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The Inpatient Dementia Guidebook: Helping Caregivers of Patients with Dementia Navigate an Acute Hospitalization

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The Inpatient Dementia Guidebook: Helping Caregivers of Patients With Dementia

Navigate an Acute Hospitalization

A dissertation submitted in partial satisfaction of the

requirements for the degree

Doctor of Nursing Practice

by

Michelle Tricia Panlilio

2021

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## ABSTRACT OF THE DISSERTATION

The Inpatient Dementia Guidebook: Helping Caregivers of Patients With Dementia

Navigate an Acute Hospitalization

by

Michelle Tricia Panlilio

Doctor of Nursing Practice

University of California, Los Angeles, 2021

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**Background:** Caregivers are the foundation of care for patients with dementia (PWD), yet they receive little support or information when the PWD is hospitalized. Insufficient caregiver support results in poor caregiver self-efficacy (SE), which is the perception of one's ability to successfully and confidently provide care for another individual. This project evaluated if a guidebook developed specifically for caregivers of PWD increased caregiver SE scores after an acute hospitalization. **Methods:** Using a single-group, single-center design, SE was evaluated in 35 caregivers before and after implementation of the Inpatient Dementia Guidebook in the geriatric unit of a large academic medical center in the Western United States. The Caregiver SE

scale was administered pre-intervention and repeated within two weeks after discharge (post-intervention). Statistical analyses included descriptive statistics and Wilcoxon tests. **Results:** After administration of the Inpatient Dementia Guidebook, caregivers showed higher scores on the Caregiver SE scale, compared to the pre-tests ( $p < 0.001$ ), which demonstrated an improvement in caregiver SE. Results also exhibited an increase in caregiver self-reported health ( $p = .002$ ) and more frequent use of community-based organizations ( $p = .02$ ) after the guidebook intervention. **Conclusion:** The provision of a guidebook was beneficial in supporting caregivers during an acute hospitalization. Thus, healthcare systems and hospitals should adopt similar measures to support caregivers for PWD.

**Key words:** dementia, caregivers, self-efficacy, hospitalization, Alzheimer's Disease

The dissertation of Michelle Tricia Panlilio is approved.

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## **Dedication**

With all my love and gratitude, this paper is dedicated to Paolo and our two daughters Isabella and Noa. To my husband and forever partner in crime, your unwavering love, support, and confidence in me was the motivation for this achievement. You are the LOML and will always be the better half of us.

Isabella and Noa, you are my inspiration for trying to become a better person every day. Mommy is so proud of you both. Daddy and I promise to spend the rest of our lives helping you follow your dreams. Mihri Hatun said it best, “At one glance I loved you with a thousand hearts...”

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## CHAPTER ONE: INTRODUCTION

Dementia currently affects an estimated 6.2 million Americans and costs the nation \$355 billion annually, with prevalence rates projected to reach 12.7 million by 2050 due to the aging baby boomer generation (Alzheimer's Association, 2021). Patients with dementia (PWD) face higher risks of being hospitalized due to dementia-related complications, roughly two to four times the rate for patients without dementia (Alzheimer's Association, 2021; Leggett et al., 2018; Zhu et al., 2014). When PWD are admitted for an acute hospitalization, these patients often experience cognitive and physical decline, which consequentially generates distress for their families and caregivers (Timmons et al., 2016).

Caregivers for PWD provided an estimated 15.3 billion hours of care in 2020, which is equivalent to \$257 billion of unpaid assistance in the United States (Alzheimer's Association, 2021). These are individuals who provide partial or complete assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) for their family member or a friend. Caregivers are the foundation of care for PWD, yet these individuals receive little support or information when their loved one is admitted into the hospital. In a systematic review by Beardon et al. (2018) which examined the caregiver's experience during an acute hospitalization, up to 50% of the caregivers were unable to navigate hospital system and processes, while 34% of caregivers reported inadequate support and information. The lack of guidance results in poor caregiver SE (SE), which is the perception of one's ability to successfully and confidently manage responsibilities related to providing care for another individual (Hampton & Newcomb, 2018). Caregivers with higher rates of SE reported lower levels of stress, whereas lower levels of SE have been linked to increased caregiver burden and higher rates of depression (Grano et al., 2017; Hampton & Newcomb, 2018; Merrilees et al., 2018). In fact, approximately 30% to 40%

of all caregivers for PWD report clinical depression at baseline (Alzheimer's Association, 2021). Low SE and worsening psychological symptoms among caregivers may then adversely affect the quality of care they provide for the PWD.

In the last ten years there has been a movement towards understanding the caregivers' experience during an inpatient hospitalization of the PWD. A qualitative study by Jurgens et al. (2012) explored this and recommended the need for healthcare providers to consider the PWD and their caregiver as a unit to optimize clinical outcomes for the PWD. This primary seminal research developed within this timeframe lead to qualitative studies by Jamieson et al. (2016) and Moyle et al. (2016), which identified themes of caregiver distress such as role confusion of healthcare personnel, insufficient information provided during hospitalizations, poor staff training on dementia, and lack of guidelines for families and caregivers regarding hospital processes. A systematic review by Beardon et al. (2018) and a meta-analysis by Burgstaller et al. (2018) further stratified these themes, however only the latter article recommended a new model of care called the dementia caregiver triad, which reinforced participation of the PWD, family members, and health professionals.

## **Background**

The dementia care program is a co-management model of care which provides outpatient dementia care for PWD and their caregivers. PWD are typically referred to the dementia care program by their primary care physician or geriatrician, who will then serve as the partnering physician with the Dementia Care Specialists (DCSs). The DCSs are nurse practitioners who manage the dementia care and provide medical, social, and behavioral recommendations to the PWD and their caregivers. Once enrolled in the dementia care program, the DCSs will follow the PWD and their caregivers as the disease progresses and the PWD declines cognitively.

The Inpatient Dementia Guidebook was a quality improvement project which developed and implemented a guidebook for the families and caregivers who belong in a large academic medical center in the Western United States. The guidebook provided information on problematic issues identified by caregivers in literature which include topics such as delirium, recommendations for visiting the PWD, items to bring to the hospital, roles and responsibilities of various healthcare personnel, fall risks, delirium precautions, discharge planning options, and community resources for the PWD and their caregivers after the hospitalization. Following the guidebook development, a pilot study of its impact on caregivers of PWD was completed. The first aim of this project was to develop a guidebook for an inpatient hospitalization for the caregivers enrolled in the dementia care program. The second aim of this project was to evaluate the impact of the guidebook on the caregiver's SE in providing care for their loved one during an acute hospitalization, as measured by the SE scale (Fortinsky et al., 2002). Once completed in the geriatric inpatient unit, one long-term objective was to have the guidebook included in all inpatient visits of PWD admitted to the two main medical centers. Furthermore, another long-term objective was to develop a guidebook that may be adopted by any healthcare organization for the use of their PWD and their caregivers.

### **Problem Statement**

The dementia care program is an outpatient program managed by a team of nurse practitioners (NPs) who provide medical, social, and behavioral recommendations for the patients and caregivers. When patients are admitted for an acute hospitalization, the dementia care program administrative and medical staff manage telephone calls from overwhelmed caregivers. Depending on the type of hospitalization (medical or psychiatric), minutes or hours can be spent addressing problematic issues with the caregivers and the inpatient medical team.



Each DCS/NP manages a caseload of three hundred patients, with an estimated four to six patients per week being admitted to the hospital. For each patient in the hospital, the DCS can spend 30 to 90 minutes coordinating care with the caregivers and the inpatient team assigned to the patient.

At the time of admission into the unit, all patients and families are supposed to receive a handbook that is specific to the geriatric population. Based on nursing and administrative staff interviews from the geriatric unit, it became evident that most of the staff did not know the handbook existed. Only the unit manager was able to identify the location of the brochures in a locked office. The handbooks are outdated by at least seven years, since many of the staff listed in leadership roles on the document are no longer employed by the organization. Additionally, the existing handbook was designed for a patient with full cognitive abilities, not a person with dementia or a neurological disorder.

### **Clinical Question**

Is there an improvement in SE scores (O) among caregivers of PWD (P) due to an inpatient dementia guidebook (I) compared with no guidebook (C) over a period of 3 months (T)?

### **Purpose and Objectives**

The first short-term objective of this project is to develop a guidebook for an inpatient hospitalization for the caregivers enrolled in the dementia care program. The second short-term objective of this QI project is to evaluate the impact of a guidebook on the caregiver's SE in caring for their loved one during an acute hospitalization. Once completed in the geriatric inpatient unit, a long-term objective is to distribute the guidebook to all families caring for patients with dementia who are admitted to the medical center. Furthermore, since dementia care

program is in the process of disseminating the program to eight other organizations nationwide, future goals include developing a blank template of the guidebook to allow customization and distribution by other sites in their own organization.

## CHAPTER TWO: THEORETICAL FRAMEWORK

### **Theoretical Framework**

Bandura (1977) first described the concept of SE and the significant role it plays on how an individual responds to distressing situations. Hampton and Newcomb (2018) defined SE as an individual's perception of their ability to successfully and confidently fulfill responsibilities related to providing care for another individual. Interventions that are aimed towards increasing education, skills training, and case management for caregivers for PWD have been associated with increased SE (Merrilees et al., 2018). Since caregivers for PWD are responsible for the daily successful completion of the patient's ADLs and IADLs, his or her SE directly impacts the clinical outcomes of the PWD. Bandura's SE theory (1977) identified a core set of four sources in developing one's SE, which determine behavior and execution (see Appendix A).

### **Concepts**

*Performance accomplishments* are previous experiences built on sustained effort and perseverance which resulted in success, and have been found to have the highest impact on SE beliefs and future behaviors (Bandura, 1977). This source encourages the concept of future growth, and individuals with performance accomplishment are not easily discouraged by failure. *Vicarious experiences* includes all experiences observed by the individual. Witnessing the success of others will inspire an individual to pursue and achieve goals as well, with modeling behaviors occurring after witnessing successful demonstration by others (Lippke, 2020). The dementia care program contributes to this aspect by providing weekly support groups and caregiver bootcamps for the program's caregivers, which is a didactic one-day workshop specifically designed to address questions and concerns about dementia (Tan et al., 2019).

*Verbal persuasion* is instruction and information which encourages an individual to believe they possess the ability to achieve goals (Bandura, 1977). The guidebook itself will be the precise source of verbal persuasion, since this will provide information and instructions on how to manage issues related to the hospitalization. In the fourth and last source, Bandura states that a person's *physiological and affective state* will influence their ability to feel confidence if his or her mood is low. Although low mood is not quite major depression, an individual with low mood may report feelings of sadness, emptiness, or gloom (Loosen & Shelton, 2019). This source can dominate a person's SE if he or she believes the low mood is from incompetence or inability to achieve a goal, and chronic feelings of low mood may encourage individuals to give up on goals or decline participating in challenges. In the dementia care program, caregivers are provided support groups and private counseling sessions, thus supporting the caregiver's physiological and affective state.

