

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## 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, pop, or other caffeine drinks later in the day
  - Do not plan too many activities during the day. A full schedule can be tiring.

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## 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 that 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.

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## 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 individual 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

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## 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.

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## 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 keep safe.
  - Might be actual concerns and not paranoia

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## 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
    - 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
  - Teamwork is key for your health and the resident's health

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## DEMENTIA CAREGIVER BURDEN: FOCUS ON SELF-CARE

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## 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.

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## 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 for the residents will also suffer
- Important to put you first to best help those around you

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## 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

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## 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 focus on working on their behalf

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## 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 a half-full or half-empty
- It is important to remember that you are not alone in your experiences

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## 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
- Take Action

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## 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 actionable steps
  - Make an action plan by deciding which step you will take first, and when.
  - Get started!

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## 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

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## 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 poorer health outcomes
- Yearly exams/physicals 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

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## Exercise

- Research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities such as 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 it's physical benefits, walking helps to reduce physiological tension.
- Walking 20 minutes a day, three times a week should be a goal.

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## Tips for Decreasing Caregiver Burden

- Learn and use stress-reduction techniques, such as meditation, prayer, yoga, or Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition. Eating healthy and drinking plenty of water.
- Exercise regularly.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, or paying for a massage.

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## 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 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, and people who care.

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## Summing everything up...

- Remember, it is not selfish to focus on your own needs and desires when you are a caregivers– 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.

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## 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

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## Post-education Knowledge Survey

- [https://ndstate.co1.qualtrics.com/jfe/form/SV\\_eVwGC66MuHmUk18](https://ndstate.co1.qualtrics.com/jfe/form/SV_eVwGC66MuHmUk18)



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## QUESTIONS OR COMMENTS?

Any questions/concerns?  
Email: [Austin.A.Anderson@ndsu.edu](mailto:Austin.A.Anderson@ndsu.edu)

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## APPENDIX C: EXECUTIVE SUMMARY

# IMPROVING CAREGIVER BURDEN FOR PROFESSIONAL CAREGIVERS OF DEMENTIA RESIDENTS

Practice  
Improvement  
Project

### PROBLEM

Dementia, a progressive neurological condition, profoundly affects cognitive functions such as memory, thinking, comprehension, language, and capacity, presenting significant challenges for caregivers. This project's goal was to support professional caregivers of people with dementia (PWD), addressing the unique difficulties they face and aiming to mitigate caregiver burden.



### PROJECT



Focused on alleviating the professional caregivers' burden, this project introduced an educational intervention at a specialized memory care unit. The initiative assessed the caregivers' burden levels and their comfort and understanding in managing dementia care before and one month after the educational sessions. The training covered critical topics such as cognitive impairment, self-care, communication techniques, and behavior management in dementia care.

### RESULTS

Administration from facility reported a perceived decrease in burden one-month following the educational session, as shown by improved communication strategies, and more supportive behavior.

Administration from facility reported a perceived increase in knowledge one-month post-educational training session.

Successful scheduling of first caregiver support group meeting on April 25th, 2024.

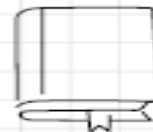
Establishing the support group fosters a sense of community among caregivers, providing a valuable platform for sharing experiences and mutual support.

### RECOMMENDATIONS


To further support caregiver well-being, the establishment of a support group beyond work hours was recommended to foster social connections and a stronger support network among colleagues.


Continuous education on the implications of caregiver burden should be provided to new staff, with invitations extended to join the support group.

Participation in a resilience training session offered by NDSU Doctor of Nursing Practice faculty is encouraged to bolster caregivers' coping mechanisms and overall resilience.