## CHAPTER THREE: REVIEW OF LITERATURE

### **Review of Literature**

When patients who are enrolled in the dementia care program are admitted to the hospital, caregivers verbalize a realm of frustrations including delirium, worsening behavioral and psychological symptoms of dementia (BPSD), poor communication with hospital staff, role confusion of hospital employees, impaired discharge planning, uncertain disease prognosis, and the seemingly rapid progression of dementia in their loved one. Literature demonstrates that these concerns are not unique to the dementia care program, as several studies identified these similar themes about the caregiver experience in the inpatient setting (Hynninen et al., 2015; Jurgens et al., 2012; Jamieson et al., 2016; Moyle et al., 2016). Although the caregiver's experience has been explored for many decades, the experience in the inpatient setting has only recently been explored in the last decade, thus research is limited and review of literature had to be expanded to ten years.

The MESH terms included to obtain literature were dementia, caregiver, experience, and hospitalization. Utilizing PubMed to search the databases for peer-reviewed articles in the past five years yielded only 112 articles, therefore the search was expanded to ten years, which provided 139 articles. Employing the CINAHL database and using the same MESH terms, a search within five years provided five articles (however one article was duplicated), while ten years elicited 891 articles. After filtering for full text articles, 55 articles were left in PubMed and 684 articles in CINAHL. The journals were screened for duplication, a diagnosis of mild cognitive impairment, systematic reviews, outpatient settings, end-of-life experience, ongoing studies, and staff experience. The majority of the articles were excluded for these reasons. In chronological order, four original articles were chosen for the purpose of exploring the thematic

categories about the caregiver's experience during an acute hospitalization, with the intention of developing content for the guidebook extracted from the findings and recommendations from the publications (see Table 1). Of note, although the articles had similar recommendations of improving care for the PWD and their caregiver, interventions to date have not addressed these issues in the inpatient setting

Jurgens et al. (2012) is a seminal qualitative study that reviewed the experience of 35 caregivers and 34 patients in the hospital setting in the United Kingdom. The authors identified six themes of frustration which included behavioral issues, physical and health problems, communication with professionals, treatment of comfort needs, tensions between family members, and difficult hospital systems to navigate. Jurgens et al. (2012) concluded that patients and caregivers should be considered as a unit, and proactive communication with caregivers should be the foundation of developing a plan of care for a PWD.

Hynninen et al. (2015) conducted a qualitative and descriptive study with seven patients and five relatives in Oulu University Hospital, Finland. Utilizing informal interviews of the patient and the caregivers experience in the hospital, the authors identified three main themes which included undignified treatment of the patient with dementia, factors that contribute to good treatment of an older person with dementia, and factors that hinder good treatment of an older patient with dementia. The authors recommended that in order to improve the treatment of patients with dementia, caregivers must be included in the plan of care.

Jamieson et al. (2016) performed a qualitative study with 30 caregivers in the United Kingdom in the home setting of the PWD after being discharged from the hospital. The authors delineated three major themes which include paradoxical feelings from the caregivers (staff expected them to provide basic care for the patient while in the hospital but neglected to include

them in planning for care), problematic transitions back home due to poor discharge planning, and importance of social support for the PWD and the caregiver in the community. Jamieson et al. (2016) concluded that communication and coordination of care needs to include the caregiver, and that discharge planning needs to incorporate access to community-based social services.

Moyle et al. (2016) conducted an exploratory-descriptive qualitative approach to interviewing 30 caregivers in various stages (emergency room to discharge) during an inpatient hospitalization in three Australian hospitals. One theme identified by the authors included uncertainty of the role caregivers felt during a hospitalization, similar to the finding identified by Jamieson et al. (2016). Additionally, Moyle et al. (2016) recognized unmet needs of the caregivers, which encompassed insufficient information from healthcare staff, lack of recognition as a valued member of the team, unmet needs of the PWD, and insufficient information provided to navigate hospital access and processes. The investigators recommended for hospitals to improve inpatient staff training on best care practices for patients with dementia, develop hospital guidelines for caregivers, and include family in treatment recommendations.

Limitations of the studies are the small samples in each study (between 12 to 35 study participants). In the study by Jurgens et al. (2012) and Hynninen et al. (2015), some interviews with the caregiver were performed in front of the patient with dementia, which can significantly limit the amount of information given by the caregivers who are trying to avoid upsetting the PWD. Furthermore, Hynninen et al. (2015) conducted interviews on the PWD during the hospitalization, not accounting for effects of delirium or the stage of dementia and therefore accuracy of the data extracted. Moreover, future studies need to develop standardized questions for caregiver interviews, as not all investigators asked the questions in the same manner (Jamieson et al., 2016). One gap in care identified in the literature includes the need to develop a

tool to categorize and standardize the themes of caregiver dissatisfaction, therefore permitting for focused interventions and extraction of quantitative data.

Once standardized tools are developed to categorize the abovementioned problems, it is evident that future implications for practice call for development of interventions to address these identified problems. As noted in the DNP essentials that will be utilized to complete this project, the DNP is ideally positioned to lead this project that requires interprofessional collaboration from the fields of patient experience, nursing, medicine, design, marketing, rehabilitation, case management, and organizational leadership.

### **Interventions in the Outpatient Setting**

The qualitative studies reviewed in the previous section of this paper identified thematic findings in caregiver dissatisfaction, however there have been no interventions or programs identified to tackle these issues in the inpatient setting. The articles reviewed in this next segment delineate interventions that focus on empowering caregivers for PWD by providing informational, emotional, and instrumental support in the outpatient setting (see Table 1).

Thyrian et al. (2017) conducted a cluster-randomized clinical trial to test the efficacy and safety of a dementia care management program in the home setting of the PWD in Germany. Of the 407 patients enrolled in the study, 291 received the intervention. Dementia care management was provided by six nurses trained in dementia, along with the collaborative efforts of a nurse scientist, psychiatrist, psychologist, and pharmacist. In partnering with the caregivers to provide dementia care, the researchers found significantly decreased behavioral symptoms due to the education from the nurses, which led to an improvement in quality of life for the PWD and their caregivers.





Kales et al. (2018) performed a randomized controlled trial with 57 caregivers to evaluate the effects of WeCareAdvisor, an electronic tool that was provided on an iPad tablet in the home setting. WeCareAdvisor was developed with the objective of enabling family caregivers to report, evaluate, manage, and document behavioral issues at home. According to Kales et al. (2018) and Majer et al. (2019), behavioral and psychological symptoms of dementia (BPSD) affect over 95% of all PWD at some point in the disease, and has been found to significantly increase caregiver distress. After participating in this trial, the caregivers in the intervention group demonstrated improved distress scores, in addition to a decrease in the frequency and intensity of the BPSD in the PWD.

Possin et al. (2019) conducted a randomized clinical trial on 512 patient-caregiver dyads to evaluate impact of the Care Ecosystem, which is an interprofessional team comprised of a pharmacist, social worker, and advanced practice nurse. Dementia care was provided over the telephone to participants in California, Nebraska, and Iowa. The study measured quality of life using the Quality of Life in Alzheimer's Disease (QoL-AD) instrument, depression using the Patient Health Questionnaire-9 (PHQ-9), and caregiver burden using the Zarit Burden Interview, as well as utilization of the emergency department, hospitals, and ambulance services. Results demonstrated that the Care Ecosystem was able to decrease emergency room utilization for the patients, in addition to decreasing caregiver depression and distress. PWD also conveyed an improved quality of life, therefore the authors determined that outpatient management with an interdisciplinary team coordinating care with caregivers was successful in alleviating burdens on the economy and the society secondary to dementia.

Merrilees et al. (2018) published their article studying a sub-cohort of three caregivers enrolled in the Care Ecosystem, which is the dementia care program discussed by Possin et al.

(2019). To improve caregiver reports of SE and preparedness, the researchers discussed the importance of incorporating psychosocial interventions into the patient-centered dementia care plan. Specifically, the authors recommended for health care providers to develop interventions and programs aimed at increasing caregiver SE through the provision of emotional, informational, and instrumental support for the caregivers of the PWD.

Reuben et al. (2019) conducted an observational study of 554 patient-caregiver dyads enrolled in University of California Los Angeles Alzheimer's and Dementia Care Program (UCLA ADC Program), which is an outpatient NP-managed dementia care program. Once enrolled, patient-caregiver dyads are provided medical, social, and behavioral recommendations during clinic appointments and through ongoing care management over the telephone and during clinic visits. Prior to enrollment (baseline) and after one year, patients and caregivers completed written questionnaires which included the Mini-Mental State Examination (MMSE), Functional Activities Questionnaire (FAQ), Cornell Scale for Depression in dementia, Functional status (ADLs and IADLs), Neuropsychiatric Inventory Questionnaire (NPI-Q), Modified Caregiver Strain Index (MCSI), PHQ-9, and Dementia Burden Scale-Caregiver (DBS-CG). After one year of being enrolled in the UCLA ADC Program, and despite the PWD exhibiting progressive worsening MMSE and FAQ scores (which was expected due to the progressive deterioration associated with dementia), caregivers demonstrated less distress over behavioral symptoms of dementia ( $\leq 6$  in NPI-Q) and decreased burden ( $\leq 18.8$  in DBS-CG).

### **Synthesis of Literature Review**

The compilation of the caregiver's experience in the hospital setting by Hynninen et al. (2015), Jurgens et al. (2012), Jamieson et al. (2016), and Moyle et al. (2016) had similar themes and recommendations for healthcare providers, with the exception of Jamieson et al. (2016) who

included recommendations for increasing caregiver access and assistance with navigating community-based organizations. In concurrence with the thematic findings of the four qualitative articles reviewed, Beardon et al. (2018) and Burgstaller et al. (2018) performed systematic reviews and documented themes of caregiver dissatisfaction. The authors of these six articles recognized the importance of the caregiver's role in the PWD, hence strongly recommending for inpatient hospital staff to partner with caregivers in planning and providing treatment to optimize clinical outcomes for the PWD.

Jamieson et al. (2016) and Moyle et al. (2016) stated the need for family-focused treatment plans, which was supported by the recommendations from Burgstaller et al. (2018) to develop a new model of patient-centered care named the dementia care triad. Moreover, in a study by Jennings et al. (2019), the researchers acknowledged the significance of the caregiver role and how inadequate support for the caregiver often resulted in poor medical outcomes for the patient. Furthermore, in a study by Maas et al. (2004) conducted in the nursing home setting, the researchers evaluated the impact of Family Involvement in Care (FIC), which was a program developed to increase the satisfaction among family members and nursing home staff. By developing a partnership with staff and caregivers, the researchers identified that caregivers reported higher satisfaction with the physical care and improved scores on feelings of loss and guilt. Additionally, after completion of the FIC intervention the authors noted that both caregivers and the nursing home staff reported a more favorable relationship working collaboratively in the care for the PWD.

Hynninen et al. (2015), Jamieson et al. (2016), Jurgens et al. (2012), and Moyle et al. (2016) found that families and caregivers were dissatisfied with staff training and education on how to properly care for a patient with dementia, both from the nursing and medical professions.

Jurgens et al. (2012) identified this problem early on in their seminal study, stating that much of the caregiver's anxiety and perception of a crisis stemmed from the caregiver's mistrust of poorly-trained staff. Hynninen et al. (2015) identified caregivers who attributed poor staff education as the cause of perceived disrespectful treatment of the PWD, noting that staff members failed to preserve patient dignity.

Impaired communication with hospital staff and insufficient information were highlighted by all four articles, with Moyle et al. (2016) concluding that improving the exchange of information should be a priority for hospital organizations. Moreover, Jurgens et al. (2012) specified that poor communication about the plan of care led to mistrust from caregivers, which further progressed to caregivers questioning staff professionalism. Jamieson et al. (2016) and Moyle et al. (2016) recommended for hospital organizations to develop simple guidelines to improve communication and provide information on hospital processes and guidance for accessing dementia-appropriate community-based services.

## CHAPTER FOUR: METHODS

### **Design**

The Inpatient Dementia Guidebook was a pre-intervention-post-intervention QI project conducted in a single inpatient geriatric unit in a large academic medical center in the Western United States.

### **Sample and Setting**

The study sample included unpaid family and friends who provided help for the PWD with activities of daily living (ADL) and/or instrumental ADLs. Paid professional caregivers were excluded since caregiving is their form of employment and they are not responsible for making medical decisions for the patient. Caregivers who understood English were invited to this study because the guidebook was written in English. Participants were incentivized to participate in the study by being provided the Inpatient Dementia Guidebook. To determine the needed sample size for a paired t-test, the G Power software was utilized. Given a two-tailed test, an alpha of  $p < .05$ , a medium effect size, and sufficient power (.80), a sample of 34 patients was needed. Should there be non-normal distributions in either the pre-intervention or post-intervention data or a smaller sample size, the paired t-test was supplemented with a Wilcoxon matched pairs test. Caregivers for all PWD admitted to the geriatric unit were recruited using convenience sampling. According to the Institutional Review Board, this QI project did not meet the definition of human subject research, thus approval or certification of exemption was not required.

### **Instruments**

To analyze demographic characteristics of the caregivers, this project utilized descriptive statistics (see Table 1). Variables collected included age, gender, highest educational level,

ethnicity, relation to the PWD, and if the participant resided in the same residence as the PWD (see Appendix B).

The primary dependent variable for the project is caregiver SE, which was evaluated by the caregiver SE scale (Fortinsky et al., 2002). The tool is a validated questionnaire which consists of fifteen questions self-rated by the caregiver during a telephone interview (see Appendix C). Only the first ten questions were utilized for this project, since the latter five questions were related to caregiver SE on medication administration and management. Each question is scored using a Likert scale from one (not at all certain) to ten (very certain). Overall scores may range from ten to 100, with higher scores indicative of higher levels of SE. Reliability and validity of the scale was confirmed in a study by Steffen et al. (2002), with a Cronbach's alpha greater than .80. Dr. Richard Fortinsky provided written permission and interview guidelines for his tool to be utilized for the purposes of completing this project (see Appendix E).

The secondary dependent variable measured was the single-item self-reported health (SRH) question, where caregivers were asked to rate their health as excellent, very good, good, fair, or poor (see Appendix B). SRH is a tool used to measure overall health in the elderly, and has been suggested as a dependable method of assessing general health which may include comorbid illnesses, psychological distress, health behaviors, and functional status (von Känel et al., 2018). The reliability of the SRH was confirmed in a study by Zajacova and Dowd (2011), where the authors found a Kappa coefficient of 0.43. Merrilees et al. (2018) stated that ratings of caregiver SE have been strongly associated with caregiver SRH, identifying that caregivers with higher ratings of SRH are more likely to report lower ratings of burden, less depression, fewer physical symptoms, and lower levels of distress. Additionally, in a study by Abdollahpour et al.

(2014), the researchers determined that caregiver burden was the strongest predictor of SRH in caregivers with dementia. The authors made recommendations that interventions need to be developed to reduce caregiver burden, since such interventions to promote the overall health of caregivers.

The tertiary dependent variable measured was the utilization of community-based organizations (CBOs). The dementia care program has long established collaborative relationships with several CBOs in Los Angeles. Services provided by CBOs have been instrumental in providing comprehensive dementia care for the PWD and caregivers of the dementia care program, which include financial counseling, private case management, counseling for caregivers, adult day care programs for the patients, educational programs for caregivers, and support groups for caregivers. Tremont et al. (2016) assert that although these services are available, many caregivers wait until there is a crisis to access these services. Correspondingly, in a study conducted by Robinson, Buckwalter, and Reed (2013), only 20% to 30% attended support groups or utilized respite services. Both authors concluded that caregivers for PWD are reluctant to use CBOs because they have insufficient knowledge of the services or they simply do not think they or the PWD need the services. For the purpose of measuring this variable for this project, caregivers were asked about their frequency of contact with CBOs in the pre-intervention and post-intervention questionnaire.

## **Implementation Process**

### Writing the Inpatient Dementia Guidebook

Evidence supports that interdisciplinary collaboration to provide dementia care for patient-caregiver dyads is best practice (Jennings et al., 2019; Possin et al., 2019; Thyrian et al., 2017). After extracting thematic findings and recommendations from the literature search, the

investigator sought counsel from dementia care program, outpatient geriatric faculty, hospital leadership, inpatient geriatrics medical and nursing leadership, geriatric nursing staff, coordinators for Nurses Improving Care for Healthsystem Elders (NICHE), and caregivers of the dementia care program. Additionally, the investigator reviewed current practices by other healthcare organizations in addressing the inpatient needs of caregivers for PWD. The guidebook was developed over a period of 5 months. After the content for the guidebook was finalized in English, the investigator collaborated with the departments of marketing and design to ensure compliance with the medical center's brand voice requirements.

#### Staff Education on Dementia

Hynninen et al. (2015), Jamieson et al. (2016), Jurgens et al. (2012), and Moyle et al. (2016) identified a theme of caregiver dissatisfaction due to insufficient staff training on dementia. The geriatric unit utilized for the study is staffed with geriatric physicians and registered nurses, recently ranked one of the best hospitals for geriatric patients (U.S. News and World Report, 2020). Furthermore, the medical center is a designated NICHE hospital, designed to improve the inpatient care for older adults (NICHE, 2020). Therefore, the investigator anticipated staff training on dementia and the purpose of the Inpatient Dementia Guidebook would be minimal. Since this project was executed during the COVID-19 pandemic, the investigator provided two twenty-minute in-service presentations to the nursing staff utilizing Zoom video conferencing. The purpose of these trainings was to introduce the investigator, present the guidebook quality improvement project, and to encourage staff participation in identifying potential participants. The investigator provided additional training on the significant role played by the caregivers in the lives of the PWD.



Prior to implementation, the unit director identified three volunteer registered nurses (RN) to serve as “dementia champions.” Since the investigator’s office is located several miles away from the geriatric unit, the dementia champions provided on-site assistance during implementation. Their responsibilities included distributing the paper guidebooks and collecting the demographic and pre-intervention questionnaires from caregivers (see Appendix B and Appendix C). For caregivers who preferred electronic access, the investigator emailed PDF guidebooks. The dementia champions received additional training regarding project execution from the investigator prior to implementation. Once the pre-intervention questionnaires were scanned (without personal identifiable information) and sent as an encrypted email to the investigator, the dementia champions were not required to assist in other activities.

### **Intervention**

When a patient in the dementia care program is admitted in the emergency room or the hospital, the DCSs are automatically notified by Epic electronic medical records. Per program policy, all caregivers are contacted by the DCS assigned to his or her care within one to two days of admission to provide assistance. For the purposes of completing this project, all caregivers for patients with dementia during this time frame were contacted by the investigator on the phone or the dementia champions in the hospital to request participation (first six weeks of the project only when hospital visitation was permitted during the COVID-19 pandemic). Caregivers who were amenable to participating completed a pre-test questionnaire and were provided the Inpatient Dementia Guidebook in their preferred manner, either an emailed PDF file or a guidebook in the hospital. The investigator and the dementia champions reviewed the guidebook contents and provided instructions to the caregiver prior to distribution.

## Timeline of the Project

Data collection began during the last week of October 2020. Approximately six weeks later, the rates of COVID-19 infections soared to an all-time high nationwide and particularly in the state of California, thus forcing state officials to require stricter quarantine guidelines for all residents (Centers for Disease Control [CDC], 2021). The medical center revised hospital visitation rules, prohibiting all visitors in the hospital until the end of the project implementation in January 2021. Consequently, data from the last six weeks of collection was obtained via telephone and all guidebooks were provided through email. Implementation took place over three months, wherein thirty-five pre-interventions and thirty-five post-interventions were successfully obtained. Data collection of the dependent variables (caregiver SE, SRH, and CBO utilization) was conducted on day one or two of the hospitalization and repeated within ten days after discharge.

Once the PWD was discharged from the hospital, the investigator contacted the caregivers by telephone within ten days post discharge. During this telephone call, if the caregiver confirmed utilization of the guidebook, the investigator completed the post-intervention questionnaire. Subsequently, caregivers were encouraged to verbalize additional comments or insight about the guidebook. Caregivers who reported not utilizing the guidebook were excluded from data collection.

## **Data Analysis**

If the project is successful, caregivers would ideally report higher levels of SE. Given the brief time frame in between the admission date and ten days after discharge, the author expected a modest ten percent increase in pre-intervention and post-intervention scores. Wilcoxon tests were used instead of the more common paired  $t$  tests based on the sample size ( $N = 35$ ) and the

ordinal level ratings for each of the 10 individual SE items. In addition, as a measure of clinical relevance, it will also be determined what percentage of caregivers increase their score at least ten percentage points from pre-intervention to post-intervention. Future studies could evaluate SE with a longer time frame after discharge (such as one month) or if there was increased patient and caregiver utilization of services from community-based organizations listed in the guidebook.