## APPENDIX D: PERMISSION TO USE IOWA MODEL

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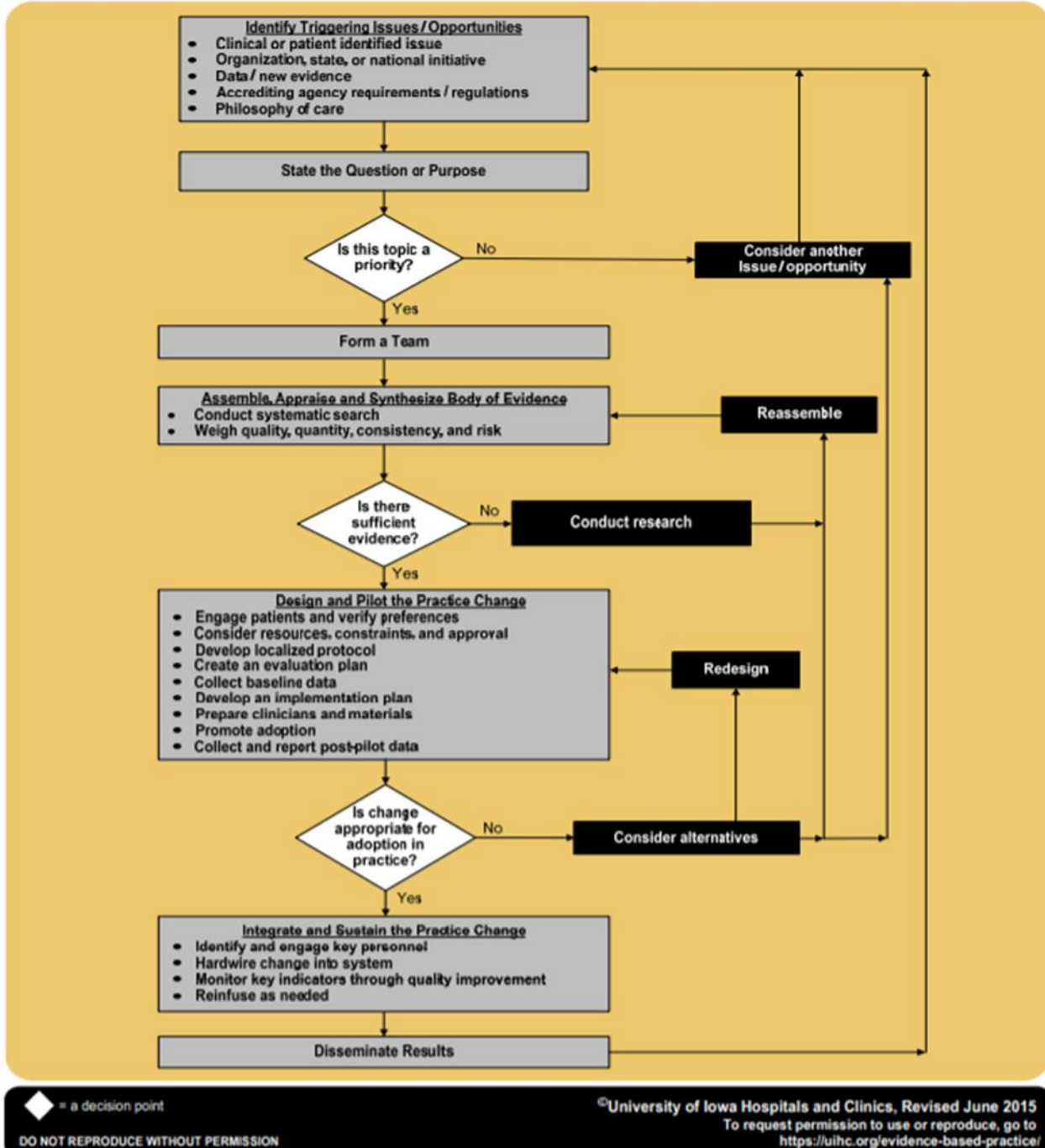
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## APPENDIX E: IOWA MODEL

# The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



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**APPENDIX F: PROFESSIONAL CARE TEAM BURDEN SCALE**



<b>Age:</b> _____ <b>Gender:</b> _____ <b>Job Title:</b> _____ (RN, LPN, CNA) <b>Number of years you have worked with dementia patients:</b> _____ <b>Number of years you have worked at the agency:</b> _____
---

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

**Pre-Education Scale**

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

(Auer et al., 2015)

**APPENDIX G: PRE-AND-POST EDUCATION KNOWLEDGE SURVEY**

Age: _____ Gender: _____ Job Title: _____ (RN, LPN, CNA) 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 for dementia patients?	1	2	3	4	5
2	How knowledgeable do you feel about caring for individuals with dementia?	1	2	3	4	5
3	How knowledgeable do you feel about managing difficult behaviors for those with dementia?	1	2	3	4	5
4	How knowledgeable do you feel about ways to decrease feelings of burden?	1	2	3	4	5

**5. How important would you consider taking care of yourself? (Circle one)**

Very important    Important    Moderately important    Slightly important    Not Important

## APPENDIX H: INFORMED CONSENT FOR CAREGIVERS



NDSU Dept. 2670  
Fargo, ND 58108-6050  
701-231-7395

### **Improving Caregiver Burden for Professional Caregivers of Dementia Patients**

Dear Caregivers,

I am seeking help with a practice improvement project for professional caregivers who formally take care of individuals diagnosed with dementia.