## CHAPTER FIVE: RESULTS

The goal of this QI project was to develop and evaluate the impact of an inpatient dementia guidebook on caregiver SE during an acute hospitalization. This project also evaluated the impact of a guidebook on how caregivers rated their own health (SRH) and how often CBOs were utilized. Utilizing Wilcoxon tests to compare pre-intervention and post-intervention variables, outcomes included significantly higher scores compared to the pre-tests ( $p < 0.001$ ) after administration of the Inpatient Dementia Guidebook, which demonstrated an improvement in caregiver SE. Results also exhibited an increase in caregiver self-reported health ( $p = .002$ ) and more frequent use of community-based organizations ( $p = .02$ ) after the hospitalization. A total of 35 caregivers participated in this project. Results are presented in the sections below.

### **Descriptive Statistics**

Table 1 displays the number and percentage of the demographic variables. Ages of the participants ranged from 31 to 50 years (22.8%) to 71 to 90 years (14.3%) with the median age of  $Mdn = 55.50$  years. There were significantly more female (71.4%) than male (28.6%) caregivers. Most participants (80.0%) were college graduates and 77.1% were married. About three-quarters (74.3%) of the sample were the child of the patient, while 14.3% were spouses. Of the 35 caregivers who participated, 42.9% of them lived with the PWD. About two thirds of the sample (68.6%) were White. Overall, 25 of 35 respondents participated in the dementia care program (71.4%). It was found that program participants were younger ( $p = .006$ ) and were more likely to be the child of the patient ( $p = .04$ ).

**Table 1:** Demographic Characteristics of Participants  $N = 35$ 

Variable	Category	<i>n</i>	%
Age Category <sup>a</sup>	31-50	8	22.8
	51-60	12	34.3
	61-70	10	28.6
	71-90	5	14.3
Gender	Female	25	71.4
	Male	10	28.6
Schooling	Less than college	7	20.0
	College graduate	15	42.9
	Graduate school	13	37.1
Marital Status	Single	5	14.3
	Married	27	77.1
	Other	3	8.6
Relation to Patient	Spouse	5	14.3
	Child	26	74.3
	Other	4	11.4
Live with Patient	Yes	15	42.9
	No	20	57.1
Race/Ethnicity	Black	2	5.7
	Asian	3	8.6
	White	24	68.6
	Other	6	17.1
Enrolled in Dementia Care Program	Yes	25	71.4
	No	10	28.6

<sup>a</sup> Age: *Mdn* = 55.50 years old.

## Caregiver Self-Efficacy

Table 2 displays the Wilcoxon tests comparing caregiver SE pre-intervention and post-intervention variables, which demonstrated the 11 SE variables (total mean score and each of the 10 individual items) were significantly higher at the post-intervention at the  $p < .001$  level.

**Table 2:** Caregiver Self-Efficacy: Wilcoxon Tests Comparing Pre-intervention and Post-intervention Variables,  $N=35$

Variable	Time	<i>M</i>	<i>SD</i>	<i>z</i>	<i>p</i>
SE Scale				5.16	.001
Total mean score	Pre-intervention	5.61	1.64		
	Post-intervention	7.81	1.33		
Subscales					
1. Handle any problems your loved one has, like memory loss, wandering, or behavior problems?				3.44	.001
	Pre-intervention	6.74	2.38		
	Post-intervention	7.89	1.84		
2. Handle any problems that might come up in the future about your loved one's care?				3.83	.001
	Pre-intervention	6.40	2.51		
	Post-intervention	7.89	1.69		
3. Deal with the frustrations of caring for your loved one?				4.33	.001
	Pre-intervention	5.97	2.61		
	Post-intervention	7.66	2.15		
4. Do something to keep your loved one as independent as possible?				4.35	.001
	Pre-intervention	5.26	2.82		
	Post-intervention	7.63	1.94		
5. Get answers to all your questions about your loved one's problems?				3.77	.001
	Pre-intervention	7.34	1.98		
	Post-intervention	8.57	1.50		
6. Care for your loved one without help from organizations or agencies that provide services?				4.07	.001
	Pre-intervention	3.83	2.47		

	Post-intervention	5.69	2.65		
7. Find organizations in the community that provide services to help you or your loved one?				4.78	.001
	Pre-intervention	5.51	2.74		
	Post-intervention	8.17	1.67		
8. Get answers to all your questions about these services?				4.93	.001
	Pre-intervention	5.37	2.64		
	Post-intervention	8.23	1.50		
9. Arrange for these services yourself?				4.95	.001
	Pre-intervention	4.80	2.58		
	Post-intervention	8.17	1.58		
10. Find services available to me to help me provide care?				4.89	.001
	Pre-intervention	4.89	2.62		
	Post-intervention	8.20	1.57		

*Note.* SE = self-efficacy.

### **Caregiver Self-Reported Health**

Table 3 displays the results for caregiver SRH, which demonstrated that 62.9% of the caregivers reported having either excellent or very good health at the pre-intervention. When post-intervention questionnaires were collected, 77.1% of the caregivers reported having either excellent or very good health, therefore exhibiting that caregiver health was better at post-intervention ( $p = .002$ ).

Of the 35 caregivers who participated, two participants did not report improvement on SRH after participating in the project. The first participant was a daughter who served as the primary and sole caregiver for her mother. Due to lack of respite care for her mother, she was unable to have a surgical procedure to resolve a chronic medical problem and therefore expected her medical issues to progress over time. The second participant was a daughter-in-law who was diagnosed with multiple malignancies, reportedly undergoing chemotherapy and radiation treatment.

**Table 3:** Comparison of Caregiver Self-Reported Health Pre and Post Intervention,  $N=35$ 

Caregiver SRH Pre-intervention			Caregiver SRH Post-intervention		
	<i>n</i>	%		<i>n</i>	%
Excellent	10	28.6	Excellent	14	40.0
Very good	12	34.3	Very good	13	37.1
Good	6	17.1	Good	5	14.3
Fair	5	14.3	Fair	1	2.9
Poor	2	5.7	Poor	2	5.7

Variable	Time	<i>M</i>	<i>SD</i>	<i>z</i>	<i>p</i>
Caregiver's self-reported health status <sup>a</sup>				3.13	.002
	Pre-intervention	2.34	1.21		
	Post-intervention	1.97	1.10		

*Note.* SRH = self-reported health. <sup>a</sup> Health: 1 = *Excellent* to 5 = *Poor*.

### Community-Based Organization Utilization

Table 4 displays the contact with CBOs, which revealed that 82.9% of the respondents had no contact at pre-intervention while at post-intervention 65.7% had no contact. Of the caregivers who established contact with CBOs, 17.1% reported either weekly or daily contact. Hence, contact with the CBO was more frequent ( $p = .02$ ) after the hospitalization.

**Table 4:** Comparison of Community-Based Organization Utilization Pre and Post Intervention,  $N=35$ 

CBO Utilization Pre-intervention			CBO Utilization Post-intervention		
	<i>n</i>	%		<i>n</i>	%
No	29	82.9	No	23	65.7
Monthly	4	11.4	Monthly	6	17.1
Weekly	2	5.7	Weekly	4	11.4



Daily 	0	0	Daily	2	5.7
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Variable	Time	<i>M</i>	<i>SD</i>	<i>z</i>	<i>p</i>
Contact with CBO <sup>a</sup>				2.40	.02
	Pre-intervention	1.23	0.55		
	Post-intervention	1.57	0.92		

*Note.* CBO = Community-Based Organization. <sup>a</sup> Contact: 1 = *No* to 4 = *Daily*.

## CHAPTER SIX: DISCUSSION

### **Contribution to Science**

Literature demonstrated that the caregivers' experience in the inpatient setting has been only recently explored in the last decade, with Beardon et al. (2018) and Burgstaller et al. (2018) summarizing themes of caregiver dissatisfaction with PWD care during acute hospitalizations. While these articles identified sources of frustration and provided recommendations of how to address the challenges, none of the available literature had concrete interventions that had been implemented in the inpatient setting.

The Inpatient Dementia Guidebook was an original project which demonstrated the development of a tool and the successful implementation of this project in the inpatient geriatric unit in a large academic medical center. This was an initial attempt to tackle the distress experienced by caregivers for PWD in the inpatient geriatric unit, perhaps serving as baseline scientific information for future researchers attempting to address this issue. The author and investigator of the Inpatient Dementia Guidebook is in the process of composing a generic template of the guidebook, designed to be personalized and disseminated by interested healthcare organizations. This contribution to science, the nursing profession, dementia care, and healthcare organizations may be altered and improved upon by future investigators.

### **Valuable Contextual Information**

Two caregivers lived out of state, therefore the amount of information they received was limited through telephone calls with the medical team. Managing daily medical issues and dementia care from a distance can be difficult, and an acute hospitalization often exacerbates the challenges faced by these caregivers. One caregiver found the information in the guidebook

reassuring, particularly when she read about the explanation and prevention of delirium and other behavioral and psychological symptoms of dementia (BPSD). Another caregiver verbalized appreciation that her concerns were seemingly acknowledged by the guidebook, stating her relief that there were “tangible” community resources that could assist after the hospitalization. She further verbalized her appreciation for the additional contact with a medical provider from the healthcare organization, since she the amount of information she received was reportedly insufficient.

Incidentally, one of the caregivers who participated in the project was an experienced physician. He was also the only child and primary caregiver for his mother who had advanced dementia. After his mother was hospitalized, he stated his newly-found insight into the caregiver’s experience during an acute hospitalization made him reconsider his previous treatment recommendations for his own patients with dementia. Although he was a seasoned provider, he acknowledged the need to alter future approaches to providing medical care for the patient-caregiver dyad. Furthermore, his experience during the hospitalization allowed him to fully grasp and appreciate the various roles and responsibilities of the interdisciplinary team discussed in the guidebook, again modifying his future practice as a physician.

### **Comparison of Results to the Literature**

Merrilees et al. (2018) examined the importance of integrating psychosocial interventions in the care plan of the PWD, and made specific recommendations for healthcare systems to improve interventions and programs aimed at increasing caregiver SE. The authors further stated that multi-faceted approaches are needed to address emotional, informational, and instrumental needs of this population. This QI project demonstrated that with the additional support and

guidance of an Inpatient Dementia Guidebook, a DCS, trained nursing staff, and connections to community-based organizations, caregiver SE and SRH were significantly increased.

### **Implications for Nursing Practice and Future Research Opportunities**

Caregivers are the foundation of care in providing medical treatment for a PWD, yet 29% to 50% of caregivers are dissatisfied with the hospital experience (Beardon et al., 2018). Recent publications identified thematic causes for caregiver dissatisfaction in the inpatient setting, which include inadequate information provided to caregivers, poor staff training on dementia, insufficient access to community support after discharge, difficulty navigating hospital processes, and most of all being excluded from the plan of care for the PWD. These topics have been researched and systematically reviewed, however there have been no interventions developed. Implications for practice calls for health providers to follow recommendations to improve caregiver support and clinical outcomes for the PWD during an inpatient hospitalization. The development of an Inpatient Dementia Guidebook is an important first step to ameliorate these issues.

Availability and access to CBOs have been identified as one of the recommended interventions for the PWD and their caregivers, to positively influence health behaviors, mental illness, and physical disease (Alzheimer's Association, 2021; Jamieson et al., 2016; Jennings et al. 2019). Access to community services for this population has been identified as a social determinant of health, however research reveals that PWD access fewer community-based services compared to other patient populations who need assistance (Healthy People, 2020; Phillipson et al., 2014; Stephan et al., 2018; Vecchio et al., 2016). The dementia care program has established relationships with several local community-based organizations, however barriers

such as lack of transportation and financial limitations continue to persist. As a nation dealing with a progressive disease that is costing the United States \$355 billion annually, it is essential to tackle these barriers at the community level before they overwhelm the nation financially (Alzheimer's Association, 2021). As a result of this QI project, the amount of caregivers who reported they had no contact with CBOs (82.9%) was significantly lower post-intervention 65.7%.

### **COVID-19 Impact**

The COVID-19 pandemic was catastrophic worldwide, but the impact of the virus had a profound effect on healthcare workers across the globe. Participating in a QI project during the pandemic in addition to daily nursing responsibilities was an extreme challenge, with much of the nursing staff too overwhelmed with their urgent responsibilities to collect data. Additionally, in the midst of data collection and recruitment for willing participants, the hospital placed additional restrictions which prohibited caregivers (or any guests) from visiting patients in the hospital for the duration of the project.

In response to these challenges, the investigator ramped up recruitment by calling all potential caregivers on the telephone. These calls were made to inquire about participation and to collect pre-intervention information. Since physically distributing printed guidebooks was no longer an option due to the pandemic, the investigator provided PDF copies through email access instead. As a result of self-reported inability to access email or the dementia care program website, three caregivers were excluded from the study. The investigator was fortunate to have considered electronic media in addition to the printed material, as recruitment would have otherwise been halted or postponed.

Despite the additional effort of recruiting caregivers singlehandedly, the silver lining was brought on by the pandemic itself. Since most of the caregivers and the population were mandated to quarantine at home by state officials, the investigator found many agreeable project participants willing to spend time on the telephone. Recruitment continued as scheduled and data collection was completed according to the original project timeline.

The COVID-19 pandemic initially forced all CBOs to cease their in-person services (such as adult day care activities), however many CBOs made alterations in their programs to make it available on zoom videoconferencing as the pandemic progressed. Additionally, some CBOs resumed case management and support groups several months after the quarantine. During the telephone calls to collect data, many caregivers were surprised to find out that CBOs were continuing to provide services (albeit some alterations). This information may have contributed to the increased CBO utilization after the caregivers participated in the QI project.

### **Future Application of Project Implementation and Findings**

Once data collection and analysis were completed, the investigator continued to work with the medical center's department of marketing and information services and solutions to take measures to increase project sustainability. With the assistance of these two departments, the Inpatient Dementia Guidebook was made available on the medical center's inpatient hospital admissions website and in all bedside iPads in the inpatient geriatric unit. Furthermore, all geriatric providers were provided an electronic health record *dotphrase*, which allows any provider to send the Inpatient Dementia Guidebook to their own patients and caregivers. As mentioned above, current project status is focused on creating a generic guidebook for any healthcare system interested in adopting the guidebook into their own organization.

The Inpatient Dementia Guidebook is available in English. Future researchers may translate this document into different languages and consider implementation in diverse cultures. The photos depicted in the guidebook reflect a variety of individuals from the Western United States, however these photos may also be replaced with photos to reflect individuals from more diverse cultural backgrounds.

### **Limitations**

Although the findings of our study were promising, there were several limitations to be acknowledged. The study used a quasi-experimental design without a control. Our sample size was small and study participants were predominantly White, women, and adult children. Therefore, our findings cannot be generalizable to caregivers in different background such as those living in rural area, racial/ethnic minority groups, male caregivers, or those with different caregiving roles (e.g., spouse, having multiple care recipients). The author hypothesized that the provision of a guidebook would influence the caregivers' rating of their SE, however there are other factors which may have influenced the increase in scores. It is possible that the perceived increased support could have come from the increased amount of telephone contact with the DCS. Additionally, it is possible the caregivers who participated in the study were more receptive or hopeful in establishing relationships with the listed community organizations, support groups, and educational programs. Furthermore, while caregiver SE may influence caregiver distress and depression, measurement of these variables was not included in the analysis due to the limited time frame between the pre-intervention and post-intervention. Future studies with a longer project duration would be prudent to measure caregiver distress and depression among this population.

This project was conducted in a large organization with a substantial amount of resources, which was able to provide financial support and the expertise of experienced professionals in developing the guidebook. Additionally, the dementia care program is a benefit specifically developed to address the needs of the patient-caregiver dyad who belong within the medical system. Smaller facilities or rural-based hospitals may not be able to replicate this intervention in the same capacity as in the large healthcare system due to limited resources. However, the guidebook can still be adapted to various settings tailored to their staff availability and institutional levels. For example, the guidebook can be offered as a shorter version of booklet/brochure (online or hard copy) in different languages.

### **Role of DNP-Prepared Nurse**

This DNP project utilized essentials I to VIII identified by the American Association of College of Nurses (AACN, 2006). Essential I (scientific underpinnings of practice) and Essential VII (clinical prevention and population health) laid the foundation of practice as a Dementia Care Specialist, since patients and caregivers are treated as dyads. Personalized care plans incorporate medical, social, and behavioral recommendations for each member of the dyad. The investigator was cognizant of the environmental, social, and financial ramifications associated with a chronic disease and therefore established collaborative efforts with community-based organizations such as the Alzheimer's Association, Wise and Healthy Aging, Jewish Family Services, and Opica. It is through these partnerships that the dementia care program was able to increase access and use of formal and informal dementia care for caregivers and PWD, which is one of the social determinants in this population (Healthy People, 2020; Stephan et al., 2018).



Essential II (organizational and systems leadership for quality improvement), Essential III (clinical scholarship), and Essential VI (interprofessional collaboration) were essentials that were heavily utilized due to the coordination required to develop a guidebook based on evidence-based practice and the expertise of an experienced interdisciplinary inpatient and outpatient team. This academic institution encourages and supports quality improvement efforts, however change agents must be trained and educated to navigate these large organizations in order to implement programs successfully. The DNP-prepared advance practice nurse is ideally poised to meet this challenge.

Essential IV (patient care technology for the improvement and transformation of health care) was applied when the guidebook was made available as a PDF that may be accessed by caregivers through Epic health records and through the dementia care program website. Essential V (health care policy for advocacy in health care) was employed after the DNP project was completed, as the investigator had to advocate with organizational leadership for the guidebook to be adopted in the two main medical centers and not just in the geriatric unit. Essential VIII is currently being utilized to develop the generic template for other institutions.

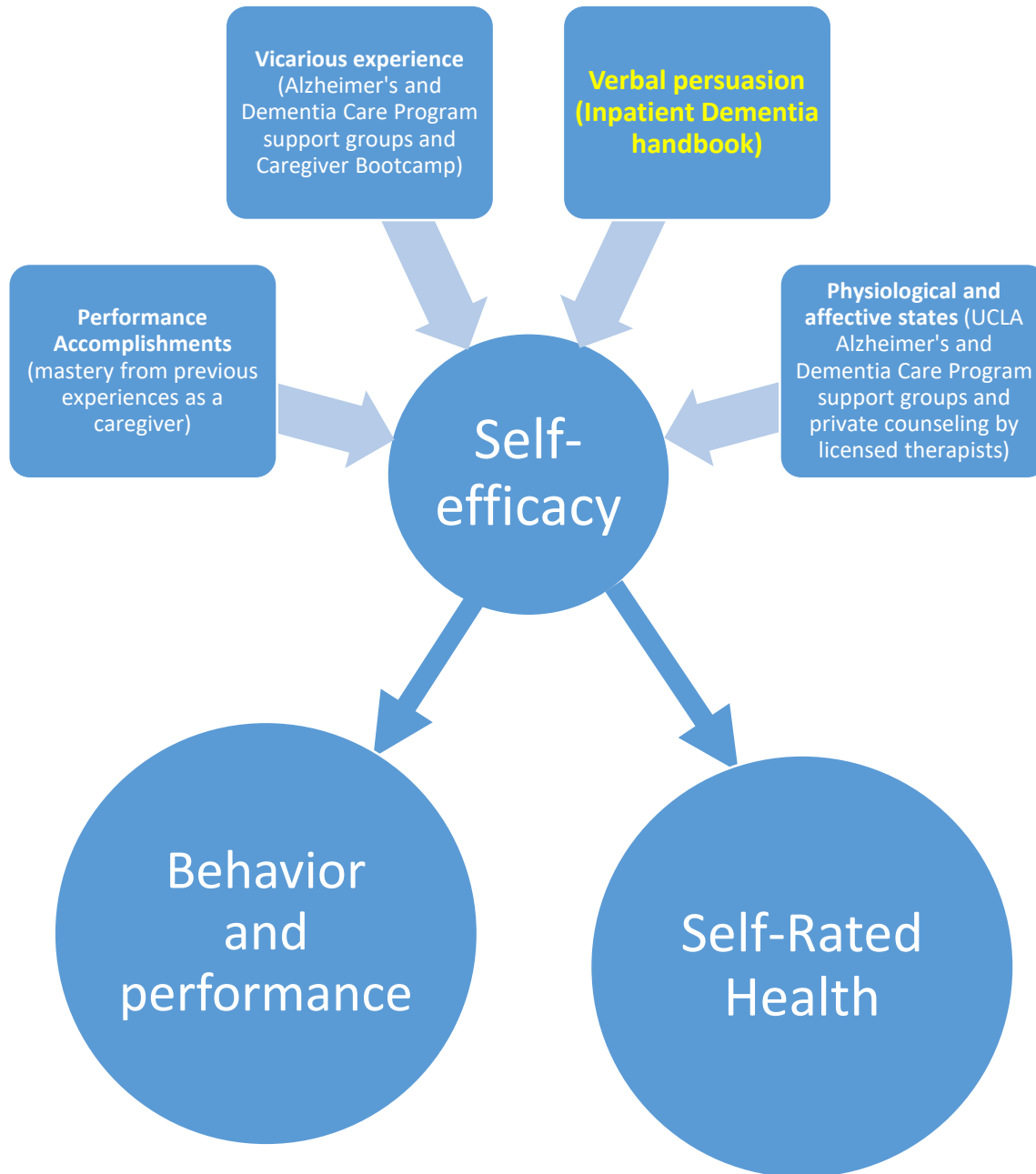
## CONCLUSION

PWD and caregivers experience significant distress during acute hospitalizations. Although the thematic issues recognized by the publications reviewed in this paper are complex and multifactorial, the DNP prepared nurse is ideally prepared to develop organizational and interdisciplinary interventions that are aimed to improve patient care. DNPs are in a unique position to act as an expert advocate for patients and a coordinator within the healthcare system. It is the hope of this author that the Inpatient Dementia Guidebook, along with continued

participation in the dementia care program, will provide caregivers with information and resources specifically tailored to meet their unique needs during the hospitalization and afterwards.