#### **Introduction:**

My name is Austin Anderson; I am a 3<sup>rd</sup> year Doctor of Nurse Practice/Family Nurse Practitioner student at North Dakota State University. I am conducting a practice improvement project to help professional caregivers understand dementia more deeply and improve caregiver burden. By participating in the project, my goal is to increase knowledge of dementia and decrease caregiver burden as it relates to taking care of patients with dementia.

#### **Purpose of the project:**

The current project seeks to understand how significant caregiver burden levels are at baseline (pre-education) and aspires to see an improvement in burden over a 1-month period (post-education).

#### **Procedures:**

By deciding to participate in this practice improvement project, you will be asked to listen to an educational presentation and complete a small professional burden scale and survey. The educational session will discuss stress management, dementia as a disease process, challenges of caring for individuals with dementia, and caregiver burden. The research data gathered will utilize a professional burden scale (10-item) tool to categorize a caregiver's level of burden. Additionally, 1-month after the educational session you will voluntarily complete a brief survey and burden scale for follow up.

#### **Benefits:**

The benefit to participants will be an increase in their knowledge and awareness of caregiver burden.

#### **Risks:**

There is thought to be very limited risk to participants enrolled in this study.

**Confidentiality:**

All survey responses will be kept confidential. Any identifiable information such as your name, and address will not be collected. All information will be stored on a password protected flash drive and will be deleted upon completion of the study.

**Explanation of Consent:**

- You understand that you must respond to the questionnaires and surveys to participate in the project.
- You understand that your consent is completely voluntary, and you can choose to withdraw at any time.
- You understand that all information gathered during the project will be confidential.
- You understand that the co-investigator will use an electronic scanner for the paper survey and integrate the data into Microsoft excel to gather information.

**Consent for Research:**








- Your consent is given freely and without coercion.
- You understand that you may contact the co-investigator (A.A) via email ([Austin.a.anderson@ndsu.edu](mailto:Austin.a.anderson@ndsu.edu)) or the principal investigator (D.G) via email ([Dean.Gross@ndsu.edu](mailto:Dean.Gross@ndsu.edu)). You may also call 701-231-8016 at any time to withdraw this consent or to ask any questions regarding the project. You may withdraw consent verbally or in writing.
- You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, by email at [ndsu.irb@ndsu.edu](mailto:ndsu.irb@ndsu.edu), or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

**Implied Consent:**

- The Co-Principal investigator (Austin Anderson) has provided you with the information letter and invitation to participate in the practice improvement project. You understand the terms and conditions mentioned above. By attending the educational session, you are giving implied consent to the co-investigator (A.A.) to participate in this practice improvement project. Furthermore, your voluntary participation in completing the survey will also constitute consent to participation in this evidence-based practice project.



## APPENDIX I: PERMISSION TO USE PCTB SCALE

SA Stefanie Auer <Stefanie.Auer@donau-uni.ac.at>    Reply  Reply all  Forward  

To: Anderson, Austin Wed 11/22/2023 2:45 AM

Cc: Margit Höfler <margit.hoefler@donau-uni.ac.at>

Dear Ms Anderson,

Thank you for your request- it is my pleasure to grant you with the permission to use the PCTB scale for your research. I would appreciate if you send your result (paper).

All the best for your research on this very important topic.

Stefanie

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**Von:** Anderson, Austin <austin.a.anderson@ndsu.edu>  
**Gesendet:** Mittwoch, 22. November 2023 02:15  
**An:** Stefanie Auer <Stefanie.Auer@donau-uni.ac.at>  
**Cc:** Stefanie.Auer@mas.or.at  
**Betreff:** Permission to Use and/or Reproduce the Professional Care Team Burden (PCTB) Scale

You don't often get email from [austin.a.anderson@ndsu.edu](mailto:austin.a.anderson@ndsu.edu). [Learn why this is important](#)

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