## APPENDICES

## Appendix A: Bandura's Self-Efficacy Theory



## Appendix B: Demographic Questionnaire

Please answer the following questions about yourself. Please mark the boxes that apply to you.

1. What is your age?	<input type="checkbox"/> 20-30 years <input type="checkbox"/> 41-50 years <input type="checkbox"/> 61-70 years <input type="checkbox"/> 81-90 years <input type="checkbox"/> 31-40 years <input type="checkbox"/> 51-60 years <input type="checkbox"/> 71-80 years <input type="checkbox"/> 90 +
2. What is your gender?	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Prefer not to answer
3. How much school did you complete?	<input type="checkbox"/> Less than 8th grade <input type="checkbox"/> Some college <input type="checkbox"/> Some high school <input type="checkbox"/> High school graduate <input type="checkbox"/> College graduate <input type="checkbox"/> Graduate school
4. You are presently	<input type="checkbox"/> Single or never married <input type="checkbox"/> Living with a partner <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced/Separated <input type="checkbox"/> Married
5. What is your relationship to the patient?	<input type="checkbox"/> Spouse or Significant other <input type="checkbox"/> Hired or paid caregiver <input type="checkbox"/> Child <input type="checkbox"/> Other: please specify _____ <input type="checkbox"/> Friend
6. Do you live with the patient?	<input type="checkbox"/> Yes <input type="checkbox"/> No
7. In general, would you say your health is:	<input type="checkbox"/> Excellent <input type="checkbox"/> Good <input type="checkbox"/> Poor <input type="checkbox"/> Very good <input type="checkbox"/> Fair
8. What is your race?	<input type="checkbox"/> American Indian or Alaskan Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> Native Hawaiian or Pacific Islander <input type="checkbox"/> Other (please specify: _____)
9. In the past month, how often have you had contact with any community-based organizations (Alzheimer's Association, OPICA, Jewish Family Services, Wise & Healthy Aging, Senior Concerns, OneGeneration, etc.)?	<input type="checkbox"/> No contact <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly
10. Is your loved enrolled in the UCLA Alzheimer's and Dementia Care Program?	<input type="checkbox"/> Yes <input type="checkbox"/> No

## Appendix C: Caregiver SE Questionnaire

Please indicate how certain you are right now about the following issues

On a scale of 1 to 10, how certain are you right now that you can...	Not at all 1	2	3	4	5	6	7	8	9	Very certain 10
1. Handle any problems your loved one has, like memory loss, wandering, or behavior problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Handle any problems that might come up in the future about your loved one's care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Deal with the frustrations of caring for your loved one?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do something to keep your loved one as independent as possible?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Get answers to all your questions about your loved one's problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Care for your loved one without help from organizations or agencies that provide services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Find organizations in the community that provide services to help you or your loved one?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Get answers to all your questions about these services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Arrange for these services yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Find services available to me to help me provide care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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## Appendix D: Post-Test Questionnaire

<b>FOR POST-INTERVENTION ONLY</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
1. Did you use the guidebook?	
2. In general, would you say your health is:	<input type="checkbox"/> Excellent <input type="checkbox"/> Good <input type="checkbox"/> Poor <input type="checkbox"/> Very good <input type="checkbox"/> Fair
3. In the past month, how often have you had contact with any community-based organizations (Alzheimer’s Association, OPICA, Jewish Family Services, Wise & Healthy Aging, Senior Concerns, OneGeneration, etc.)?	<input type="checkbox"/> No contact <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly
4. Please tell us what you liked about the guidebook: <hr/>	5. Please tell us how we can improve the guidebook: <hr/> <hr/> <hr/>



## Appendix E: Permission and Directions to use caregiver SE Questionnaire

May 31, 2020

Dear Michelle,

As you requested, I've attached Word documents with the questions we use to measure symptom management self-efficacy, community support services self-efficacy (reported in the 2002 article you cited), and (although not reported in our published work) medication management self-efficacy. Thus far in our research with the medication management items, we have found that most caregivers rate their self-efficacy for medication management extremely highly, so you might expect to observe ceiling effects with that measure if you are interested in using it.

The symptom management and support services pages of the attachment contain most of the necessary instructions. Two additional instructions/notes for your interviewers, or to provide in instructions for self-administered format:

1. Mention to the respondents as part of the introduction to these items, that "you can answer anywhere in between 1 and 10 for any of the questions."
2. In interview formats, we do NOT provide "DK" and "Refused" as options to the respondents. We use those categories to code such responses only after the interviewer cannot get the respondent to commit to a "number". In practice, this occurs extremely rarely, especially with well-trained interviewers skilled in obtaining valid responses. We have, in short, very little missing data for these items. However, we have not used these items in self-administered format. If that is what you choose, I would recommend that you include only the "DK" (don't know) response but include in your instructions that this answer should only be used if the respondent cannot provide a best estimate of how certain they are about a specific item. Discourage respondents from choosing the DK option so that you minimize your missing data.

The attached forms are "read only" documents. You may recreate the item series in whatever format(s) you choose for your data collection purposes. But please give proper attribution to the original source of these measures wherever appropriate.

As for scoring, the items covering dementia symptom management and community support services self-efficacy factored slightly differently in the published 2002 paper than as they are listed in the forms. We continue to group items into subscales for analysis purposes as explained in the publication, not as they appear in the forms, but we have retained the identical item order in the forms as in our original work for consistency over time and across studies.

I would be pleased to discuss scoring issues by telephone if you wish.

Feel free to contact me with any questions. Thanks and good luck with your work; I'd be very interested in comparing your results with those we have found. Please keep me posted on your progress, and thanks for your interest in our work.

Sincerely,  
Richard H. Fortinsky, PhD  
Professor of Medicine  
UConn Center on Aging  
University of Connecticut School of Medicine  
Farmington, CT 06030-5215  
Email: [Fortinsky@uchc.edu](mailto:Fortinsky@uchc.edu)

## Appendix F: Letter from the Institutional Review Board



Lillig, Paul <PLillig@research.ucla.edu>

Mon 9/14/2020 12:28 PM

To: Panlilio, Michelle T.



Hi Michelle,

Thank you for the call today. Based on our discussion and the information provided below, your DNP project does not meet the definition of human subjects research as defined by federal regulations for human subject protections (45 CFR 46.102(d) - <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.102>).

Therefore, neither certification of exemption from UCLA IRB review nor UCLA IRB approval of the proposed activities is required.

Please retain this email as formal documentation of this determination.

Please contact our office for an update to this determination if the scope or aims of the activities are revised.

Thank you,

Paul Lillig

GIRB Administrator

310.206.2091

Email: [plillig@research.ucla.edu](mailto:plillig@research.ucla.edu)

Zoom: <https://ucla.zoom.us/j/3194880206>

TABLE OF EVIDENCE

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
<p>Jurgens, F. J., Clissett, P., Gladman, J. R. F., Harwood, R. H. (2012). Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. <i>BMC Geriatrics</i>, 12(57). <a href="http://www.biomedcentral.com/1471-2318/12/57">http://www.biomedcentral.com/1471-2318/12/57</a></p>	<p>To identify causes for caregiver dissatisfaction during inpatient hospitalizations.</p>	<p>Participants were admitted to the emergency room, screened for dementia upon admission.</p> <p>35 caregivers (age 46-79) and 34 patients (age 70-99). Mean age for patients was 87 y/o, 56% were female, 21% were widows. 5 patients died between discharge and follow up interviews.</p> <p>Caregivers (35 total): 9 were spouses, 15 were children. Average age was 63 y/o and 69% were female.</p>	<p>Qualitative study using convenience sampling method. Patients without caregivers were excluded.</p> <p>Qualitative observational study was conducted on the patient in the units and “interview study” was conducted after discharge for the caregivers.</p> <p>Transcripts were recorded, transcribed and analyzed utilizing a grounded theory methodology.</p> <p>Coding performed by 3 researchers using constant comparative method.</p>	<p>Identified 6 themes in caregiver frustration: 1. The PWD 2. Family caregivers 3. Communication with medical staff 4. Treatment 5. Tensions between family and friends 6. Difficulty navigating the hospital.</p>	<p>Caregivers often become angry and resentful, carry on these feelings to the next hospital admission.</p> <p>Strengths: Seminal article. Identified cycle of discontent.</p> <p>Limitations: Some interviews were conducted weeks after discharge, may have been too long. Some interviews were done in the presence of the PWD, thus some carers may have limited what was divulged (to avoid upsetting the PWD).</p> <p>Proposed interventions:</p>

		Setting: Patient or caregiver's home after discharge from an inpatient teaching hospital in the United Kingdom			Patients with dementia and their caregivers should be considered a unit.  Caregivers need to give critical information about the patient, and be offered chance to participate in care.
Hynninen, N., Saarnio, R., & Isola, A. (2015). Treatment of older people with dementia in surgical wards from the viewpoints of the patients and close relatives. <i>Journal of Clinical Nursing, 24</i> , 3691-3699. <a href="https://doi:10.1111/jocn.13004">https://doi:10.1111/jocn.13004</a>	To describe the treatment of PWD during an inpatient hospitalization, based on observations of the PWD and their relatives	Participants: 7 patients with dementia, mean age 81 years old (age 74-85), 5 women and 2 men. 5 close relatives, mean age 67 years old (age 52-78), 4 spouses and 1 child.  Setting: Inpatient setting in Oulu University Hospital, Finland.	Qualitative, descriptive design  Convenience sampling after patients were identified by head nurses as meeting criteria upon admission.  Interview began with "Can you describe how it feels to be in the hospital as a patient/patient's close relative?"  Unstructured taped interviews were conducted with the PWD and their caregiver, which was then subjected to	3 main themes were identified: 1. Treatment of the patient with dementia 2. Factors that contribute to good treatment of an older person with dementia 3. Factors that hinder good treatment of an older patient with dementia.	The structure of acute care settings is not adapted to care for PWD.  Role of the caregiver significantly impacts the patient's clinical outcomes in the acute setting. Caregivers play a significant role in providing mental and emotional support.  Resources being provided to caregivers are inadequate to meet criteria for best practice.

			<p>inductive content analysis.</p> <p>Qualitative data analysis, followed by open coding. Key sentences were grouped, then subcategories with similar content were clustered into general categories.</p>		<p>Hospital stays for the caregivers was emotionally difficult and often led to exhaustion, secondary to feelings of worry and shame.</p> <p>Relatives needed better communication from the treatment team, physicians were difficult to reach.</p> <p>Nursing staff were focused on completing tasks to ensure physical well-being (wound care, assistance with meals, administering medications), did not have time to spend evaluating the emotional component of the hospital stay.</p> <p>Strengths: Real-time documentation of the patient's hospital experience.</p>
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					<p>Limitations:  researchers interviewed PWD during a hospitalization. Depending on the stage of dementia and presence of delirium, the information may be inaccurate.  Interview questions were unstructured, researchers did not prepare set questions.</p> <p>Proposed interventions:  To improve the treatment of patients with dementia, caregivers must be included in the plan of care.</p> <p>Nurses need to spend more time with the patient, instead of focusing on tasks and responsibilities.</p> <p>Medical and nursing staff need more</p>
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					<p>training on dementia.</p> <p>Caregivers need more care and support from healthcare providers.</p>
<p>Jamieson, M., Grealish, L., Brown, J., &amp; Draper, B. (2016). Carers: The navigators of the maze of care for people with dementia – a qualitative study. <i>Dementia</i>, 15(5), 1112-1123. <a href="http://DOI:10.1177/1471301214554930">http://DOI: 10.1177/1471301214554930</a></p>	<p>To investigate the experiences of caregivers after the PWD is discharged home from a hospitalization.</p>	<p>30 caregivers for patients who had been hospitalized in the past 2 years.</p> <p>26 were female and were the spouse or relative. 28 lived with the patient.</p> <p>Setting: Patient home after hospital discharge in Canberra, Australia</p>	<p>Qualitative, descriptive design</p> <p>Data was obtained by individual telephone interviews with primary caregivers. Interviews were recorded, lasting 30-90 minutes.</p> <p>Each researcher first identified themes using thematic content analysis, then all researchers came together as a team to discuss findings.</p> <p>Caregivers were recruited from Alzheimer’s Australia New South Wales (AA NSW). Caregivers were self-selected/volunteers after having made contact with AA NSW.</p>	<p>Thematic results:</p> <ol style="list-style-type: none"> <li>1. Paradox in the hospital because caregivers were asked to participate in personal care but ignored in decision-making</li> <li>2. Difficulty transitioning home from the hospital setting</li> <li>3. High value placed on community-based social support</li> </ol>	<p>Historically, role of the carer has been deemed “important,” but has not been deemed as central in “patient centered” care.</p> <p>Caregivers are the “experts” in patient care.</p> <p>Support and help with navigating community-based services is paramount in caring for the patient and caregiver. Much frustration is related to the complexity of accessing community-based services.</p> <p>Strengths: 3 semi-structured questions</p>

					<p>were asked for all caregivers.</p> <p>Limitations: Data was collected for experiences as long as 2 years prior. Participants were all recruited from AA NSW as volunteer participants, which could form an “elite bias.”</p> <p>Proposed interventions: Strong emphasis on discharge planning to include access to home support and community-based services.</p> <p>Hospital staff need to develop a better understanding of the importance of the role played by caregivers.</p> <p>Hospital staff need better training on dementia.</p> <p>Discharge planning needs to be a</p>
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					coordinated process by the hospital.
<p>Moyle, W., Bramble, M., Bauer, M., Smyth, W., &amp; Beattie, E. (2016). "They rush you and push you too much...and you can't really get any good response off them": A qualitative examination of family involvement in care of people with dementia in acute care. <i>Australasian Journal on Ageing</i>, 35(2), E30-E34. <a href="https://doi.org/10.1111/ajag.12251">https://doi.org/10.1111/ajag.12251</a></p>	<p>To explore the role and needs of the family caregiver (spouse, family, partner or friend) during acute stages of the hospitalization.</p>	<p>30 caregivers: 9 caregivers came from Tasmania emergency department, 11 were from Queensland in the surgical or medical wards, and 10 caregivers from Victoria close to the day of discharge or within one week after discharge.</p> <p>Each site had key personnel to identify potential participants. An information sheet was provided to explain the study, and caregivers would sign consent if they were agreeable to participating.</p> <p>Setting: Various stages during an inpatient hospitalization in</p>	<p>Exploratory-descriptive qualitative study</p> <p>Independent semi-structured, in-person, digitally recorded interviews. The recordings were then transcribed verbatim.</p> <p>Purposeful analysis was done through reading the transcripts, creating initial codes across the data, and classifying the themes into the codes.</p>	<p>Thematic results:</p> <ol style="list-style-type: none"> <li>1. Family caregiver's role</li> <li>2. Needs from the caregiver (highest priority was need for information)</li> <li>3. Needs of the PWD</li> <li>4. Increasing effective family involvement</li> </ol>	<p>Family experience was highly critical of acute inpatient hospitalizations.</p> <p>Family needs to be actively engaged and involved by the medical professionals in planning for the patient's care.</p> <p>Hospitals need to develop basic guidelines to promote caregiver involvement in care.</p> <p>Team-based culture between medical staff and caregivers need to be established.</p> <p>Strengths: Participants only included caregivers, not patients.</p> <p>Limitations: Interviews were done at different</p>

		3 Australian hospitals, from the emergency room to discharge.			<p>stages of the hospitalization, difficult to obtain objective data.</p> <p>Proposed interventions: Hospital staff need better training on dementia, specifically “relationship-centered care.”</p> <p>Hospital staff need to partner with the caregivers.</p> <p>Access to care is difficult for the older population (driving and finding parking). Hospital infrastructure needs to be improved to accommodate the needs of this population (handicapped parking, side rails and ramps).</p>
Thyrian, J. R., Hertel, J., Wucherer, D., Eichler, T., Michalowsky, B., Dreier-Wolfgramm, A.,	To evaluate effectiveness and safety of dementia care	407 patients with dementia age 70 or older and	Design: Cluster randomized intervention trial. Systematic screening	Regression analyses was performed to evaluate the treatment	BPSD, caregiver burden, and pharmacologic treatment with

<p>Zwingmann, I., Kilimann, I., Teipel, S., &amp; Hoffmann, W. (2017). Effectiveness and safety of dementia care management in primary care: A randomized clinical trial. <i>JAMA Psychiatry</i>, 74(10), 996–1004.  <a href="https://doi.org/10.1001/jama-psychiatry.2017.2124">https://doi.org/10.1001/jama-psychiatry.2017.2124</a></p>	<p>management in the treatment and care of people with dementia living at home and caregiver burden.</p>	<p>living at home, mean age was 80.</p> <p>291 were in the treatment group, 178 (61.2%) were women, and 151 (51.9%) lived alone. Mean MMSE was 22.8. 227 patients had a caregiver.</p> <p>116 patients were in the control group, 70 (60.3%) were women, and 53 (45.7%) lived alone. Mean MMSE was 22.7. 75 patient had caregivers.</p> <p><u>Setting:</u> Home setting in Greiswald, Germany</p>	<p>with DemTect procedure. Patients were invited to participate by their PCP, along with their caregiver. PCPs received allowances for screening (equivalent to \$11.15 per patient) and study enrollment (\$115.54 per patient). 136 total PCPs participated and were randomized.</p> <p>1:1 randomization without stratification or matching was utilized. Descriptive statistics were also used. Pre and post intervention values were compared utilizing paired <i>t</i> tests or McNemar tests.</p> <p>Interventions: Trained dementia care managers (6 registered nurses) provided education and support to the home for 6 months.</p> <p>Measures/Instruments used: Quality of Life in Dementia Scale, Berlin</p>	<p>effect of the dementia care management.</p> <p>Significant decrease in behavioral and psychological symptoms (<math>b=-7.45</math>; 95% CI, <math>-11.08</math> to <math>-3.81</math>; <math>P&lt;.001</math>) and caregiver burden (<math>b=-0.50</math>; 95% CI, <math>-1.09</math> to <math>0.08</math>; <math>P=.045</math>) compared with care as usual.</p> <p>Increased treatment with antedementia drug treatment in treatment group 114 of 291 [39.2%] vs care as usual, 31 of 116 [26.7%]) after 12 months (odds ratio, 1.97; 95% CI, 0.99 to 3.94; <math>P = .03</math>).</p>	<p>antedementia drugs benefitted most from interventions.</p> <p>Strengths: Large sample size. Measures/instruments utilized in study were extensive and commonly used in the caregiver population. Highlighted the role and impact of dementia-trained registered nurses.</p> <p>Limitations: Bias due to payments for PCPs for each patient screened and enrolled. Limited generalizability due to region and healthcare system used, due to limitations in access and resources. 50.1% of PWD lived alone, thus data from this population is not reliable due to their dementia and associated cognitive</p>
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			Inventory for caregivers Burden scale, and Bayers activity of the daily living scale were done at baseline and repeated at 12 months.		impairment. Selection bias from referring general practitioners (GPs)  Cost effectiveness studies need to be evaluated to incorporate this model into other healthcare systems or models of care.
Kales, H. C., Gitlin, L. N., Stanislawski, B., Myra Kim, H., Marx, K., Turnwald, M., Chiang, C., & Lyketsos, C. G. (2018). Effect of the WeCareAdvisor on family caregiver outcomes in dementia: A pilot randomized controlled trial. <i>BMC Geriatrics</i> , 18(1), 113. <a href="http://doi:10.1186/s12877-018-0801-8">http://doi:10.1186/s12877-018-0801-8</a>	Determine efficacy of WeCareAdvisor™ on family caregiver outcomes	57 dementia family caregivers, age 65.9 ± 14.0 years old. 75 % of caregivers were female. Nearly half (49%) were spouses of patient with dementia. 27 caregivers were randomized to WeCareAdvisor™ and 30 caregivers in waitlist control. 83% (control) and 85% ( WeCareAdvisor™) had greater than a high school education. 63% for both cohorts were White.	Two-site randomized controlled trial.  Participants were recruited by provider or medical personnel referral, on-site research staff, and caregiver response.  Subjects were randomized to 2 groups, 27 subjects allocated to use WeCareAdvisor™ and 30 subjects placed on Wait-List control for one month.  Instruments: iPad with the WeCareAdvisor™ website link and email account.	Improved distress (6.08 ± 6.31 points, t = - 4.82, p < 0.0001). Additionally, frequency of behaviors (- 3.60 ± 5.05 points, t = - 3.56, p = 0.002), severity of behaviors (- 3.24 ± 3.87 points, t = - 4.19, p = 0.0003), and NPI score decreased (- 6.80 ± 10.73 points; t = - 3.17, p = 0. 004) after one month of use. Wait listed group demonstrated worsening (- 6.40 ± 10.30, t = - 3.40, p = 0.002).	WeCareAdvisor™ could have a role in caregiver management of BPSD, however more studies need to be performed on how this contributes to caregiver distress. Impact on caregiver confidence not clear.  Strengths: Measures included neuropsychiatric inventory questionnaire, Zarit burden scale. Identified a tool to assist families in behavioral management in the home setting.

		<p>Patient MMSE &lt;24. Not on a stable dose of psychotropics for at least 60 days. Not residing in facility. Patient mean MMSE 16.5 ± 8.3.</p> <p>Caregivers managing ≥ 1 behavioral symptom, was the primary caregiver, residing with or near the PWD, English-speaking, familiarity with technology (smartphone or computer).</p> <p><b>Setting:</b> Home setting of the patient and caregiver in the United States.</p>	<p>Baseline interviews performed at home, which ended with randomization to group assignments. One group was able to use WeCareAdvisor™ immediately, while the control group had to wait one month to use the tool.</p> <p>Phone calls 2 to 3 days after baseline, then weekly phone calls. One-month in-home follow-up interviews for both control and intervention group.</p> <p>Logistic regression utilizing Wald <math>\chi^2</math> test. T-test was used to compare baseline and one-month results.</p>		<p>Limitations: Authors did not select a particular aspect of BPSD (e.g. agitation), lack of heterogeneity. One month may not be long enough to affect behavioral outcomes. Small sample size limits generalizability. Caregivers who were not familiar with technology were excluded.</p>
Merrilees, J. J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E., ...	To illustrate that psychosocial interventions	780 patient-caregiver dyads. 512 dyads	Article comparing 3 case studies	3 cases were evaluated from the intervention cohort, selected	SE is demonstrated to be influenced by psychosocial

<p>Possin, K. L. (2018). The Care Ecosystem: Promoting SE among dementia family caregivers. <i>Dementia (London)</i>, 1471301218814121. <a href="https://doi:10.1177/1471301218814121">https://doi:10.1177/1471301218814121</a></p>	<p>aimed at increasing caregiver SE among caregivers who are enrolled in Care Ecosystem.</p>	<p>received the intervention and 268 were the control group.</p> <p>Only 3 cases were selected. 2 male PWD aged 61 and 81, 1 female PWD age 75. Patient race was Latino, Caucasian, and Chinese.</p> <p>Caregivers: 2 male (33 y/o son and 75 y/o husband) and 1 female (51 y/o daughter)</p> <p>Setting: Home of the patient with dementia</p>	<p>Intervention: Care Ecosystem, which is a dementia coordination program aimed to provide personalized dementia care to the patient-caregiver dyad. Care is delivered by phone, email, regular mail, and in person. Unlicensed staff receive 80 hours of dementia training.</p> <p>Tool: Baseline, 6-month, and 12-month follow up, dyads complete a telephone interview of the Care Ecosystem Caregiver SE scale, Zarit burden scale, caregiver depression, and caregiver's report on patient quality of life. Patients were randomized to the intervention (Care Ecosystem) or control (standard care). For this article, 3 cases were selected to evaluate caregiver SE.</p>	<p>because of the lowest caregiver SE scores at baseline and with marked improvement at six months. The cases exemplified how Care Ecosystem focused interventions to improve caregiver SE and preparedness.</p> <p>3 overarching themes to improve SE: emotional support (encouraging caregiver to take care of themselves), informational support (provide caregiver education), and instrumental support (create links to community support services).</p>	<p>support interventions.</p> <p>Limitations: Only 3 dyads were evaluated in entire sample of 780. Possible the 3 who enrolled in their case study were more hopeful and open to psychosocial help. Ratings did not include caregiver burden or depression. Availability of support services in California are plentiful, will not be generalizable to other states.</p>
<p>Possin K. L., Merrilees J. J., Dulaney S., et al.</p>	<p>To determine if the Care</p>	<p>780 patient-caregiver dyads.</p>	<p>Single blind</p>	<p>571 of the 780 PWD-caregiver dyads</p>	<p>Care Ecosystem was an effective</p>

<p>(2019). Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The care ecosystem randomized clinical trial. <i>JAMA Internal Medicine</i>, 179(12), 1658-1667. <a href="https://doi:10.1001/jamainternmed.2019.4101">https://doi:10.1001/jamainternmed.2019.4101</a></p>	<p>Ecosystem is effective in improving outcomes important to patients, caregivers, and payers.</p>	<p>512 dyads received the intervention and 268 were the control group.</p> <p>Inclusion: Patients age 45 or older, and with Medicare eligibility in CA, Nebraska, or Iowa. Excluded if in nursing home. 780 PWD (56.3% female; mean [SD] age, 78.1 [9.9] years) and 780 caregivers (70.9% female; mean [SD] age, 64.7 [12.0] years). Dyads: 59% from California, 36.5% from Nebraska, 4.5% from Iowa. 79.9% were white, 6.6% Asian, 4.3% African American, and 9.2 mixed race.</p> <p>Setting: over telephone in urban San</p>	<p>parallel-group pragmatic randomized clinical trial with imbalanced randomization</p> <p>Intervention: The Care Ecosystem. Telephone-based and internet-based dementia care coordination (advanced practice nurse, social worker, and pharmacist). Calls were performed as needed, based on patient-caregiver dyad need, mean (SD) number of calls was 15.3 in 12 months.</p> <p>APNs were the center of the “hubs” and available for medical needs, problematic behavioral issues from the patient, safety concerns, and care coordination with other professionals.</p> <p>Measures/Instruments used: Collected at baseline, 6 and 12 months. QoL-AD, Patient health</p>	<p>completed the 12-month trial. Care Ecosystem improved Primary outcome measure was patient quality of life, QoL-AD scores was based on caregiver interview (B,0.53; 95%CI,0.25-1.30; P=.04). Reduced emergency department visits (B,-0.14; 95% CI, -0.29 to -0.01; P=.04). Decreased caregiver depression measured by PHQ-9 (B,-1.14; 95% CI, -2.15 to -0.13; P=.03). Decreased caregiver burden scored by Zarit Burden Interview (B,-1.90; 95% CI,-3.89 to -0.08; P=.046).</p> <p>Caregiver SE increased at both 6-months e (B, 0.86; 95% CI, 0.42-1.29 points; P &lt; .001) and but not sustained at 12 months (B,0.64;95%CI,0.14-1.41;P = .11)</p>	<p>dementia care management tool. Telephone-based dementia care can be delivered through centralized areas to supplement usual care to burdens from society and the economy.</p> <p>Significant improvement in PWD quality of life, as reported by caregivers.</p> <p>Reduced emergency room visits, but did not significantly lower hospitalization rates.</p> <p>Strengths: Highlighted the role and impact of APNs, working in tandem with an interdisciplinary team.</p> <p>Limitations: Will be difficult to generalize since this was in a large institution, smaller</p>
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		<p>Francisco, CA, Iowa, and rural Omaha, Nebraska homes.</p> <p>All patients had a dementia diagnosis and spoke English, Spanish, or Cantonese.</p>	<p>questionnaire-9, Zarit Burden interview.</p>		<p>organizations may not have the resources to develop a program similar to Care Ecosystem. Missing dementia severity. Faulty process of consenting only disclosed the possibility of advance the quality of care of PWD, and did not include other benefits of being a part of Care Ecosystem.</p>
<p>Reuben, D. B., Tan, Z. S., Romero, T., Wenger, N. S., Keeler, E., &amp; Jennings, L. A. (2019). Patient and caregiver benefit from a comprehensive dementia care program: 1-year results from the UCLA Alzheimer's and Dementia Care Program. <i>Journal of the American Geriatrics Society</i>, 67(11), 2267–2273. <a href="https://doi.org/10.1111/jgs.16085">https://doi.org/10.1111/jgs.16085</a></p>	<p>To examine clinical outcomes of the patient-caregiver dyad after participation in a comprehensive dementia care program.</p>	<p>554 patient-caregiver dyads completed the surveys, out of the entire cohort of 991.</p> <p>Patient age 53-101, mean 82.3 years old. 71% White, 9% Black, 13% Hispanic, and 7% non-Hispanic. 89% diagnosed with Alzheimer's disease.</p>	<p>Observational study</p> <p>Intervention: Enrollment in the UCLA Alzheimer's and Dementia Care Program. NP-led team served as lynchpin to coordinating care which implemented medical, social, and behavioral recommendations.</p> <p>Questionnaires were completed at baseline and 1 year after being enrolled in the UCLA</p>	<p>All tests results were two-sided, <math>P &lt; .05</math> was considered statistically significant. 58% (314/543) of PWD demonstrated clinical benefits (defined as lower NPI-Q scores).</p> <p>63% (282/447) of caregivers had clinical benefit (lower DBS-CG scores).</p> <p>Indicators for maintaining low burden after one year: male caregivers, patients</p>	<p>As expected, patients declined cognitively (lower MMSE and Functional activities questionnaire scores) but BPSD and depressive symptoms worsened. Nonetheless, caregivers improved in DBS-CG.</p> <p>BPSD: patient-caregiver dyads had improvement of symptoms and</p>



		<p>Caregivers: 65% females. Relationship to the patient: 52% spouse and 30% child.</p> <p>Setting: Outpatient clinical within a large academic medical center</p>	<p>Alzheimer's and Dementia Care Program.</p> <p>Tools collected at baseline and after 1 year. For the PWD: MMSE, functional activities questionnaire, ADLs and IADLs, and Cornell scale for depression. Caregiver: NPI-Q, MCSI, PHQ-9, and dementia burden scale (DBS-CG).</p>	<p>with less depressive symptoms, less BPSD, and increased PWD FAQ impairment at baseline.</p>	<p>maintenance of low symptoms.</p> <p>Health system-based dementia management is a novel and promising intervention which is beneficial for PWD-caregiver dyads.</p> <p>Strengths: Extensive tools collected on the PWD and caregiver.</p> <p>Limitations: Did not discuss financial sustainability and generalizability to other organizations.</p>
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*Note.* PWD = patient with dementia; BPSD = behavioral and psychological symptoms of dementia; SE = Self-efficacy; MMSE = Mini-mental state examination; PCP = Primary Care Physician; APN = advanced practice nurse; ADL = activities of the daily living; IADL = instrumental activities of the daily living; DBS-CG = dementia burden scale of the caregiver; MCSI = Modified Caregiver Strain index; PHQ-9 = Patient Health Questionnaire – 9; NPI-Q = Neuropsychiatric Inventory Questionnaire; QOL-AD = Quality of Life in Alzheimer's Disease

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